

Introduction:

The Olmstead Survey was designed to assist AHCCCS with updating the Olmstead Plan by seeking input from members, family members, provider staff, and representatives from health plans and state agencies.

Background:

In June 1999, the United States Supreme Court rendered a decision, *Olmstead v L.C.*, which provides an important legal framework for the efforts of state and federal governments to integrate individuals with disabilities into the communities in which they live. Under the Court's decision, states are required to provide community-based services for persons with disabilities, who would otherwise be entitled to institutional services, when such placement is:

- Appropriate,
- Agreed upon by the individual, and
- Reasonably recommended, taking into account the resources available to the State and the needs of others who are receiving State-supported disability service

Community-based services:

Community-based services are important because they help keep people in their homes, schools, and local communities, resulting in a more positive effect on the person and their family. Community-based services can be defined as services provided in community settings that are outside of hospital, institution, and outpatient settings. This includes, but is not limited to, case management, day programs, personal care, community-based housing subsidies and supports, and employment services and supports. These services may be provided in a building or facility, but the building or facility must be located within the community.

Survey details:

The survey was first published to the AHCCCS Olmstead web page on July 6, 2021, and closed on November 5, 2021. Participants were asked to base their responses on their experiences with community-based services in Arizona when completing the survey. Participants were asked to identify themselves into one of the three following categories: 1) Provider/Health Plan/State Government staff; 2) Member; or 3) Family Member. Each of the questions asked were the same questions for each stakeholder but worded slightly differently to accommodate their frame of reference. Participants were asked to rank their top three responses from a predetermined list of responses as to which AHCCCS efforts and initiatives have had the most positive/negative effect on the availability and accessibility of community-based services. Participants were also asked to rank their top three populations, or groups, that might be disproportionately experiencing barriers or challenges to the availability and accessibility of community-based services. For each question the respondent was given the option to write-in a response.

The community had a number of ways to learn about the Olmstead Survey, while being encouraged to complete the survey and share with others, including through the AHCCCS website, social media (Facebook, Twitter, and LinkedIn), the AHCCCS Office of Individual & Family Affairs (OIFA) Newsletter, the Arizona Council of Human Service Providers, and through disability advocates. AHCCCS also marketed the Olmstead Survey through external presentations to the Behavioral Health Planning Council, the Arizona Peer & Family Coalition, the Autism Spectrum Disorder Committee, the Arizona Long Term Care System (ALTCS) Advisory Council, and two Community Stakeholder Meetings.

Summary:

The summary below includes the total responses for each question, separated by stakeholder category. The summary also includes notable observations and summarized statements of the write-in responses.

Survey Response Count:

- Provider/Health Plan/State Government – 68 responses
- Member – 12 responses
- Family Member – 54 responses

AHCCCS greatly appreciates the community in taking time to provide feedback on the Olmstead Survey. AHCCCS is further analyzing the data internally to continue leveraging the next steps of the Olmstead Plan development.

Responses:

| Approximately how long have you worked, received services, or friend/family received services within the Medicaid system? | | | | |
|---|---------------------------------------|-----------|---------------|------------|
| Responses | Provider/Health Plan/State Government | Member | Family Member | Total |
| 10+ years | 33 | 5 | 27 | 65 |
| 6-10 years | 16 | 2 | 10 | 28 |
| 1-5 years | 13 | 5 | 12 | 30 |
| Under 1 year | 6 | 0 | 5 | 11 |
| Total | 68 | 12 | 54 | 134 |

Observations:

- **Almost half (49%) of the total respondents have either worked, received services, or a friend/family member received services within the Medicaid system for more than 10 years.**
- **Only 9% (12/134) of the total respondents were identified as Members.**

In your opinion, how has the availability and accessibility of community-based services changed since you started working/receiving services within the Medicaid system?

| Responses | Provider/Health Plan/State Government | Member | Family Member | Total |
|-----------------------|---------------------------------------|-----------|---------------|------------|
| Has slightly improved | 25 | 3 | 15 | 43 |
| Has declined | 8 | 2 | 11 | 21 |
| Has slightly declined | 9 | 2 | 9 | 20 |
| Has improved | 15 | 3 | 8 | 26 |
| Has greatly declined | 3 | 2 | 8 | 13 |
| Has greatly improved | 8 | 0 | 3 | 11 |
| Total | 68 | 12 | 54 | 134 |

