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Arizona's Medicaid-Funded System of Supports for Individuals with Intellectual and Developmental Disabilities

A Pioneering Approach with Valuable National Lessons for Today's Home and Community Based Services Programs

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Executive Summary

Arizona's Medicaid-funded system of supports for individuals with intellectual and developmental disabilities (I/DD) is unique. Under a special Medicaid authority known as a Section 1115 Demonstration Project Waiver, Arizona's Division of Developmental Disabilities (DDD) serves as a managed care organization (MCO). This arrangement is one-of-a-kind in that the DDD has a contract to provide or arrange the full array of health, behavioral health, as well as home and community-based services to all eligible individuals. This arrangement can be advantageous in providing a holistic, person-centered approach to services that considers all aspects of the individual's care. The additional benefit of Arizona's approach is the ability to provide timely services and supports to all individuals with I/DD who are eligible for the program, rather than having individuals and their families face waiting lists of years or even decades to receive any home and community-based services (HCBS).

This paper provides the historical origins of Arizona's DDD system and includes an overview of the strong practices in use in Arizona that can help other states. This paper examines Arizona's approach to support coordination that includes a strong focus and important practice of building a relationship with an individual and his/her family, instead of solely relying on assessment instruments. The paper explores Arizona's approach to serving a culturally and geographically diverse population while ensuring strong stakeholder engagement. Then it reviews the benefits of Arizona's DDD overseeing the full array of services and supports an individual may need. The paper also surveys opportunities for ongoing work and/or improvement within Arizona's Medicaid-funded system of supports.

In addition to the Arizona-specific information, there is great activity nationally with the recently published HCBS regulations. Although Arizona's system of supports is through a Section 1115 waiver, these new requirements will apply. These regulations have strong requirements for ensuring that individuals receive services in settings that are truly home and community-based, providing full access to the community.

Introduction

Arizona's system of supports for individuals with I/DD and their families holds national significance in innovative and integrated service delivery. United Cerebral Palsy's Case for Inclusion 2014, ranks Arizona number one in the country across a number of domains, including promoting independence, tracking health and safety, and supporting families.¹ Arizona offers a system that supports people eligible for Medicaid long-term services in their homes and communities without a waitlist — unique only to California. The service and support system is of significant benefit to persons served, their families and the program's bottom line.

This paper will explore Arizona's system of service delivery and those attributes that have contributed to Arizona's success in providing strong community services for individuals with I/DD. The paper will also identify some of the challenges faced and employed strategies to address them. In addition, this paper will provide a brief overview of the changing national landscape for HCBS and potential implications for Arizona.

Historical Perspective

To understand both the uniqueness and significance of the Arizona approach in supporting individuals with I/DD, it is important to understand the history of Arizona's publicly-funded health, behavioral health, and long-term service and support programs.

In 1965, Congress enacted Title XIX of the Social Security Act (SSA) — known as the Medicaid program — into law. This federal and state entitlement program pays for medical assistance for certain individuals and families with low incomes and resources. While state participation in Medicaid is voluntary, states were encouraged and enticed to participate in this program through federal funding that would broadly apply to certain social service programs. States

¹ United Cerebral Palsy, The Case for Inclusion 2014

participating in the program must agree to cover certain eligibility groups and services, with the option to cover additional groups and services left to the state's discretion. By 1972, all but one state, Arizona, elected to participate in Medicaid.

The federal Medicaid structure was based in large measure on its predecessor program, the Kerr-Mills Act. An important feature in the Kerr-Mills Act was to extend medical benefits to a new category of people who, at the time, were known as the medically indigent — persons age 65 or over, not receiving old age assistance cash payments, but whose incomes would be “. . . insufficient to meet the costs of necessary medical services. . . .”² This provided a template for the categories of eligibility eventually included in the Medicaid program. Like Medicaid, the Kerr-Mills program was a voluntary program for states. Arizona was one of only 10 states that did not ultimately participate in the Kerr-Mills program.

