



We have the legal right of way.

July 31, 2019

Ohio Department of Medicaid
Office of Contracts and Procurement
Managed Care Procurement RFI
MCProcurement@medicaid.ohio.gov

Director Corcoran:

Thank you for the opportunity to provide comments regarding Ohio's Medicaid managed care system. Disability Rights Ohio ("DRO") is the state designated and federally authorized protection and advocacy system for people with disabilities. Our mission is to advocate for the human, civil, and legal rights of people with disabilities in Ohio. DRO submits these comments to the Ohio Department of Medicaid's Request for Information (ODM RFI), which seeks input from the public on experiences with the state's managed care system as it conducts a competitive managed care procurement.

The state must address a number of systemic issues affecting people with disabilities and their families in the managed care system. DRO will be addressing five categories in these comments, including: the state's managed care appeals and grievance system; the Early and Periodic Screening, Diagnostic and Treatment ("EPSDT") program; the provider shortage and workforce crisis in Ohio; the unlawful coercion of natural supports; and the need for a robust system of community-based mental health services. These categories relate to the following topics from ODM's RFI: Communication and Engagement, Grievances and Appeals, Provider Support, Benefits and Delivery System, and Care Coordination and Care Management.

Further, DRO conducted a survey that was responded to by parents, guardians, individuals with disabilities, providers, and individuals without disabilities. This survey generated forty-eight (48) responses that discuss issues individuals have had with their managed care plan. These results are attached as an addendum and reflect many of the issues described in these comments.

DRO also endorses the comments submitted by the eight legal services organizations, who raise many important issues that impact people with disabilities, including social determinants of health and medical-legal partnerships, grievances and appeals, benefits and delivery systems (such as non-emergency medical transportation), care coordination and case management, and access and quality.

I. THE MANAGED CARE SYSTEM’S APPEAL AND GRIEVANCE PROCESS IS FLAWED IN MANY RESPECTS AND DENIES PEOPLE CRUCIAL PROCEDURAL PROTECTIONS. (Grievances and Appeals -all questions)

A. Issues

DRO has observed a number of trends that exist in the managed care system’s appeal process. Managed care plans sometimes deny people with disabilities and their families continued services or benefits after they file a timely appeal following an adverse benefit determination and a notice of action. Furthermore, DRO has received calls from people whose managed care plans denied services they urgently needed, and then narrowly or wrongly interpreted the standards for an expedited resolution of an appeal, preventing a prompt resolution. The legal services organizations also noted in their comments repeated failures by managed care plans in complying with these legal requirements. DRO has also seen that managed care plans do not always resolve appeals and grievances within required timelines.

DRO has also heard from people about the lack of clarity as to the issues on which an appeal can be filed and those for which only a grievance can be filed. And managed care plans also do not always treat grievances under the process delineated under state law, and instead address complaints or requests for assistance as something less than a grievance, despite its broad legal definition. One managed care plan’s handbook refers people who file grievances to file a complaint with the Ohio Department of Medicaid’s compliance office and the Department of Insurance, which are unlikely to assist the individual in addressing their unique issues.

DRO has also heard from a prominent home health agency that one managed care plan discourages providers from requesting specific services for people, stating that the request will be rejected if it is made. This denies people due process and an opportunity to challenge decisions made by a managed care plan, essentially controlling which decisions are appealed and which are not.

B. Legal standard

Ohio Adm.Code 5160-26-08.4(H) says managed care plans must continue one’s services or benefits pending an appeal as long as the appeal was filed within 15 days of the issuance of the notice of action. Ohio Adm.Code 5160-26-08.4(E)(1) requires managed care plans to establish and maintain an expedited review process to resolve appeals when “ the member requests and the MCP determines, or the provider indicates in making the request on the member’s behalf or support the member’s request, that the standard resolution time frame could seriously jeopardize the member’s life, physical or mental health or ability to attain, maintain, or regain maximum function.”

Ohio Adm.Code 5160-26-08.4(D)(6) says that managed care plans must review and resolve each appeal as expeditiously as the person’s health condition required, but not more than 15 calendar days from the receipt of the appeal. The managed care can ask the state for an

extension under paragraph (F)(2), and it must be supported with documentation that the extension would be in the person's best interest.

Ohio Adm.Code 5160-26-08.4(A)(3) broadly defines a "[g]rievance" as a "member's expression of dissatisfaction about any matter other than an adverse benefit determination." A grievance could include "the quality of care or services provided, and aspects of interpersonal relationships such as rudeness of a provider or employee, or failure to respect the member's rights regardless of whether remedial action is requested." Grievances may be filed orally or in writing, and managed care plans must follow a process that has specific timelines. Ohio Adm.Code 5160-26-08.4(C).

The state of Ohio also has obligations under the Americans with Disabilities Act to ensure effective communication with people with disabilities. *See generally* 28 C.F.R. 35.160.

C. Impact

These flaws in the managed care appeal system have real impacts on people with disabilities and their families. In one case, two children, one age 6 and another age 8, received notice that the managed care plan would remove their home health aide services entirely. The mother filed a timely appeal, but the managed care failed to continue benefits during the appeal as legally required. This sudden loss of services, without due process, can be devastating.

In another case, the mother, the primary caretaker of a 7-year-old boy with cerebral palsy and serious medical needs, had repeatedly asked her son's managed care plan for nursing services for him so she could undergo a much-needed surgery. The request was denied, and she promptly filed an appeal with the managed care plan about eight days before her surgery. She requested an expedited resolution of her appeal, which the managed care plan inexplicably denied. Without adequate services for her son or a resolution of her appeal, she was forced to cancel her surgery. Only after DRO threatened litigation did the managed care plan finally approve the necessary nursing services; however, the mother has not been able to reschedule the surgery until the end of this year, causing additional needless delay and hardship.

Another family experienced much frustration with the appeal system, as the managed care plan issued a written denial of a prior authorization request for applied behavior analysis ("ABA") therapy services for two children, both age 12 at the time. The parent filed timely appeals for both; the managed care plan denied the appeal for one child but never issued a decision for the second child. The parent then filed a second appeal and still never received an appeal resolution. The parent requested a state hearing but it was denied because she allegedly never exhausted the managed care appeal process for the second child. So the parent filed a third appeal.

A person with significant medical needs and a power wheelchair had been struggling to obtain accessible transportation services. Neither the transportation provider, nor the person's managed care plan, was helpful in resolving this problem, which was affecting her health and

well-being. She was not permitted to file an appeal because the managed care plan determined it had not technically denied her the service, leaving her with no resource. She filed dozens of verbal appeals and grievances but the managed care records showed only a few were actually documented as grievances.

D. Recommendations for change

The current appeals system is too complex and confusing for people with disabilities and their families and may cause needless delay. DRO concurs with the recommendations of the legal services organizations in Ohio. People should have, similar to what the Bureau of State Hearings offers, multiple ways to file an appeal with a managed care plan (a self-mailer with the notice of action, telephone, fax, email, or online portal). The state should uniformly require all managed care plans to allow these methods.

