

Cover Sheet for Margaret Carter's Testimony to Support the Self-Direction Act.

Document A Cover sheet

Document B SDAN Testimony for Self-Direction

Document C About SDAN

Document D: Testimony shared by Edward Willard, self-advocate

Document E: Statistical analysis of DDA budget data demonstrating cost-savings of self-direction, prepared by Genevieve Houston-Ludlum PhD.

Document F: Text of CMS *guidelines Regarding the Provision of Care by Relatives and Legally Responsible Adults*. This document states that relatives and legally responsible adults may provide care under extraordinary circumstances. It defines those circumstances **as any care above and beyond that which would be provided to a typical peer.**

Self-Direction Act

Presented by the Self-Directed Advocacy Network of Maryland

While provider-managed services are perfect for many people with developmental disabilities, they are not a good fit for others. That's where self-direction comes in.

Not everyone fits the provider-managed paradigm.

Sunny Cefaratti spent eight years in a sheltered workshop before self-Direction changed her life. She is the co-founder of the Musical Autist and an SDAN board member. She is now a disability advocate and mentors other people with autism. Sunny is a wonderful example of the power of self-direction.

History of Maryland's extraordinary Self-Direction Program

Maryland's extraordinary self-direction program was initiated in 2005 by people with developmental disabilities and those who loved them—not by state administrators. **Both self-advocates and family advocates believed they could create high quality programming in their own homes and communities with the same money—or less—than DDA allotted to providers. They had two compelling arguments—cost effectiveness and human rights. They implemented two common-sense strategies: directing funding as closely as possible to the intended target and reducing administrative costs.**

What makes Self-Direction Different?

Participant Choice and control of services is self-direction's keystone. With help from family members and professional advocates like support brokers, people with DD can create and realize their own person-centered plans. Budget authority allows them to allocate funds according to their unique needs and goals. Employer authority allows them to choose their own staff-- and pay them a living wage. Those employees provide the customized supports people with DD need to pursue our own Good Life.

Self-Direction allows people of all abilities to have the Good Life

What is the Good Life?

It's getting your Master's degree in Public Policy, volunteering at Goodwill, or working at a childcare center. It's crafting mosaic tiles and marketing them online or helping out at a community food pantry. It's finding new friends or making cookies for veterans. It's studying graphic design or running a community petting zoo on the family farm. It's building a cupcake baking business or having your own produce stand. It's delivering meals to seniors or helping out at your church. It's riding your favorite horse or exercising with friends. It's working in the kitchen at Mod Pizza, or learning a vocation in horse care. It's calling an Uber, *instead* of your Dad. It's going to the beach or grabbing lunch from Chipotle after a hike at Fort McHenry. It's speaking out for others or leading Troupe for the Musical Autist. It's

swimming at ACAC, feeling the warmth of the sun on your face, and enjoying the crunchy sound of fall leaves. It's learning how to shop, cook, craft, garden, do laundry, and buckle your own seatbelt. It's having a *home of your own* or *choosing* to live with those you love.

For people of all abilities, the Good Life means making choices and finding a place in the community.

Self-Direction is a win-win for both participants and the State

Maryland's SD program exceeds federal requirements for inclusion and choice. It also allows people with intense needs to remain in their homes—eliminating costly residential placements. It saves Maryland an average of 25% over provider-managed services.

Threats to Self-Direction—Why HB318 is Needed

Despite its remarkable outcomes Maryland's SD program is now at risk.

Although Self-direction was initiated as a departure from the standard provider-managed path, since 2014 DDA has sought to align it with provider-managed services. Instead of improving self-direction, DDA's changes have resulted in more barriers, and fewer choices for people with DD.