In fact, even after the availability of Medicaid, Arizona continued to provide healthcare through a system of county-run health care programs. This practice, which had begun in the mid-1800s, lasted until 1981, when the counties asked the state for relief.³ It was at this time that Arizona sought federal participation in their healthcare programs. The requested approach to Medicaid, however, was a solution and a construct tailored to Arizona's specific needs and specifications. In 1982, Arizona gained approval under Section 1115 of the SSA from the Centers for Medicare & Medicaid Services — formerly known as the Health Care Financing Administration — for a demonstration program to implement the Arizona Health Care Cost Containment System (AHCCCS). Arizona's Section 1115 is the longest-operating demonstration project in the country.

² Moore, Judith D.; Smith, David G. *Legislating Medicaid: Considering Medicaid and Its Origins*. Health Care Financing Review/winter 2005-2006/Volume 27, Number 2

³ *Brief history of AHCCCS. Arizona Health Care Cost Containment System.*
<http://www.azahcccs.gov/Careers/History.aspx>

With the entire program authorized under a Section 1115 Demonstration Waiver and based entirely on a managed care service delivery system, Arizona had a one-of-a-kind structure within the national Medicaid landscape for many years. While in current times, many states operate limited or comprehensive 1115 programs and almost all states have shifted some or all of their Medicaid services to managed care, these approaches were uncommon in the early 1980s in Medicaid. Moreover, as explained later in this document, Arizona still stands alone in its unique approach in supporting people with I/DD.

Arizona added a system of long-term services and supports for individuals who were aging, individuals with physical disabilities, and individuals with intellectual and developmental disabilities in 1988. The program entitled the Arizona Long Term Care System (ALTCS) followed a similar approach to arranging for and delivering services, paying an entity a capitated amount of money each month for the delivery of all needed services and supports. For individuals with developmental disabilities, this entity was the DDD within the Department of Economic Security (DES). The use of DDD as the managed care entity represented another rare arrangement on the federal Medicaid landscape. The contract with DDD is a risk-based contract that comports with all applicable federal managed care regulatory requirements. DDD is contractually responsible for the full array of services, including acute, behavioral health, and long-term services and supports — both community based and institutional. Arizona's broad approach to eligibility enabled the state to engage with people early, not solely waiting until crisis occurred.

With the responsibility and authority to arrange for and deliver the array of services for individuals with I/DD and their families, DDD set a course for a system based upon the strengths of the Arizona communities, families and the individuals served. As many states were tweaking vestiges from institutional service models to fit a community-oriented system, Arizona and key stakeholders within the state were able to build a community-based system of supports, rather than one based upon institutional services. Without having to spend significant time and dollars on deinstitutionalization efforts that meet the expectations of

individuals and their families, and comply with Olmstead, Arizona has been able to invest continually into community systems improvement.

As of June 2014, DDD was providing acute, behavioral, and long-term services and supports to more than 26,904 individuals through Medicaid ALTCS. DDD also provides case management/support coordination to 4,207 additional individuals who have Medicaid eligibility, but who do not meet the eligibility criteria for ALTCS, as well as provides support to 2,822 individuals who are not Medicaid eligible. The vast majority of individuals — more than 90% — are served in settings, such as their own home, a family home, adult developmental home, or other small group settings, including individually designed living arrangements with fewer than three residents.¹ Arizona's services for individuals with I/DD are structured such that all individuals are able to enter the 1115 without waiting, unlike 1915(c) waivers in other states that have limitations on enrollment. Few people live in-group settings, contributing to lower cost, and more person-centered services.

In addition to the historical perspectives, the demographics of Arizona are also important to consider. Arizona has a population under 7 million people, with more than 25% of whom are Hispanic/Latino.⁴ There are 22 federally recognized Native American tribes in Arizona, which represent a vast majority of tribal land in the nation. DDD has undertaken strong efforts to ensure that staffs working with the tribes have a deep understanding of the specific tribal cultural considerations, in some cases from first-hand knowledge. While there are urban centers within Phoenix having more than 5 million people, and Tucson having more than a half million people, there are also small, very rural areas throughout the state, with varying climate and topography. This variation requires strong person- and family-centered approaches to service delivery to appropriately address cultural considerations or unique issues related to service access, such as providing services in more remote or rugged areas of the state that present physical barriers to reaching individuals.