Managed care plans currently do not adequately review their own decisions or have an incentive to ensure the appeals process works efficiently, effectively, and properly. The state should ensure stronger oversight so that people's rights are upheld, including the right to a continuation of benefits or services when a timely appeal is filed or the right to expedited resolution of an appeal.

For issues not subject to the state hearing process, the state should ensure that managed care plans follow the legal requirements and timelines for addressing grievances and should strictly enforce these requirements. Consistent with ADA legal requirements, the state should also ensure that the notices and other communications from managed care plans, including those concerning appeals and grievances processes, are written in clear and simple language. This is especially important for people who have cognitive limitations.

II. THE EPSDT INFORMING PROCESS IS LIMITED AND INEFFECTIVE. (BENEFITS AND DELIVERY SYSTEM; DELIVERY SYSTEM MODEL (QUESTION 23), INTEGRATION OF BEHAVIORAL HEALTH AND PHYSICAL HEALTH (QUESTION 26))

A. Issue

There is a general lack of knowledge among eligible families and providers about the federal Early and Periodic Screening, Diagnostic and Treatment ("EPSDT") program (called "Healthchek" in Ohio). This lack of knowledge stems from Ohio's limited, ineffective informing activities. The lack of knowledge among families leads to poor performance on state participation in EPSDT screenings (particularly as children get older) and underutilization of EPSDT services. The "treatment" component and the expanded coverage available through EPSDT have also been underemphasized by Ohio Medicaid. Many families and providers think of EPSDT as "well-child" checkups only.

B. Legal standard

Ohio Medicaid is required to inform eligible families about EPSDT. Ohio's informing activities should use a combination of written and oral methods using clear and non-technical language to inform families about the benefits of the EPSDT program, including the benefits of preventive healthcare, and the breadth and scope of services available and how to get them. 42 C.F.R. 441.56; *see also* 28 C.F.R. 35.160 (ADA effective communication requirements).

The purpose of EPSDT is to discover and treat childhood health conditions before they become serious or disabling.

C. Recommendations for change

Ohio should re-evaluate its informing practices, including ensuring that its managed care plans are effectively informing their members.

Contracts between Ohio and its managed care plans must clearly describe the managed care plan's obligations regarding informing families of the EPSDT/Healthchek benefit. The language should clearly advise families of the broad scope of coverage available, including that medically necessary treatment services are available under the broader medical necessity standard of EPSDT. If more families understood the breadth of coverage available through EPSDT and its more inclusive medical necessity standard, they would be encouraged to have their children screened early for necessary treatment.

All Medicaid partners, including the managed care plans, should use the same language when describing the EPSDT/Healthchek program in materials for enrollees/providers. A review of the managed care plan member/provider manuals shows that a variety of descriptions are used to define the benefit. Using the same language would help families understand the program, and help to improve state participation rates across regions.

Ohio Medicaid should regularly train and re-train key managed care plan staff regarding the informing requirement of EPSDT, and conduct regular reviews of the efficacy of managed care plan informing activities.

III. THE EPSDT MEDICAL NECESSITY STANDARD IS UNKNOWN TO MANY IN THE SYSTEM. (CARE COORDINATION/ CARE MANAGEMENT; SPECIAL POPULATIONS (QUESTION 30) AND CROSS-SYSTEM COLLABORATION (QUESTIONS 31))

A. Issue

Parents, providers, managed care plan employees, hearing officers, and others working to secure healthcare for children often are unaware of the expanded definition of medical necessity for children, leading to underutilization of EPSDT services.

Ohio's definition of medical necessity for children is relatively new. For years, Ohio's definition of medical necessity failed to include a distinct definition for children that complied with EPSDT requirements. During that time, families, providers, and others working in the system, inaccurately believed that children should be treated just like adults in the Medicaid program, resulting in incorrect denials of services, and a system that functioned as a barrier to necessary healthcare for children.

Many individuals in the system still operate according to the old system, applying the incorrect standard of medical necessity to children. The lingering effects of the past system are still seen today. For example, a physician, whose requests for prior authorization of a service were denied over and over as not medically necessary under the old definition of medical necessity, may have a current practice of telling parents not to pursue the service because it will just be denied by the prior authorization system, in spite of the current EPSDT medical necessity rule. Similarly, other historical barriers still exist in systems that applied the old, incorrect definition of medical necessity to children, including in managed care and the Medicaid fair hearings and prior authorization procedures.

B. Legal standard

Ohio has a distinct definition of medical necessity for children at Ohio Adm.Code 5160-1-01 that incorporates the federal EPSDT standard: all medically necessary 1905(a) services that correct or ameliorate physical and mental illnesses and conditions are covered for EPSDT-eligible beneficiaries ages birth to twenty-one, in accordance with 1905(r) of the Social Security Act.

C. Recommendations for change

Contracts between Ohio and its managed care plans must clearly state and describe the full EPSDT benefit available to eligible families. Contracts should identify, define, and specify the amount, duration and scope of each service that the managed care plan is required to furnish to enrollees. 42 CFR 438.210(a)(1).

The full EPSDT benefit, including the unique definition of medical necessity, must be clearly stated and described in contracts between the state and the managed care plans. However, simply defining the benefit in a contract is not enough to ensure systems change. Ohio Medicaid must engage in a strong educational campaign targeting the individuals and systems involved in EPSDT implementation to ensure that all partners are applying the correct standard in all components of the program.

IV. MANAGED CARE PLANS DO NOT ROUTINELY APPLY THE EPSDT STANDARD TO PRIOR AUTHORIZATION DECISIONS RESULTING IN UNNECESSARY TREATMENT LIMITS AND DELAYS. (PROVIDER SUPPORT; STANDARDIZATION ACROSS MANAGED CARE PLANS (QUESTION 13 AND 14))

A. Issue

Access to necessary treatment can be delayed because managed care plans do not always apply the medical necessity standard of EPSDT when making prior authorization decisions for children. Delays also occur when managed care plans apply inappropriate limits on type, amount, scope, or duration of a service. These limits vary among managed care plans and are often internal policies or procedures applicable to specific services (e.g., orthodontia). While a family may be able to access the service through a Medicaid fair hearing or other remedial process, pursuing these options results in significant delay in accessing services. In a well-functioning EPSDT program, children's health problems are addressed before they become advanced and treatment becomes more difficult and costly.

B. Legal standard

Ohio is required to provide to children all health care services that are coverable under the federal Medicaid program and found to be medically necessary to treat, correct or ameliorate illnesses and conditions discovered, regardless of whether the service is covered in Ohio's Medicaid plan. Section 1905(r)(5) of the Social Security Act. It is the responsibility of Ohio Medicaid to determine medical necessity on a case-by-case basis.

Ohio may establish tentative limits on the amount of a treatment service a child can receive (for utilization control) and require prior authorization for coverage of medically necessary services above those limits. Sections 1905(a) and (r) of the Social Security Act. However, prior authorization must be conducted on a case-by-case basis, evaluating each child's needs individually. Importantly, prior authorization procedures may not delay delivery of needed treatment services and must be consistent with the "preventive thrust" of EPSDT. Hard, fixed, or arbitrary limits or caps on services for all children are prohibited.