An option that was once individualized, person-centered, and efficient is morphing into one that is ever more *standardized, statecentered, and costly*. Policy changes have included the following:

- Elimination of overnight support from trusted employees for people with intense needs
- Elimination of individualized transportation arrangements
- Restrictions on customized goods and services, such as therapeutic riding or music therapy
- Elimination of choice and competition for essential fiscal management services
- Restrictions on who is eligible to self-direct
- Restrictions on the participant team's choice to hire family members
- Restrictions on the participants' access to a support broker— the only professional on the team with a fiduciary duty to the person
- Use of provider rates to determine self-directed budgets-- which may overfund many participants while underfunding others

These policy changes have:

- Removed existing choices for all participants
- Delayed services by months or years for others
- Forced some people out of self-direction into more costly provider-managed services
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- What will the Self-Direction Act do?

The Self-Direction Act will preserve cost savings for Maryland taxpayers and restore choice and control to people with DD—people like me. The Act will gather stakeholders from around the state to craft a program that is flexible, efficient, and accountable. The Act will:

- **C**reate a strong state advisory council to *re-establish* the principles of self-direction & DDA accountability
- **A**llow participants to continue to choose family members as support staff
- **R**estore the participants' right to choose a support broker as their fiduciary
- **E**nsure participants' choice and control of services
- **M**andate that *anyone* eligible for DDA services can self-direct

CARE Maryland!

The Self-Direction Act is supported by the following organizations

Maryland Developmental Disabilities Council

The Arc Maryland

People on the Go Maryland

Disability Rights Maryland

Pathfinders for Autism

Special Needs Advocacy Coalition

Maryland Commission on Caregiving

Baltimore County Commission for Women

Self-Directed Advocacy Network of Maryland.

About the Self-Directed Advocacy Network

SDAN formed in 2016 because of participant concerns regarding changes DDA was making to the SD Program. It is an all-volunteer organization which has worked to preserve choice and control of services for people with developmental disabilities. Membership in SDAN is free and meetings are open to the public. Nearly all board members are self-advocates who participate in SD *or* are family members of someone who does. Since 2016 SDAN has consistently reached out to DDA administrators with recommendations for preserving and improving the SD program. SDAN produced a well received video promoting self-Direction in 2020 called *Self-Direction and the Good Life: Many Lives, Many Choices*.

Detailed History of SDAN's advocacy since 2016.

- Formed in August 2016 in response to Amendment 2 proposals; monthly/bi-monthly meetings since October 2016
- Developed State-wide outreach through social media, community and public events
- Developed an online presence in all areas of social media and website
- Communicated with legislators at the local, state, and Federal level representing the needs of individuals who self-direct their services and regarding concerns re DDA changes
- Held fundraiser event (Hear Our Voice t-shirts) to help spread our message
- Participated in all DDA listening sessions, helping with transportation for participants for their voices to be heard
- Organized a petition with over 600 signatures to stop Amendment 2; Ultimately Amendment 2 was abandoned by DDA
- Participated in Work Groups that gave extensive input to DDA on Amendment 2
- Testified at DDA Budget Hearings in Annapolis, March 2017
- Established as a nonprofit 501(c)(3) in August 2017
- Ongoing, face-to-face quarterly meetings with DDA administrators
- Reviewed, researched, and made formal comments on Waiver Proposal, resulting in changes to waiver
- Testified at DDA Budget Hearings in Annapolis, February/March 2018
- Advocated for multiple FMS providers to maintain participant choice in options

- **Met with Governor's Staff in September 2018 to education on the importance of self-direction**
- **Working with Secretary of Maryland Department of Disabilities, Carol Beatty, to promote and support self-direction in Maryland**
- **Membership on the Transformation Committee**
- **Membership on Employment First Leadership Team**
- **Quarterly and working meetings with DDA**
- **Meeting with DD Coalition members**

Good afternoon, I am Edward Willard an advocate for the rights of Citizens with disabilities. This afternoon I will be representing myself as a citizen of Maryland. I have worked on Self-Directed Services from its conception in 2004. My history includes working at and with the Developmental Disabilities Administration on and off for ten years as a contractual Employee. My final position at DDA was as the Director of Advocacy Supports. Due to significant health issues I had to retire in 2017. Therefore, my testimony speaks to how Self-Directed Services **were intended to be**, and the gross dilution and failed promises DDA has made over an eleven-year span.