⁴ <http://www.arizona.com/demographics.html>

Contributors to Success

There are some basic system attributes, including continuous quality improvement, that lead to a system that learns and improves over time. Arizona's system encompasses many of these attributes. (Refer to Appendix A for a listing of DDD's specific role and activities.)

Leadership that Values Stakeholder Engagement

DDD's leadership consistently focuses the system on values undergirding all aspects of work, providing expectations for team members that emphasized community involvement, and person and family centered systems of care. As a result, the voices of individuals and families are highly valued in Arizona. The state contracts with family groups for family mentoring, peer support, training, and technical assistance for families and professionals. Importantly, the state also seeks individual and family input on all aspects of policy analysis and development, contributing to a stronger final product. The state also supports self-advocacy organizations' ability to mentor other self-advocates. These investments help foster greater self-advocacy within the state, supporting individuals with the skills and abilities to advocate for themselves, in addition to developing a model for self-advocacy for others to promote system changes over time. State support for self-advocates requires ongoing nurturing to ensure that self-advocates have a firm understanding of the service system and the tools needed to effectively advocate for themselves and others.

Eligibility, Access and Services

The eligibility for the ALTCS/DD program is linked to intellectual disabilities and other specific related conditions, including autism, cerebral palsy and epilepsy. DDD determines eligibility into the system, while AHCCCS determines eligibility into the long-term care system based on an individual's level of support needs, developmental disability and related evaluative materials.

There are no wait lists for ALTCS eligible individuals, so eligible individuals are able to promptly access needed services. Individuals may experience a wait time for services, if additional provider capacity in certain areas or for certain services is needed. Provider identification and recruitment efforts are ongoing to address shortages.

Support coordinators, who are knowledgeable about all aspects of the service system, including acute and behavior support services, engage individuals in a conversation to determine what services and supports would be needed. The state does not use an algorithm, rate bands or rate tools, and instead empowers support coordinators to engage in a conversation to determine the individual's needs. The conversation focuses on understanding the person's top priorities, what is currently happening in his/her life, what supports are needed to reach priorities and outcomes, the individual's daily schedule to assist in understanding the rhythm of the day, and where supports are needed. The support coordinator also helps the person understand their options, including that they can choose from among established provider(s) or recruit a family member, friend or someone from a spiritual community to support them. While there are still authorization controls, such as prior-approval for certain services or for certain levels of service, as an MCO, this conversation-based approach provides a framework for individual and family outcomes in service delivery as described below. For example, a support coordinator may be permitted to authorize certain levels of respite directly, while requiring higher levels of review for a plan with multiple nursing hours.

While expenditures for individual members are limited to an individually determined amount (based on what it would cost to support that particular person in an institutional setting), exceptions are permitted to address short-term needs and/or conditions.

This conversation builds a relationship between the individual, his/her family, and the support coordinator, based on understanding and trust. These relationships have formed the foundation for the system where individual satisfaction is high, and service costs are among

the lowest nationally. This relationship can also be helpful in solving conflicts when individuals' wishes differ from his/her family's wishes.

DDD provides for the full range of acute, behavioral and long-term services and supports for eligible individuals. The service package includes services, such as habilitation, employment services, respite, behavioral health services, therapies and transportation.⁵

DDD has used the opportunity throughout the life of the program to evolve these services to incorporate best practices in the field. Specifically, DDD has always had a strong emphasis on strategies to support families and people with DD to remain at home or in their communities. There has also been an increased emphasis to prioritize employment, as evidenced by the state's movement toward an Employment First Initiative and to ensure that individuals are able to access positive behavior supports (PBS) as they need it. DDD is able to utilize the tools available in a managed care environment to weave best practices nimbly as they emerge. PBS consultants have been able to work as part of a team where people live and spend their day with access to acute medical care information that may be affecting behavior, due to the integrated nature of AZ's DDD system.