C. Impact

These issues are particularly relevant in the areas of mental health services, at-home nursing services, respite care, transportation, and durable medical equipment.

In the area of mental health, DRO continues to hear from families about the frustrating lack of access to needed mental health services for children. Too often, families are forced to give up custody of their children to obtain residential mental health services. This occurs even though under EPSDT, Ohio must provide services when needed to correct or ameliorate a psychiatric, behavioral, or emotional condition whether or not such service services are covered in the state plan. 42 U.S.C. 1396a(a)(43); 42 U.S.C. 1396d(r)(5). Under EPSDT, children and families have

the right to access the full continuum of mental health services, including intensive home-based services, intensive care coordination, crisis services, therapeutic foster care and intensive residential services. Too often DRO hears from families that they cannot get these needed services, whether because of denials by a managed care plan or a lack of adequate providers.

D. Recommendations for change

If Ohio Medicaid intends for managed care plans to provide for the full EPSDT benefit, the managed care contracts must be clear. If the plan is expected to provide all services but allowed to impose treatment limits, that must be specified, and Ohio Medicaid must ensure that medically necessary services are provided to each eligible child. The combination of benefits provided by the managed care plan and the state must guarantee children have access to the full EPSDT benefit in a timely fashion.

Ohio should guard against inconsistencies among plans in their administration of the EPSDT benefit. Internal utilization control policies or procedures that are not compliant with EPSDT should be prohibited, and procedures for accessing a particular service should not be different, or more or less burdensome, depending on the managed care plan. And, as asserted above, Ohio Medicaid must engage in a strong educational campaign targeting the individuals and systems involved in EPSDT implementation to ensure that all partners are applying the correct standard in all components of the program.

V. MANY PEOPLE WITH DISABILITIES AND THEIR FAMILIES FIND IT DIFFICULT OR IMPOSSIBLE TO FIND RELIABLE PROVIDERS FOR AUTHORIZED SERVICES. (PROVIDER SUPPORT; WORKFORCE DEVELOPMENT (QUESTION 19))

A. Issue

Many Ohioans with disabilities currently find themselves unable to find reliable providers for the authorized services to which they are entitled. These problems are endemic in Ohio, and go beyond the managed care system. Health professional shortage areas (“HPSAs”) are geographic areas, population groups, or health care facilities that have been designated by the Health Resources and Services Administration (“HRSA”), an agency of the U.S. Department of Health and Human Services, as having a shortage of health professionals. According to the HRSA, Ohio had 412 HPSAs in 2018 in the disciplines of primary care, dental health, and mental health.¹

However, the problem is not limited to primary care, dental, and mental health professionals. The statewide shortage of home care aides is at crisis level. Home care occupations—which include both home health aides and home personal care aides—are one of Ohio’s fastest growing professions.² Despite this, approximately a quarter of home health aides leave their

¹ See HRSA Fact Sheet for FY 2018, available at <https://gisportal.hrsa.gov/factsheetmaps/>

² See Paraprofessional Healthcare Institute (PHI), <http://phinational.org/policy/states/ohio>.

job over the period of a year, while nearly half of all home personal care aides quit their job within a year.³

Several causes contribute to the high turnover and vacancy rates associated with this workforce. Wages and benefits are not competitive with other jobs in the marketplace. The reimbursement rates for home care aides are extremely low. Many home health aides do not have any employer benefits. According to some statistics, less than 40% of direct care workers have employer-sponsored health insurance.⁴

In addition to low wages, caregiving is a physically and emotionally demanding job, with high rates of job-related injuries. Home care aides are more vulnerable to occupational injuries and illnesses than other occupations. Furthermore, home care agencies offer few advancement or training opportunities to employees, and it appears many agencies employ aides on a part-time basis. Other factors contribute to the provider shortage including delays in reimbursement and geographic disparities between rural and urban areas.

B. Legal standard

Under federal and state law, the state of Ohio must ensure that all services covered by a managed care organization's plan are available and accessible to people in a timely manner. 42 C.F.R. 438.206(a). The state must ensure managed care plans maintain a provider network that can furnish adequate access to all covered services for all enrollees of the plan and provides out-of-network services to enrollees if the provider network cannot deliver the necessary covered services. 42 C.F.R. 438.206(b); *see also* Ohio Adm.Code 5160-26-03. Managed care organizations must also give assurances with supporting documentation that it provides an appropriate range of specific services, and maintains a provider network sufficient in number, mix, and geographic distribution, to adequately service the anticipated number of enrollees in the service area. 42 C.F.R. 438.207.

For Medicaid-eligible people under age 21, the state of Ohio must "make available a variety of individual and group providers qualified and willing to provide EPSDT services." 42 C.F.R. 441.61(b).

C. Recommendations for change

DRO continues to hear from individuals that obtaining providers is increasingly difficult. The findings of our survey, which is attached, reinforce this. Those on managed care plans have difficulty finding providers for psychiatric care, skilled nursing, and services like occupational therapy and physical therapy. Additionally, individuals reported problems with their managed care plan refusing to cover certain providers. For those in HPSAs this poses an additional issue,

³ "Low wages, high turnover in Ohio's home-care industry," Policy Matters Ohio, Spring 2015, available at <https://www.policymattersohio.org/files/research/home-care-wages-4-20-153.pdf>.

⁴ *See* <https://phinational.org/policy-research/workforce-data-center/#var=Health+Insurance&states=39>

if there is already a lack of providers and their managed care plan refuses to cover providers within the area, individuals are at risk of not receiving care.

The state should ensure through its contracts with managed care plans that a robust pool of well-trained and adequately compensated providers exists for members to receive the services they need. Further, the state should require managed care plans to incorporate a person-centered approach when considering whether to cover providers individuals choose.

VI. SOME FAMILIES REPORT THAT THEY ARE COERCED TO PROVIDE NATURAL SUPPORTS.

A. Issue

DRO has heard from people with disabilities that managed care plans inform them that they cannot receive additional services (nursing services or home health aide services, for example) or their services will be reduced because their needs can be met by “natural supports.”

Natural supports are unpaid, voluntary care and assistance that people with disabilities receive from parents and other family members, friends, neighbors, and other members of the community. This usually includes help with basic personal care (like eating, bathing, dressing, grooming, hygiene, medication administration, mobility and transfers, and so forth), nursing, and transportation.

Natural supports provide enormous levels of assistance to people with disabilities across the nation. “Family and friends provide the majority of at-home assistance in this country, valued upwards of \$470 billion per year.”⁵ And this unpaid work “has become more intense and complex over time,” as “[m]ore than half of family caregivers reports handling health-related tasks such as wound care, tube feedings, and injections.” *Id.* Family members can easily become exhausted without adequate Medicaid-funded supports, which in turn puts their loved one at risk of harm or institutionalization. *Id.* Coercion of natural supports also sometimes affects a person’s desire to live independently. An adult with a disability may want to live on their own but is forced to live with their family because insufficient services are authorized.