Observations:

- **Overall, 60% (80/134) reported some sort of improvement**
 - **71% (48 out of 68) from Provider/Health Plan/State Government;**
 - **50% (6/12) from Members; and**
 - **48% (26/54) from Family Members.**

Of those listed below, please choose which have had the **most positive effect on the availability and accessibility of community-based services? (Please only select your top 3)**

| Responses | Provider/Health Plan/State Government | Member | Family Member | Total |
|---|---------------------------------------|--------|---------------|-------|
| Peer Support | 32 | 9 | 13 | 54 |
| Availability of Telehealth services (virtual services) | 24 | 4 | 21 | 49 |
| Ability to receive both physical health and mental health services under the same Health Plan | 16 | 4 | 11 | 31 |
| In-home wrap-around services, such as skills training and development, personal care, etc. | 16 | 1 | 10 | 27 |
| Awareness of available services | 15 | 2 | 8 | 25 |
| Care coordination | 11 | 3 | 9 | 23 |
| AHCCCS policies & procedures | 10 | 1 | 11 | 22 |
| Community-based housing subsidies and supports | 7 | 2 | 13 | 22 |
| Family-run organizations | 0 | 0 | 21 | 21 |

| | | | | |
|--|------------|-----------|------------|------------|
| Family Support | 19 | 2 | 0 | 21 |
| Access to services in the area where you work/live | 8 | 2 | 10 | 20 |
| Members able to receive both physical health and mental health services by the same Provider | 11 | 2 | 5 | 18 |
| Number of available services in the area where you work/live | 9 | 2 | 5 | 16 |
| Behavioral health crisis services network | 5 | 1 | 5 | 11 |
| Employment services and supports | 6 | 0 | 5 | 11 |
| Waiting period to receive services | 4 | 1 | 4 | 9 |
| Voice and Choice initiative | 3 | 0 | 3 | 6 |
| Crisis facilities, including detox | 2 | 0 | 4 | 6 |
| Administrative procedures (paperwork and processes) | 4 | 0 | 2 | 6 |
| Justice initiatives/Reach-in activities | 2 | 0 | 2 | 4 |
| Peer-run organizations | 0 | 0 | 0 | 0 |
| Total | 204 | 36 | 162 | 402 |

Observations:

- 75% (9/12) of Members selected “Peer Support” as one of their responses.
- Of the 21 total responses for “Family-run organizations”, 100% came from Family Members.
- “Peer Support” had the most responses with 54, however “Peer-run organizations” did not have a single response.
- Of the 21 total responses for “Family Support”, none were from Family Members.

There were 40 write-in responses, including several comments identifying positive endorsements for peer support and family support services. There were also a number of responses acknowledging the roles of organizations in supporting the availability and accessibility of community-based services, including naming specific advocacy agencies, like NAMI and the Arizona Peer and Family Coalition.

Lastly, there were several responses that reiterated items that were already on the list, including peer/family-run organizations, peer/family support, voice and choice, employment support, housing support, telehealth services, care coordination, in-home wrap-around services, and crisis services.

Of those listed below, please choose the biggest challenges to the availability and accessibility of community-based services. (Please only select your top 3)

| Responses | Provider/Health Plan/State Government | Member | Family Member | Total |
|---|---------------------------------------|--------|---------------|-------|
| Waiting period to receive services | 29 | 4 | 20 | 53 |
| Awareness of available services | 22 | 5 | 16 | 43 |
| Administrative procedures (paperwork and processes) | 25 | 4 | 12 | 41 |