Data and Quality

DDD knows a great deal about its service delivery system by using a successful data collection and analysis strategy, which includes service utilization, patterns and costs. Data is used at all levels of the system, from the support coordinators to the program administrators, to make sound and timely decisions. For example, data is used in the course of daily job performance for all DDD team members, including support coordinators who are using information to make on-the-spot decisions to provide support to individuals and their families, including authorizing supports up to certain levels, such as respite care.

⁵ State of Arizona, Arizona Long Term Care System, Member Handbook 2013-2014; <https://www.azdes.gov/InternetFiles/Pamphlets/pdf/PAD-465english.pdf>

Data also form the basis for the state's approach to quality, which is embedded within the state's approved 1115 demonstration. DDD utilizes its timely data and program information to make decisions for program improvement. Through the aggressive use of performance improvement projects (PIPs), Arizona has been able to make significant progress in improving quality across the program. One example of such a successful PIP is the state's dramatic decrease in decubiti ulcers among individuals served.

Areas of Opportunity

While there are many successes within the Arizona system of services for individuals with I/DD, there are, as with any state, opportunities for continued improvement. These include:

- Ensuring that barriers to information stemming from organizational silos do not emerge for individuals and families.
- Continuing efforts to ensure choice, advocacy and self-advocacy.
- Increasing the numbers of individuals who are employed in competitive jobs.
- Increasing the quality and availability of strong behavioral health supports. All states, including Arizona, are striving to improve the availability and quality of behavioral health supports for individuals with I/DD.
- Continuing improvement of shared living opportunities with a focus on true relation based living arrangements, such as Shared Living.⁶
- Addressing the support needs of a growing number of children diagnosed with autism through the provision of clinical and support services to meet the needs of the children and the family.
- Supporting aging caregivers, including engaging with caregivers to plan for future options.

⁶ Shared Living Guide; Robin Cooper, Kara LeBeau, and Nancy Thaler, NASDDDS May 2011 Revised October 2011

The Changing National Landscape for HCBS: Implications for Arizona

Important for all states, CMS has issued final regulations that include significant changes that affect all HCBS authorities. CMS has indicated through guidance that these rules will also be applied to HCBS delivered under the authority of an 1115 demonstration.⁷ These regulations, effective March 17, 2014, include requirements related to person-centered planning, quality, the nature and characteristics of settings that may be considered allowable in an HCBS authority and other important provisions. These final rules are the culmination of a multi-year effort by CMS and other federal agency partners to define the attributes of settings that are considered home and community-based, rather than institutional. Only those settings meeting the HCBS characteristics established in the new regulations and guidance will be eligible for Federal Financial Participation (FFP), i.e., what the federal government provides to match the state's general fund dollars. In Arizona's case, the Federal government contributes 68.46% in FFP for allowable expenditures.⁸

The impetus for this rule was twofold. First, to better align Medicaid funding and program requirements with the civil rights protections afforded to individuals with disabilities under the Americans with Disabilities Act (ADA) and affirmed through the Supreme Court's Olmstead decision. Second, to address concerns that current Medicaid HCBS mechanisms were being used in some states to fund institutional-style settings (both residential and non-residential) that did not afford individuals the opportunities necessary to enable them to meaningfully engage in their communities.

⁷ See Federal Register - <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf>

⁸ ASPE FMAP 2015 Report; Federal Financial Participation in State Assistance Expenditures; Federal Matching Shares for Medicaid, the Children's Health Insurance Program, and Aid to Needy Aged, Blind, or Disabled Persons for October 1, 2014 through September 30, 2015

The new Medicaid rule identifies qualities of HCB settings and services that must be met by states and providers. CMS has provided preliminary implementation guidance to states related to settings in which residential supports are delivered and has announced that guidance related to the application of these rules to non-residential settings will be forthcoming. Specifically, the rule provides that to qualify as home and community-based, a setting must minimally have all of the following qualities based on the needs of the individual as indicated in his or her person-centered service plan:

- The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the individual from among setting options, including non-disability specific settings, and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan, and are based on the individual's needs, preferences, and in the case of residential settings, the resources available for room and board.
- The setting ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- The setting optimizes but does not regiment individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- The setting facilitates individual choice regarding services and supports, and who provides them.