B. Legal standard

Federal and state laws in other contexts confirm that natural supports are voluntary in nature and should not be coerced. Federal regulations for section 1915(c) waiver programs define “natural supports” as “unpaid supports that are provided voluntarily to the individual in lieu of” waiver services. 42 C.F.R. 441.301(c)(2)(v); *see also* 42 C.F.R. 441.725(b)(5) (1915(i) HCBS state plan option), 42 C.F.R. 441.540(b)(5) (1915(k) Community First Choice Option services); Ohio Adm.Code 5123:2-9-01(B)(7) (defining natural supports for the Individual Options waiver for Ohioans with intellectual and developmental disabilities).

⁵ *See* Justice in Aging, *Medicaid Enrollees Put At Risk When State Medicaid Programs Assume Support from Family Caregivers*, Oct. 2018, available at <https://www.justiceinaging.org/wp-content/uploads/2018/10/Medicaid-Enrollees-Put-at-Risk-When-State-Medicaid-Programs-Assume-Support-from-Family-Caregivers.pdf>.

An Ohio appellate court has concluded that the “compulsion of ‘natural supports’ is antithetical to law.” *Mocznianski v. Ohio Dept. of Job & Family Servs.*, 195 Ohio App.3d 422, 2011 -Ohio-4685, 960 N.E.2d 522, ¶ 45 (6th Dist.). In that case, the brother of a person with developmental disabilities enrolled in the Individual Options waiver program had been providing substantial care to his sister, a large part of it unpaid. The services authorized by Medicaid had been reduced under the assumption he could provide more unpaid care. The appellate court overturned this decision, emphasizing the voluntary nature of natural supports and noting that “the question of caregiver fatigue . . . is a valid concern” that should be addressed when determining the sister’s authorized services. *Id.* at ¶ 47.

C. Impact

One family’s story is particularly illustrative of the problem of coercing natural supports to the detriment of the individual and their family. A 7-year-old boy has developmental disabilities and serious medical needs. His managed care plan, however, has authorized limited nursing services, and he relies to a substantial extent on his single mother and even his 12-year-old brother to provide nursing care for him. His mother has her own medical problems, and she has struggled to schedule a much-needed surgery because of the lack of sufficient services in place for her son. The managed care plan has put this child and his family in a precarious situation by assuming that his family can meet most of his needs, despite clear evidence to the contrary.

D. Recommendations for change

The state of Ohio should ensure that, in its contracts with managed care plans, the voluntary nature of natural supports is respected and not coerced. The state should require standards for managed care plans to carefully consider the availability, willingness, and appropriateness of natural supports when determining an appropriate level of services for an individual.

The state should also ensure managed care plans avoid assumptions about family members and other natural supports. Sometimes a family member may be willing but unavailable, because of work or other commitments, at the times the person needs support. A person’s roommate may not be able to physically provide assistance that is needed (for example, assistance with mobility or transfers). A parent of an adult may be willing, but unable to meet his or her own needs, like work or sleep, or may have other family members who rely on him or her. These various potential scenarios must be evaluated.

Furthermore, even when natural supports are determined to be willing and able, clear communication is essential (e.g., who is expect to provide the voluntary support, what type of support, when, and how much).

VII. THE COMMUNITY-BASED MENTAL HEALTH SYSTEM FOR ADULTS WITH SERIOUS MENTAL ILLNESS MUST BE FIXED TO ENSURE PEOPLE ARE NOT UNNECESSARILY INSTITUTIONALIZED. (CARE COORDINATION/CARE MANAGEMENT; SPECIAL POPULATIONS (QUESTION 30))

A. Issue

Because of inadequate service capacity in the community mental health system in Ohio, thousands of people with serious mental illness are institutionalized in nursing facilities throughout Ohio. A considerable segment of people with serious mental illness in nursing facilities is younger than age 60. Others without access to community services, care, and treatment struggle with homelessness, psychiatric hospitalization, and incarceration in prisons or jails. Many people cycle through these various settings.

B. Legal standard

Under Title II of the Americans with Disabilities Act and the Supreme Court's decision in *L.C. v. Olmstead*, 527 U.S. 581 (1999), the state of Ohio must administer its programs and services to people with disabilities in the most integrated setting appropriate to individual needs and avoid unnecessary segregation in institutions.

Federal law requires that states "ensure that all services covered under the State plan are available and accessible to enrollees" of managed care plans." 42 C.F.R. 438.206(a); *see also* 42 C.F.R. 438.207; *see, e.g.*, Ohio Adm.Code 5160-27-01, et seq. (Medicaid coverage of behavioral health services). The Mental Health Parity Act of 1996 and subsequent legislation also requires managed care plans to ensure an adequate system of mental health benefits and services, on par with medical or surgical benefits and services.

C. Impact

DRO hears from clients regularly about the lack of mental health services in the community. This lack of services translates into unnecessary institutionalization in a variety of settings. Discharge planning from psychiatric hospitals is made much more difficult because of the lack of community mental health services throughout Ohio. In many cases, this leads to individuals with mental illness being placed in nursing facilities on a long-term basis, where rather than recovery-oriented mental health treatment they usually receive medication and "supervision."

D. Recommendations for change

To address these systemic issues and identify solutions, Disability Rights Ohio has been collaborating with the Ohio Department of Mental Health and Addiction Services "(OhioMHAS)". Our regular meetings and discussions with OhioMHAS and our review of the system are continuing, but DRO has concluded thus far that the community mental health system is seriously underfunded and has numerous structural flaws. These issues are complex and involve multiple systems and state agencies that go beyond the managed care plans.

Most importantly, Ohio must have an adequate array of recovery-oriented community mental health services that are properly funded. This includes ensuring that Medicaid managed care plans provide access to community mental health services and have a network of providers to meet people's needs in the community, with sufficient rates and an effective billing system.

VIII. CONCLUSION

DRO appreciates the ability to highlight several issues impacting care provided by Medicaid managed care plans. To ensure quality and person-centered care is provided to people with disabilities, changes in several areas of the managed care structure should be considered including the themes discussed in our comments and reflected in our survey results: the need for case management training; uniformity among the managed care plans; informing clients on services that can be provided; ensuring natural supports are not a barrier to individuals receiving care; providing more robust information about the appeals and grievance process; and ensuring services are person-centered.

Again, thank you for the opportunity to provide comments regarding Ohio's Medicaid Managed Care System. DRO looks forward to being a resource on issues impacting our clients as this process continues. If you have any questions or wish to discuss these issues further, please feel free to reach out to Lisa Wurm, Director of Policy at lwurm@disabilityrightsohio.org or 614-466-7264 x102.