| | | | | |
|---|------------|-----------|------------|------------|
| Number of available services in the area where you work/live | 17 | 2 | 18 | 37 |
| Care coordination | 19 | 0 | 17 | 36 |
| Access to services in the area where you work/live | 10 | 3 | 15 | 28 |
| Community-based housing subsidies and supports | 14 | 3 | 11 | 28 |
| AHCCCS policies & procedures | 12 | 4 | 6 | 22 |
| Behavioral health crisis services network | 9 | 4 | 4 | 17 |
| Employment services and supports | 8 | 1 | 7 | 16 |
| Family Support | 7 | 1 | 6 | 14 |
| In-home wrap-around services, such as skills training and development, personal care, etc. | 4 | 1 | 7 | 12 |
| Crisis facilities, including detox | 5 | 0 | 5 | 10 |
| Peer Support | 7 | 0 | 3 | 10 |
| Voice and Choice initiative | 2 | 2 | 5 | 9 |
| Members able to receive both physical health and mental health services by the same Provider | 3 | 1 | 5 | 9 |
| Ability to receive both physical health and mental health services under the same Health Plan | 3 | 0 | 3 | 6 |
| Availability of Telehealth services (virtual services) | 4 | 0 | 1 | 5 |
| Justice initiatives/Reach-in activities | 4 | 0 | 1 | 5 |
| Family-run organizations | 0 | 1 | 0 | 1 |
| Peer-run organizations | 0 | 0 | 0 | 0 |
| Total | 204 | 36 | 162 | 402 |

Observations:

- **61% (25/41)** of the responses for **“Administrative procedures (paperwork and processes)”** came from Provider/Health Plan/State Government.
- **80% (4/5)** of the responses for **“Availability of Telehealth services (virtual services)”** came from Provider/Health Plan/State Government.
- Although **“Care Coordination”** had the fifth most responses (36), zero were from Members.

There were 56 write-in responses, including several listing challenges with the provider network, from services to policies. There were also a number of responses identifying concerns ranging from lack of accountability and oversight of the health plans and providers to rates issues.

Lastly, there were several responses that reiterated items that were already on the list, including the number of available services, access to services, awareness of services, administrative procedures, coordination of care, and waiting period to receive services.

In your opinion, are there any specific membership populations or groups that are disproportionately experiencing barriers or challenges to the availability and accessibility of community-based services? (Check all that apply) If other, please type in your answer(s) in the space provided.

| Responses | Provider/Health Plan/State Government | Member | Family Member | Total |
|--|---------------------------------------|-----------|---------------|------------|
| Members engaging in behavioral health services that do not have a SMI designation | 30 | 4 | 18 | 52 |
| Members with a Serious Mental Illness (SMI) designation | 17 | 8 | 26 | 51 |
| Members with developmental and intellectual disabilities in the ALTCS DD program | 18 | 7 | 22 | 47 |
| Members living in rural and frontier areas | 26 | 6 | 14 | 46 |
| Members coming out of an inpatient setting | 14 | 5 | 21 | 40 |
| Members with a substance use disorder (SUD) | 22 | 3 | 10 | 35 |
| Members with justice-involvement | 12 | 6 | 12 | 30 |
| Members who are elderly and/or have physical disabilities in the Arizona Long-Term Care System (ALTCS) program | 14 | 6 | 10 | 30 |
| Members with or at risk of an Autism Spectrum Disorder | 12 | 2 | 15 | 29 |
| Children in foster care | 11 | 3 | 8 | 22 |
| Members who identify as American Indian/Alaska Native enrolled with HP | 11 | 2 | 7 | 20 |
| Youth/children | 6 | 5 | 9 | 20 |
| Other | 7 | 1 | 8 | 16 |
| None that I can think of | 10 | 0 | 3 | 13 |
| Total | 210 | 58 | 183 | 451 |

Observations:

- **Of the multiple respondents, it's clear that the community is recognizing the need for equity across all populations and that all populations are experiencing some sort of barrier, as evidenced by those with the fewest pre-identified selections still receiving at least 20 responses.**

There were 16 write-in responses. Notable additions to this list include individuals having difficulty understanding and navigating the Department of Economic Security/Division of Developmental Disabilities (DES/DDD) system; individuals becoming increasingly physically impaired, but not yet ALTCS eligible; and DDD-eligible individuals who were denied ALTCS services.

Is there anything else you would like to add? Please type in your answer(s) in the space provided.

There were 33 write-in responses. Some notable matters include:

- Lack of understanding of the mental health system by DES/DDD providers
- Lack of peer and family support services offered to members with Intellectual and developmental disabilities (I/DD)
- Slow and ineffective AHCCCS response to abuse allegations in inpatient units
- Concern with DES/DDD moving toward a medical model
- Lack of services, knowledge, and equipment when working with bariatric patients
- Need to invest in workforce development
- Focus on prevention, treatment, and supportive housing
- Need services outside of working hours
- Great addition with adding pharmacists to the clinics