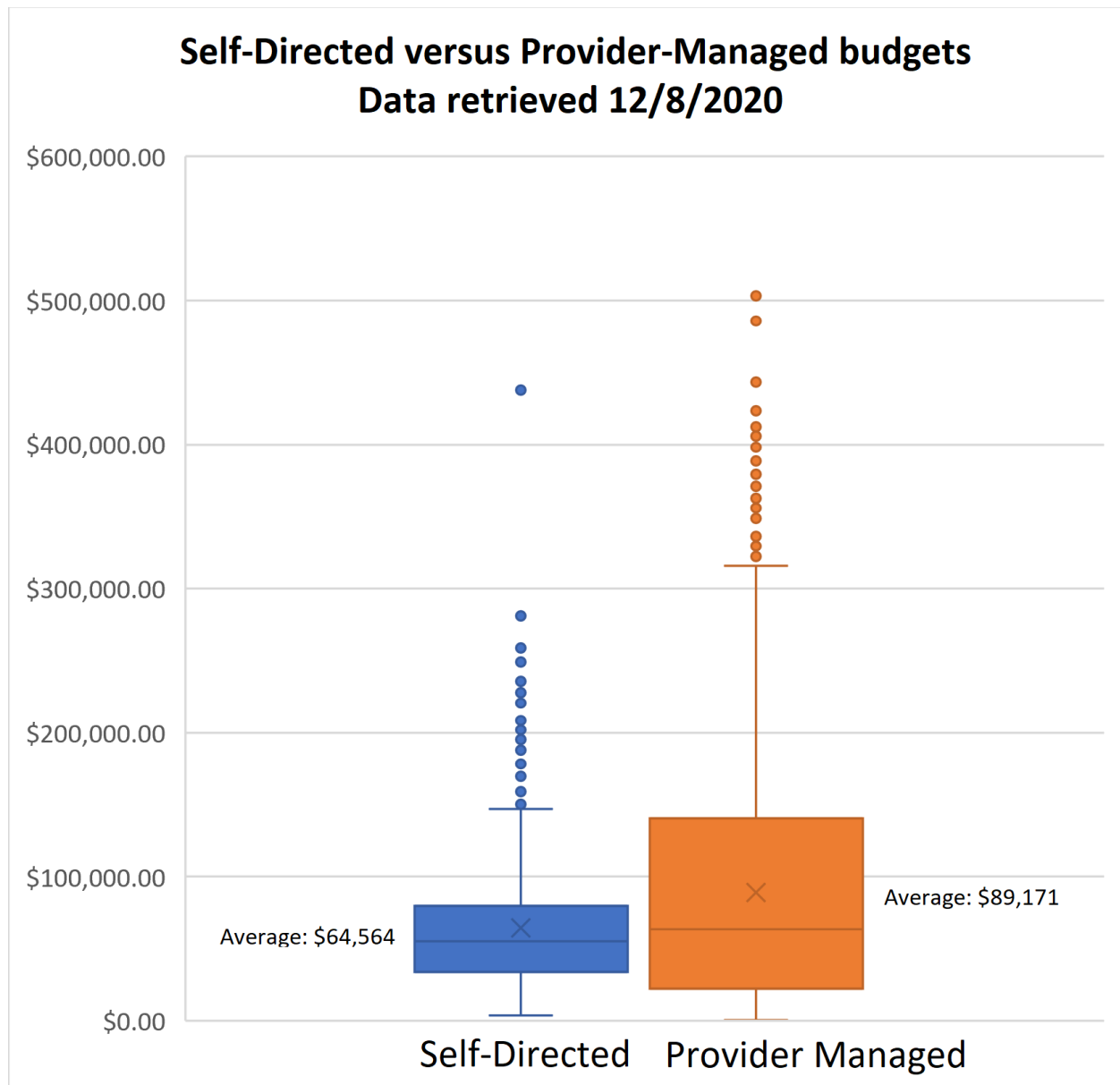
In 2005 when The Center of Medicare and Medicaid Services, CMS, awarded Maryland the New Directions Waiver, they made one point crystal clear: **They wanted people with disabilities to craft a life that made sense for them.** And Maryland's DDA did just that. Here is one example. An incredible plan developed by one participant paid for pottery classes at a community college and that person ended up opening a small business, displaying and selling their beautiful work. A key element in making this successful was that they needed minor support in class, so included in their plan was paying for their tuition and for a classmate willing to support the person, even their textbooks, and mileage. CMS said "we regularly do not pay for things such as these, but come to us and talk about the justification for these items to be reimbursed, and likely we will grant the usage of the funds." Citizens with Developmental Disabilities made lives custom tailored for themselves. It was truly person-centered and **FLEXIBLE**.