Respectfully,

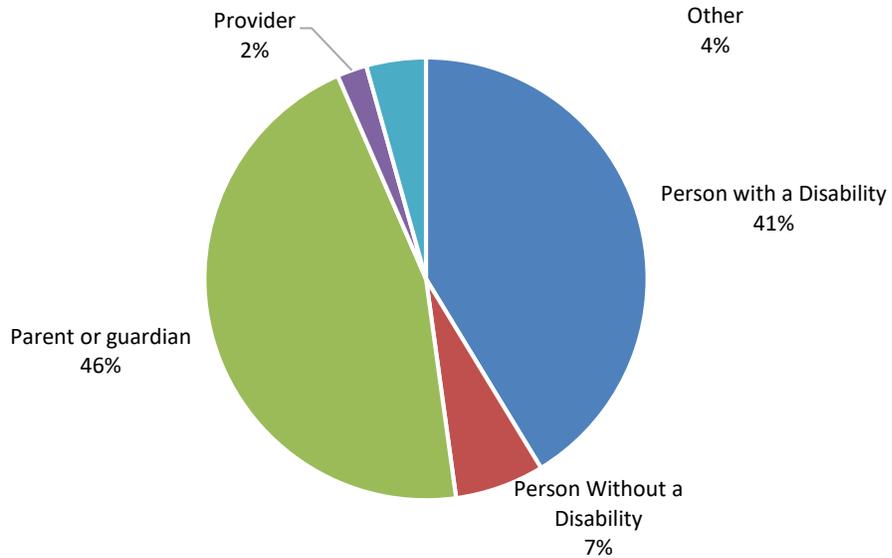
A handwritten signature in blue ink, appearing to read 'MK', with a long horizontal flourish extending to the right.

Michael Kirkman
Executive Director

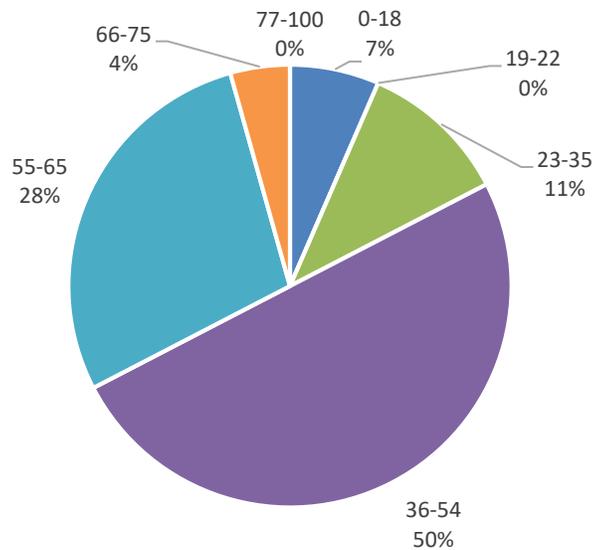
**DISABILITY RIGHTS OHIO
MEDICAID MANAGED-CARE SURVEY RESULTS
JUNE 26, 2019**

Respondents:

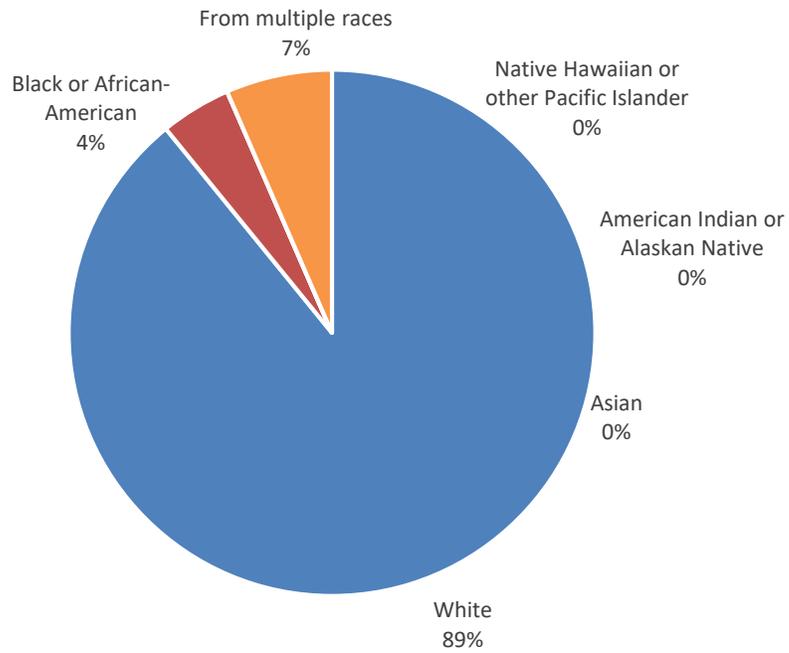
Forty-eight (48) individuals responded to the Disability Rights Ohio Medicaid Managed Care Survey (“survey”).



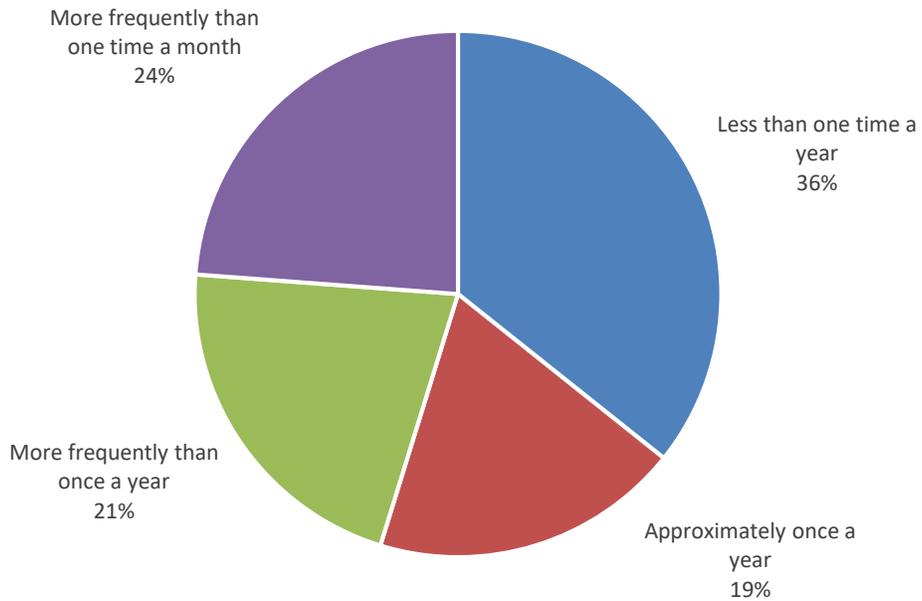
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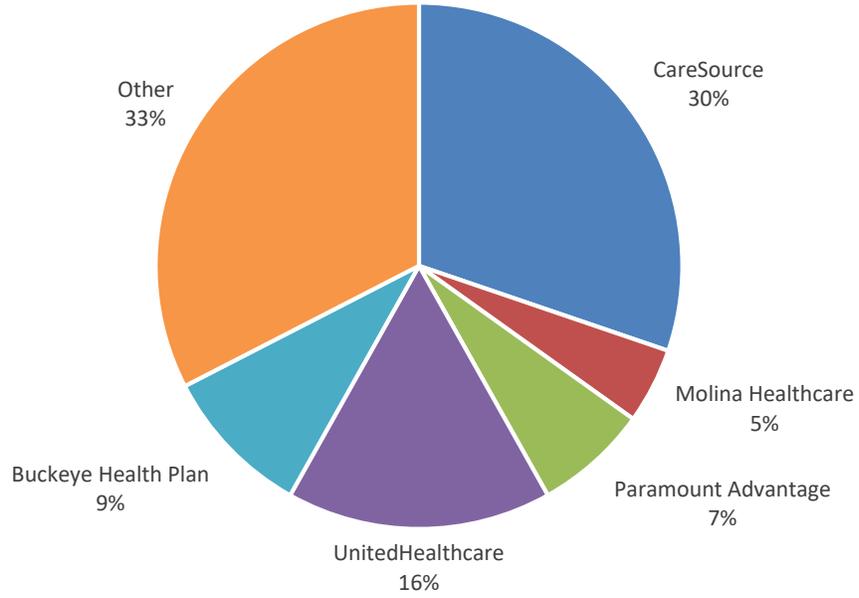
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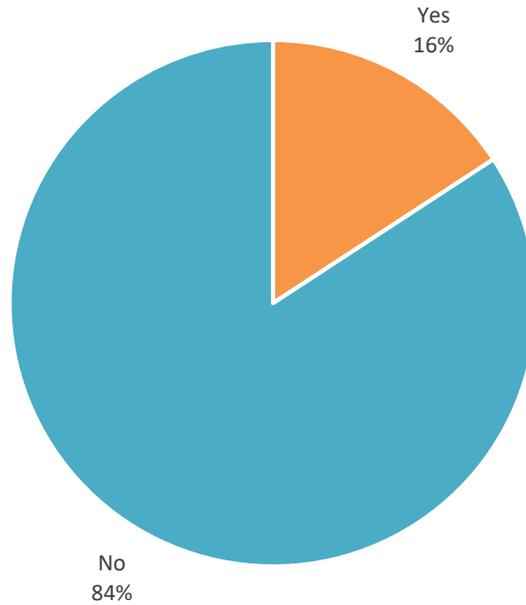
As a person enrolled in a managed care plan, how often do you have difficulty obtaining access to services?