The rule provides additional requirements related to privacy, lease and/or residency agreements, visitor policies, access to food, and choice of whether and with whom to share a room that apply when an individual receives services in a provider-owned or operated setting. Any abridgements of the qualities articulated in the rule must be documented and

address a need in the individual's plan of care. Review timelines must be included so that restrictions do not carry on in perpetuity without a basis in need.

These rules have the potential to make significant national changes to the nature of the services offered by states' in-home and community-based systems, with the goal being maximized choice and opportunities for community engagement. Each state, including Arizona, will be undertaking a careful analysis of their service system to ensure compliance with the rule. Given Arizona's service patterns, day and employment settings will require careful review and planning in addition to attention to residential services. As Arizona continues efforts toward employment, that will assist in ensuring that individuals are not isolated and are receiving services in the most integrated setting possible.

Because of Arizona's path and success in establishing a system using person-centered, non-congregate settings, many states may look to Arizona for strategies to leverage as they adjust their own systems toward compliance with these new requirements. Arizona's approach to person-centered planning and service delivery, support coordination and supporting families may assist states in their compliance strategies and long-term system sustainability.

Appendix A - Brief DDD Overview

DDD's credo is:

To support the choices of individuals with developmental disabilities and their families by promoting and providing within communities, flexible, quality, consumer-driven services and supports.

This credo is especially important considering the broad scope of services managed by DDD. As the Managed Care Organization (MCO), DDD manages the full range of services, including acute, HCBS and institutional.

By providing a continued focus on the individual being able to receive quality services — of all types — in their communities, Arizona established expectations across both health and long-term service disciplines. Importantly, home and community based services, not institutional, formed the foundation for the long-term service delivery system. This foundation, coupled with the flexibility afforded through DDD's performance as the managed care organization, has enabled Arizona to develop and deploy innovative services and emerging best practices. Importantly, Arizona:

- Supports individuals early in life and through the life span keeps families together- no waiting to enter the waiver and providing linkages and early supports to prevent crisis.
- Invests in community, inclusive models of supports and services such in-home services and supports.
- Builds supports based on family strengths and community relationships, as identified through the conversation and relationship between the support coordinator and the family.
- Utilizes their particular "brand" of managed care to keep budgets balanced, the state DD agency is highly involved, ensures the supports are person-centered, and uses managed care "tools" to increase community networks. This work can be seen in the data with Arizona providing services to individuals living in their own homes and family homes, as well as in the low costs per person as compared to other states.

- Enables support coordination to work across both health services and home and community based supports. This is important to ensure that the individual's supports for health, behavioral health and community integration are all working to further the individual's goals.
- Invests in families and self-advocates by providing supports to further family networks and helping self-advocates gain the skills they need to have a strong voice.

DDD, while accountable to AHCCCS for strong contract performance, has control and leadership on policies, procedures and methods of oversight for the program. This is a rare arrangement, where DDD has a contractual obligation to deliver the full array of Medicaid services to eligible individuals. In most states, this responsibility is fragmented, leading in some cases to disjointed care for individuals with I/DD. In addition, DDD takes a leadership role in the overall policy related to rates and reimbursements, helping to ensure rates are aligned with the state's values. For example, there have been strategies to increase the number and types of community based services and providers focused on in home and local communities. While the recession led to rate reductions across the Medicaid program, including DDD and its providers, having DDD in this role has resulted in the state's ability to leverage the content expertise necessary to design a person-centered system of supports. It has also placed the focus of accountability squarely with DDD so that they are engaged with and responsive to the community they serve. In many states, Medicaid cuts are done without regard to the specific considerations of the populations served. Arizona's model maintains I/DD program expertise, while ensuring accountability to the Medicaid agency — AHCCCS — for service delivery, as well as budgetary considerations.