The leadership of DDA at the time established a mindset throughout its Administration for the success of Self-Directed Services. It made the promised changes to the new service delivery system. At the same time, those administrators understood the responsibility for being good stewards of federal and state funds. Self-directed plans cost no more than, **and often were significantly less than**, provider-managed services—**often with more powerful results.** Having worked with three previous DDA deputy secretaries, I know firsthand about their passion and commitment to self-direction and self-determination.

However, I saw a significant change beginning in 2009, which accelerated when the New Directions Waiver was merged into the Community Pathways waiver in 2013 and continues through today. Self-Directed Services has been bastardized, diluted and bureaucratized. There no longer seems to be understanding or compassion. **It is not person-centered. It is state-centered.** There is no commitment to the intent of people controlling their lives and becoming as independent as possible. Individuals no longer have the flexibility to craft supports that make sense for them and allow them to achieve their paths. No one is asking, like CMS did in 2004 "What do you want to do and

we will work with you?” And **no one at DDA is listening to the direct stakeholders**, their families and their advocates. People with disabilities have been unnecessarily negatively impacted. I hope the establishment of the Advisory Council will allow Maryland to recapture and re-implement the principles of self-direction. Empowering individuals with disabilities to live truly self-directed lives will ultimately benefit all of us.

Self-Directed Services provide the best of both worlds- flexibility for the participant to live their best life, and cost savings for the State of Maryland! On average, Self-directed budgets are 27% lower than traditional provider-managed budgets.



Data provided by DDA from PCIS2 database on 12/8/2020. This data represents 1,162 Self-directed participants and 14,872 participants receiving traditional provider-managed services.

Guidelines regarding provision of care by relatives and legally responsible adults

Copied from

Application for a §1915(c) Home and Community-Based Waiver [Version 3.6, January 2019]

Instructions, Technical Guide and Review Criteria

Release Date: January 2019

file:///C:/Users/suppo/OneDrive/Documents/CMS%20technical%20guide.pdf

Pages 119 -124

Items C-2-d and C-2-e address similar topics but are distinct. Both concern state policies regarding payment for the provision of waiver services by individuals who are related to the participant (and, in the case of Item C-2-e, a legal guardian of a participant). However, the scope of Item C-2-d is narrow. It solely concerns payment for the provision of personal care or similar services by legally responsible individuals (e.g., a parent of minor child or a spouse). The instructions for Item C-2d below define “personal care or similar services.” Item C-2-e addresses state policies regarding the payment for the provision of any type of waiver service by a relative or legal guardian, including the provision of services other than personal care by legally responsible individuals (keeping in mind that the provision of personal care or similar services by such persons has been addressed in Item C-2-d). In this item, a state specifies whether it permits payments to relatives or legal guardians for waiver services and, if so, any conditions or limitations that the state places on such payments. For example, a state may decide to make payments to relatives or legal guardians only in certain circumstances, for limited periods of time, or permit payment to be made only to specified types of relatives (e.g., relatives who do not reside in the same household as the participant). It is up to the state to decide whether to provide for either type of payment and, when such payments are made, to specify the circumstances when they are permitted. In the Appendix C-3 service specification template, there are check-offs as to whether the state allows for the provision of a service by a legally responsible individual and/or a relative/legal guardian. The conditions on payment specified in Items C-2-d and C-2-e apply to these check-offs. For example, if a state provides in Item C-2-e that a relative may furnish waiver transportation services only when there is no other provider available, then that condition applies when “relative/legal guardian” is checked as a potential provider of the transportation service in Appendix C-3. Whenever a legally responsible individual or relative/legal guardian is paid for the provision of a waiver service, the person must meet the provider qualifications that apply to a service and there must be a properly executed provider agreement. In addition, other requirements such as the proper documentation and monitoring of the provision of services also apply. Item C-2-d: Provision of Personal Care or Similar Services by Legally Responsible Individuals Instructions Select whether the waiver provides for extraordinary care payments to legally responsible individuals for the provision of personal care or similar services. If so, specify: (a) the types of legally responsible individual(s) who may be paid to furnish such services and the services they may provide; (b) applicable state policies that specify the circumstances when payment may be authorized for extraordinary care by a legally responsible individual and how the state ensures that