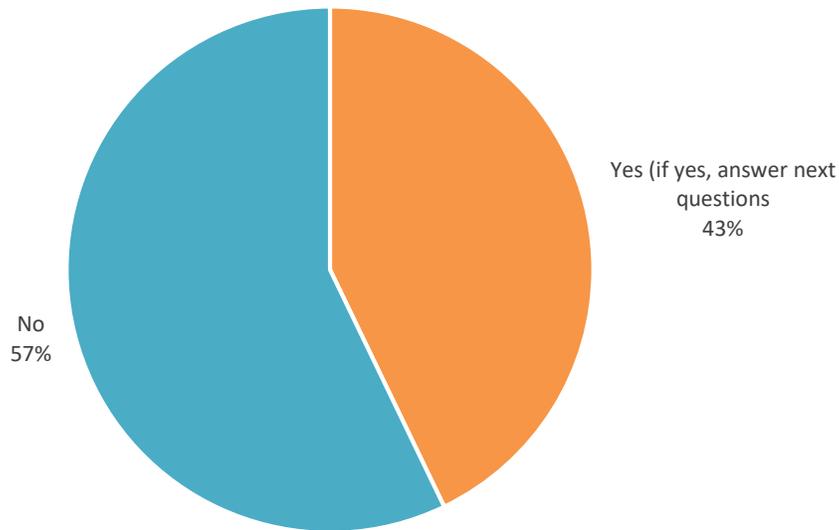
Which managed care plan do you have for Medicaid?



Have you had issues with a grievance or appeal with your managed care company?



Do you feel that you were provided correct information from your managed care company on the grievance or appeal process?



Tell us as much as you can about why you feel you were not given correct information.

- They were supposed to continue paying for my daughter’s skilled home health nursing because I filed appeal within 15 days of date on denial letter, mind you they've payed for skilled nursing for 4 1/2 years. They illegally cut off her skilled nursing payments and took me almost a month to get the repayments started. I almost lost my home because of this.
- I was given the correct information about the Grievance process.
- In cases like mine, Medicare does cover ongoing services for home care (Jimmo v. Sebelius). Many agencies erroneously believe they are not. So, in effect, the services might as well not be covered.
- Denial reason had NOTHING to do with why we were asking for equipment.

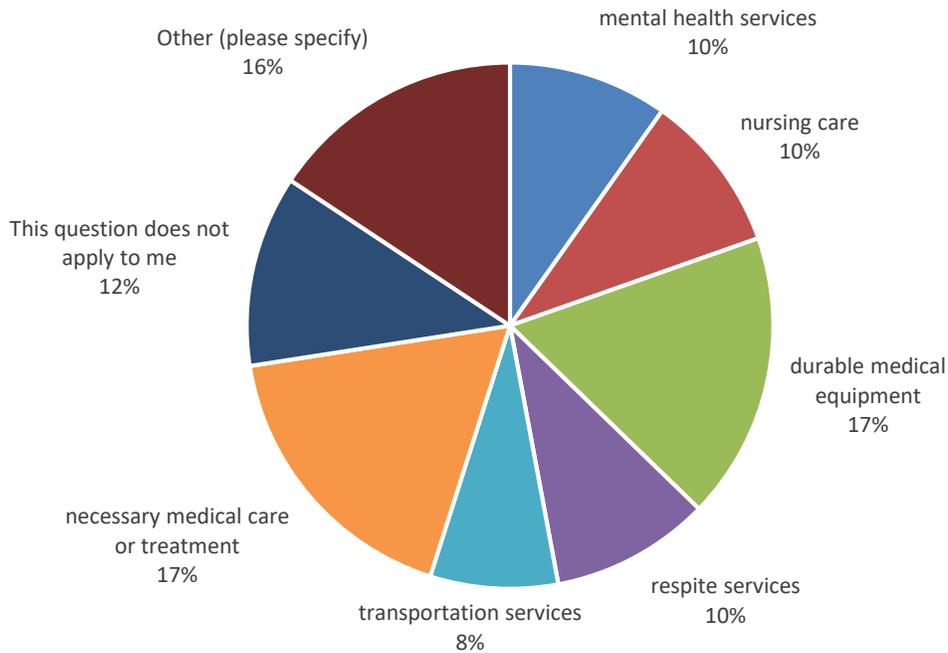
What other issues have you had with the Grievance and Appeal Process?

- No one knows what anyone else is doing and you can't get anyone to answer the phones
- I had two issues which I had to deal with the Grievance and Appeal Process. Both had to do with what I had to do before I go to surgery which delay surgery which only made my condition worse.
- Providers will not cooperate with an appeal.
- Son’s nursing services were cut.

What do you think managed care companies could do to improve the Grievance and Appeal Process?