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the provision of services by a legally responsible individual is in the best interest of the participant; and, (c) the controls that are used to ensure that payments are made only for services rendered. Technical Guidance CMS policy is that payments for personal care or similar services delivered by legally responsible individuals (as defined in state law but typically the parent of a minor child or a spouse) are not eligible for federal financial participation. Legally responsible individuals do not include the parent of an adult beneficiary (including a parent who also may be a legal guardian) or other types of relatives, except as provided in state law). 42 CFR §440.167 prohibits FFP for payments to legally responsible individuals for the provision of state plan personal care services. This prohibition is based on the presumption that legally responsible individuals may not be paid for supports that they are ordinarily obligated to provide. See also Section 4442.3.B.1 of the State Medicaid Manual. Through an HCBS waiver, a state may elect to make payment for personal care or similar services that are rendered by legally responsible individuals when such services are deemed extraordinary care so long as the state specifies satisfactory criteria for authorizing such payments. The criteria must include how the state will distinguish extraordinary from ordinary care. By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization. States are not required to, but may also specify other limitations, such as specific circumstances under which legally responsible individuals may be paid providers. Such limitations could include the lack of other providers who are available to serve the participant during periods when the legally responsible individual would otherwise be absent from the home and, thereby, must remain in the home to care for the participant or when the specific needs of the participant can only be met by a legally responsible individual. In any case, providing for payments to legally responsible individuals is a state option, not a federal requirement. In the context of this item, personal care or similar services mean: (a) personal care (assistance with ADLs or IADLs) whether furnished in the home or the community and however titled by the state in the waiver (e.g., personal assistance, attendant care, etc.) and (b) closely related services such as home health aide, homemaker, chore and companion services. When a state provides for the payment to legally responsible individuals for extraordinary care, the service must meet all the waiver criteria required when delivered by a customary provider, as well as satisfy some additional protections. The legally responsible individual must meet the provider qualifications (as specified in Appendix C-3) that the state has established for the personal care or similar services for which payment may be made, and the state must conduct monitoring of such services as provided in Appendix D-2, including the required documentation and assurance that the services are delivered in accordance with the service plan. In addition, such arrangements require the proper execution of a provider agreement. State policies should include additional safeguards such as:

- Determining that the provision of personal care or similar services by a legally responsible individual is in the best interests of the waiver participant. A state should consider establishing safeguards when the legally responsible individual has decision-making authority over the selection of providers of waiver services to guard against self-referral.
- Limiting the amount of services that a legally responsible individual may furnish. For example, a state may decide to limit the amount to no more than 40 hours in a week and

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thereby take into account the amount of care that a legally responsible individual ordinarily would provide. When there is such a limitation, it should be reflected in the limitations section of the service specification in Appendix C-3. • Implementing payment review procedures to ensure that the services for which payment is made have been rendered in accordance with the service plan and the conditions that the state has placed on the provision of such services. • Addressing other foreseeable risks that might attend the provision of services by legally responsible individuals. In addition, states should be aware that unless the waiver uses institutional eligibility rules that disregard the family income of a child waiver participant, paying a legally responsible relative may affect the child's eligibility for Medicaid. To summarize, when a state provides for payment to legally responsible individuals for the provision of personal care or similar services, the services will be equivalent to services supplied by other types of providers, with some additional protections. The waiver must specify: • Whether payment is made to the parent(s) of minor children, spouses, or both or other (as defined by state law); • The waiver personal care or similar services for which payment will be made; • How the state distinguishes extraordinary care from ordinary care and any limitations of the circumstances under which payment will be authorized; • Limitations on the amount of services for which payment will be made; • How it is established that the provision of personal care or similar services by a legally responsible individual is in the best interests of the participant; and, • How it is determined that payments are made for services rendered.

Item C-2-e: State Policies Concerning Payment for Waiver Services Furnished by Relatives/ Legal Guardians Instructions This item concerns state policies regarding payment for waiver services rendered by relatives and/or legal guardians that do not fall within the scope of Item C-2-d. Select whether the state

CMS Review Criteria When the waiver provides for the payment for personal care or similar services to legally responsible individuals for extraordinary care, the waiver specifies: • The types of legally responsible individuals to whom payment may be made; • The waiver personal care or similar services for which payment may be made; • The method for determining that the amount of personal care or similar services provided by legally responsible individual is "extraordinary care," exceeding the ordinary care that would be provided to a person without a disability of the same age; • Limitations on the amount of personal care or similar services for which payment may be made; • How it is established that the provision of personal care or similar services by a legally responsible individual is in the best interests of the participant; and, • The procedures that are used to ensure that payments are made for services rendered.

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makes payments to relatives or legal guardians for any waiver service (besides personal care or a similar service furnished by a legally responsible individual as described in C-2-d). If the state makes payments to relatives and/or legal guardians for waiver services, select one of the next three choices and provide

the additional information under the selected choice. Technical Guidance At the option of the state, waiver services may be provided by a relative and/or legal guardian of the participant. When responding to this item, keep in mind that Item C-2-d addresses extraordinary care payments to legally responsible individuals who furnish personal care or similar services to a waiver participant. For the purposes of this item, legally responsible individuals are considered to be a type of “relative” with respect to payments for the provision of waiver services other than personal care or similar services. When a relative or legal guardian may be paid to provide waiver services, the relative or legal guardian must meet the provider qualifications that have been specified for the service. Services must be monitored as provided in Appendix D2 and there must be a properly executed provider agreement. This item presents four response choices as follows:

- No Payments. A state may elect not to make payments to relatives or legal guardians for the provision of any waiver services.
- Specific Circumstances. A state may elect to pay relatives or legal guardians for the provision of specified waiver services only in specific circumstances. Such circumstances must be specified by the state. Specific circumstances might include: (a) the lack of a qualified provider in remote areas of the state; (b) the lack of a qualified provider who can furnish services at necessary times and places; (c) the unique ability of a relative or legal guardian to meet the needs of a person; and/or, (d) other circumstances specified by the state. When this choice is selected, the waiver must specify the following:
 - ☐ The types of relatives or legal guardians that may be paid to furnish waiver services. For example, a state may specify that relatives may be paid to furnish services but not legal guardians. The state may specify that only relatives who do not live in the same household as the participant may be paid to furnish services. A state may specify that certain types of relatives may be paid to furnish services (e.g., grandparents of the participant) but others may not (e.g., legally responsible individuals). A state may provide that legally responsible individuals may be paid to furnish services (other than personal care or similar services, which have been addressed in Item C-2-d) that require specialized skills (e.g., nursing or physical therapy), provided that the legally responsible individual is not legally obligated to furnish such services.
 - ☐ The types of waiver services for which payment may be made to a relative or legal guardian. Non-legally responsible individuals may be permitted to furnish personal care or similar services.
 - ☐ The specific circumstances when payment may be made to a relative or legal guardian. The waiver also must describe the method for determining when these circumstances apply.
 - ☐ When payment may be made to a legal guardian, the waiver should include safeguards for determining that the provision of services by a legal guardian are in the best interests of the waiver participant, especially when the legal guardian exercises decision making authority on behalf of the participant in the selection of waiver providers.
 - ☐ The procedures that are followed to ensure that payment is made only for services rendered, and that services are rendered in the best interest of the individual.