- I know nothing about grievance and appeal under your situation. But under most it takes way to long and if emergency it gets lost or not done.
- Actually follow the rights and rules of the process and obviously more training on the policies and procedures and answering there phones or returning you call when you leave a message
- Make the process easier and quicker.
- Proper training of customer service and easy accessibility to information. Honestly they are misinformed
- Support federal legislation that would abolish Medicaid and provide Medicare for all, including all services required by Americans with disabilities.
- Hire more honest workers who are not here for profit!
- Have an easier process for appeals; discontinue “one size fits all” care - example, individuals with autism and severe behavior are prescribed ABA therapy, but it’s not covered through insurance.
- Quick responses at least acknowledging receipt of complaint.
- Stop making it such a long drawn out process. It's like the system wants the person to give up
- Educate us on how and when to use it.
- Actually read the submission
- Is there a dedicated phone line, staffed by competent employees? Or a dedicated email address? Waiting on hold is so frustrating when you're dealing with as many medical issues as I am.

For parents or guardians: Has your child had issues receiving any of the following services under your managed care company:

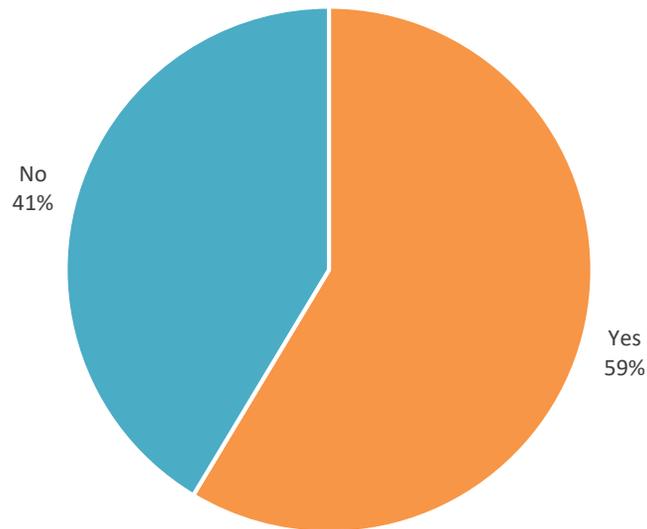


If you answered yes to any of these options, please tell us about the issues you've experienced.

- After 4 1/2 years of approving her skilled nursing care they recently denied it. And illegally stopped paying for it until we receive a decision from our hearing.
- They said she did not have insurance and she did.
- Difficulty having PT paid for
- Medical supplies such as condom catheters, briefs, leg bags, etc are no longer being paid for.
- Meds that may not be covered or he has to have more than they want to pay for
- home health aide, personal care assistant (respite for parent/caregiver AND help within the home due to caregiver's medical issues); extraordinarily long wait time to process request for walker/gait trainer for child motivated but unable to stand or walk unassisted
- Behavior therapy not covered, protective equipment not covered, respite staff not covered, lack of adequately trained staff available, medications too expensive or in accessible
- A med provider refused to accommodate me and also denied me care that Medicaid contracted. Caresource was notified! But nothing changed.
- Not enough nurses in our area because nurses are underpaid (less than or equal to educational assistant with high school diploma or equivalent).
- There are few choices in our area for a dentist.

- Doctors and nurses understand having both adhd and type 1 diabetes together, plus developmental disabilities.
- We did not know about the transportation option
- Very few mental health professionals accept managed care. Our hospital does, but they are over worked and under paid.
- No Pediatric LPNs are available or willing to work for home health agency rates and benefits in Southeastern Ohio. Pay and benefits for them need to improve.
- Equipment for daughter, nursing hours cut on son
- Lack of nursing in area. They should let the parents take a course and take care of own child for pay
- Our daughter needs mental therapy for anxiety. Medicaid treats her issues like she's just being a drama queen or something.

Have you had difficulty finding reliable providers for authorized services?

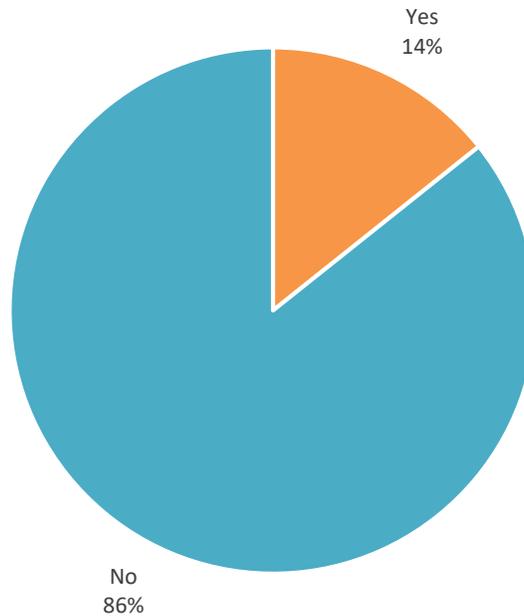


If you answered yes, please tell us about issues with finding reliable providers for authorized managed care services.

- A change was done by my Primary because I wasn't on the list to be serviced
- Yes, transportation is one - they come early and pick you up late, or they pick you up with 3 or 4 people and everyone see where you live I don't like that. At least they could ask me is it okay or something. Once I had to be at the hospital office at 7:30am they picked me up at 5:45am okay no traffic we got to the hospital 6:15am. The doors for the public didn't open up until seven and the driver wanted to leave and it wasn't in the best neighborhood and it was dark so I asked him to please wait until I could get a hold of someone. Finally, I got a hold of the security guard, and was able to wait in the double door before entering into the main hospital. Now that was so stressful!!!!
- Dental
- Direct service professionals are extremely difficult to find. And there are no benefits.
- Agency provided home health aides in the past have been unreliable in terms of showing up as scheduled or showing up on time, and one was openly discussing her personal drug addiction.
- ABA, therapists, providers, speech, occupational therapy, and residential treatment!
- Nursing generally does not provide benefits unless on salary, and positions do not pay enough for salary to be cost-effective for agencies.
- My son has Medicaid as a secondary insurance and it often doesn't correlate with the providers in my insurance network.
- The Centers of Parma, OH failed to keep appointments. Jessica, LPCC, at Grow Well in Lakewood failed to keep appointments.

- It was a struggle to find a pharmacy to fill our son's lovenox shots that insurance covered
- Respite care providers are very difficult to find.
- LPNs for skilled care and home health aids
- Psychiatrist for daughter, nurses!!! For home care for son
- No nurses in area

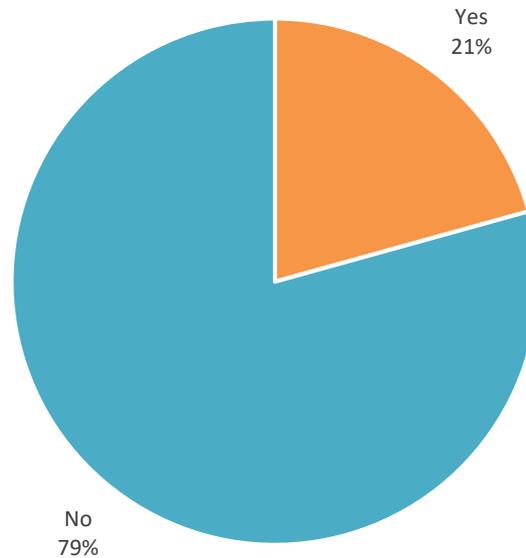
For family providers: has your managed care company not authorized services due to you providing natural supports (natural supports are unpaid, voluntary care provided by parents or family members)?