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In Appendix C-3, there is the opportunity to select whether a waiver service may be provided by a legally responsible individual or a relative/legal guardian. When this choice has been selected, the selection in Appendix C-3 is qualified by the response to this item (i.e., “relative/legal guardian” means the types that are specified in this item). It is not necessary to repeat the information provided in response to this item in the service specifications.

- Specific Circumstances Do Not Apply. A state may provide that relatives or legal guardians are permitted to be paid for rendering waiver services but not limit payment for such services to specific circumstances. That is, provided that the relative otherwise meets the

qualifications to provide a service, the state will make payment to the relative or legal guardian. When this selection is made: ☐ Specify any limitations on the types of relatives or legal guardians who may furnish services (e.g., whether legally responsible individuals are excluded). ☐ In Appendix C-3, for each waiver service that a relative or legal guardian may furnish, check off relative/legal guardian as a provider type. When relative/legal guardian is not checked off in Appendix C-3, the state does not allow relatives or legal guardians to be paid to furnish the service. For example, if this selection has been made in Item C-2-e and transportation is the only service that has been checked off in Appendix C3, then only the relatives or legal guardians specified here may be paid to furnish transportation and they may not be paid to provide any other waiver services. ☐ Specify the procedures that have been established to ensure that payment is made only for services rendered. • Other Policy. Select this choice when either of the foregoing two choices does not accommodate the state's policies. For example, the state may restrict payment for waiver services to specific circumstances in the case of some services or certain types of relatives or legal guardians but not in the case of other services or other types of relatives or legal guardians. When this choice is selected, the information provided in the text field should parallel that required in the foregoing choices, depending on whether specific or extraordinary circumstance are involved.

Item C-2-f: Open Enrollment of Providers Instructions In the text field, specify the processes that are employed to assure that all willing and qualified providers have the opportunity to enroll as waiver service providers. Technical Guidance Except when a §1915(c) waiver operates concurrently with a waiver granted under §1915(b) of the Act waiving §1902(a)(23) with respect to Medicaid beneficiary free choice of provider, any willing and qualified provider must be afforded the opportunity to enroll as a Medicaid provider. A willing provider is an individual or entity that executes a Medicaid provider agreement and accepts the state's payment for services rendered as payment in full. A qualified provider is a provider that meets the provider qualifications set forth in the approved waiver. The state must provide for the continuous, open enrollment of waiver service providers. A state may not place obstacles in the way of open provider enrollment (e.g., by selecting only a limited number of providers to furnish a waiver service through an RFP process, requiring that a provider be capable of furnishing services on a statewide basis or requiring that a provider contract with a governmental entity (other than the Medicaid agency) or affiliate with an Organized Health Care Delivery System). States have latitude in establishing qualifications to ensure that providers possess the requisite skills and competencies to meet the needs of the waiver target population. However, a state may not specify qualifications that are unnecessary to ensure that services are performed in a safe and effective manner. When CMS reviews the qualifications associated with each waiver service, it examines whether the proposed qualifications create obstacles to the enrollment of all willing and qualified providers. In response to this item, describe the processes that are employed in conjunction with the operation of the waiver to assure that all willing and qualified providers have the opportunity to enroll as waiver providers. Potential providers should have ready access to information regarding the requirements and

procedures to enroll as waiver providers. Effective processes might include making provider enrollment information and forms continuously available via the internet and/or

CMS Review Criteria When the waiver provides for the payment of services furnished by relatives or legal guardians:

- The types of relatives or legal guardians to whom payment may be made are specified.
- The waiver services for which payment may be made to relatives or legal guardians are specified.
- When relatives or legal guardians may be paid to furnish waiver services only in specific circumstances, the waiver specifies the circumstances and the method of determining that such circumstances apply.
- Limitations on the amount of services that may be furnished by a relative or legal guardian are specified.
- When a legal guardian who exercises decision making authority may be paid to provide waiver services, the waiver specifies how it is established that the provision of services by the guardian are in the best interests of the participant.
- The waiver specifies the procedures that are employed to ensure that payment is made only for services rendered and that services are furnished in the best interest of the individual.