If you answered yes, please tell us about issues service denials due to natural supports.

- I've been a nurse for 15 years. I now have a 5 year old daughter with Down Syndrome and multiple health issues that I've been her home health nurse for 4 1/2 years without any problems until this year.
- The Ohio General assembly has provided virtually no work for family caregiver. The same is true of US Congress.
- Managed Care has not done this as of yet, but our county board of developmental disability services continues to deny a waiver based on this exact reason.
- Depends on case

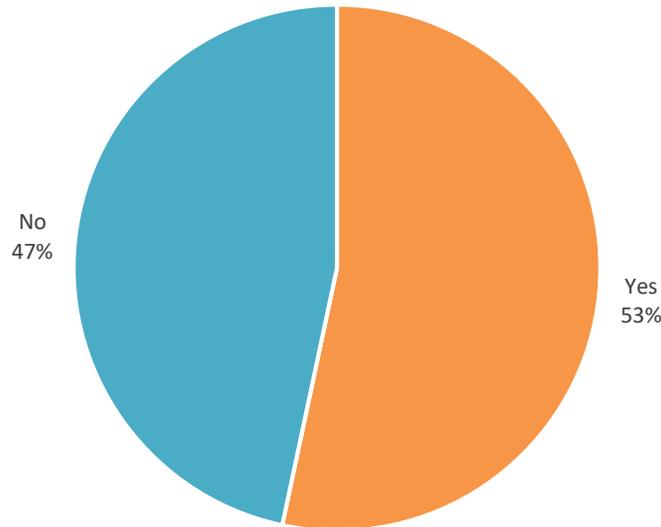
Have you had issues obtaining community mental health services as an adult? Or do you feel that there were no alternatives to institutional care (nursing facility)?



If you answered yes, please tell us about issues in obtaining mental health services in the community?

- Toledo is amazing with community mental health. If you are behind on payments they restrict prescription drug insurance.
- Frequently
- Long story! But basically the care providers knew of my disability and refused to help me find support I needed.
- Counseling ,understand my daughter multiple disabilities
- My husband is bipolar. Unless he's addicted to drugs or alcohol, he can't get mental health treatment.

Have you had difficulty finding reliable providers for authorized services?



If you answered yes, please tell us about issues with finding reliable providers for authorized managed care services.

- Specialist
- In the infancy of CareSource. My dermatologist will still not take their insurance.
- Area agencies aren't even return my phone calls regarding an inquiry for home health aide services
- EMDR is not presented. Hard to find. Plus! Doctors don't attend to my complaints. It takes years for me to figure out what can be done to help me.
- see previous answers regarding nursing shortages
- They fail to keep appointments.
- Shots, eye glasses
- Respite care
- Home health nursing agencies that have pediatric LPNs
- Home care nurses
- Lack of busing
- I have been signed up with several Home Health Agencies. They never call me with any info. When I call them they are never able to answer any questions. They seem incapable of even handling the call in a professional manner and cannot even tell me if an aid is scheduled for that day. My case manager signs me up with these agencies but the agencies never find me an aid. I call them but after a few weeks they stop returning my calls.

What do you think managed care companies could do to help you find providers for authorized services?

- Educate long before changes
- I know my Memories is not the best, and it would be nice if someone would remind me what services I have to help me. I would truly appreciate it!
- They need to call these agencies and find out why they are not sending anyone. They need to find better companies. Surely there must be some good Home Health Agencies.
- Contract with more providers. Offer better rate of pay and/or pay in a timely fashion so more people are willing contract with the MCO.
- Pay more
- Give agencies an incentive for taking on cases, particularly those that are part time and/or for pediatric clients
- Partner with hospital social workers to learn about the need
- If they were permitted to help me. Disability means i can need help.
- Create a pipeline for training and hiring.
- Keep up to date lists and have an app that provides instant search for providers. Also, find a way to align primary insurance providers with Medicaid as a secondary.
- Monitor whether or not providers actually follow thru with appointments.
- Provide a list of providers per region
- Make sure you have a case manager. I did not have one until I requested on.
- Provide more options and allow patients/caregivers to have access to reviews
- Allow independent private duty nurses
- Understand how to take care of special needs. Keep updated lists of agencies...break it down more like pediatric home care & adult home care
- Pay parents to take care of their own child
- First, agree to provide mental health care. Second, provide current listings on internet.

If you have had other issues with your managed care company, please provide as much information as you can about the issues you have with Medicaid and how you think the health care plans could be improved.

- I appreciate having Medicaid health care plan, and I like how they wanna do surveys to hear what customer care about the service that's a wonderful way to make improvements my Listening and making changes and adjustments you're on the right track.
- My insurance company needs to assign me to case managers who do their jobs and return my calls. They should be checking with the clients. Maybe they could send out a survey once a year. I should not have to wait on hold for hours only to have the phone system hang up on me. It takes too long to change your plan and get your services started. ARE all the insurance companies crappy or just mine? Medicaid and each insurance company should be sending out questionnaires every year. Why are people paying taxes to the government so they can pay all this money to insurance companies

to provide crappy services? Is anyone paying attention to how the seniors and disabled are treated? Does anyone care?

- This was a forced change to MCO for my brother with very little information as to the rationale and little to no assistance with navigating the system. For my elderly parents, they have frequently become confused with the system, how to access care, and what is actually available as a benefit. They were told that care would not change with this switch yet they have run into more denial of coverage in the past 6 months than they have in a long time (this is also combined with a Dual advantage Medicare plan).
- They need services before they end up in jail. Once they finally get the services it's great but getting them was long time coming and two trips to a jail setting
- Specialty providers, such as dentists and ophthalmologists/optometrists need incentives to accept clients, and existing PCP's for adults and pediatrics need incentives or better reimbursement rates to accept more than a short list of clients with Medicaid. We have been denied services (received letters) from providers with whom we have received regular services, stating that we would no longer be seen at these practices due to the type of our insurance - i.e., they were firing all of their Medicaid patients.
- Applied behavior therapy for those with autism and severe behavior, respite care, and residential treatment
- EVVs are a pain to use... patients get less "care" in order to answer questions on technology.
- Did not know about the transportation. I wish that the income requirements weren't as strict. Like our son is high needs but we are going to lose Medicaid after his first year due to our income. But our insurance will make it a huge struggle with our deductibles and out of pocket Max's to meet the bills, and our son will still require a lot of care. Even if I quit my job we still make more money. Why should we not receive support because we are a working family? It is very difficult and frustrating.
- I would love to have current Medicaid cards for all members of my family. Can't seem to get them issued. It's been 7 months almost. Argh!