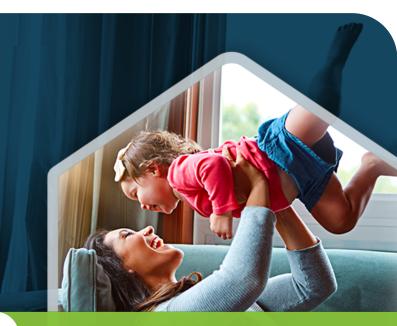
The Value of Coordinating Medicaid Services and Supports through a Health Home Approach for Children on the Autism Spectrum

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KEY HIGHLIGHTS

- Children on the autism spectrum can have a variety of healthcare and social support needs that require their families to navigate across multiple agencies and community-based services.
- Seamless coordination and integration of these resources through a health home approach can reduce fragmentation, improve outcomes, and enhance the experience of children and families.
- Managed care organizations are valuable partners in designing and facilitating access to a comprehensive health home approach in partnership with community-based providers.



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Health homes leverage the holistic approach of MCOs and the strong local ties of communitybased partners.

Overview

To meet the health and supportive service needs of children on the autism spectrum and their families, Medicaid managed care is turning towards new and innovative practices and approaches. These efforts seek to seamlessly connect children to an array of services and supports that are tailored to the children's and families' preferences, needs, and goals.

One of the emerging approaches is a health home designed specifically to support children on the autism spectrum. A health home may be provided by community-based organizations or other providers with experience and strong ties to local communities and statewide systems. When a health home is designed well—with local community-based partners who have the right expertise, experience, and trusting relationships with families children experience better coordination and integration of healthcare and supportive services.

Given the whole person approach of managed care, Medicaid managed care organizations (MCOs) are well positioned to collaborate with these health homes to support children and their families. The comprehensive approach of a health home, in partnership with MCOs, can advance access to and delivery of high-quality Medicaid services and supports as well as community resources benefiting members and their families. As states seek new and innovative approaches to improve care for children on the autism spectrum, the health home approach holds promise. For children and their families, it provides an opportunity to gain knowledge and skills, have the tools and support necessary to navigate multiple complex systems, and secure needed

Meet "Veronica"

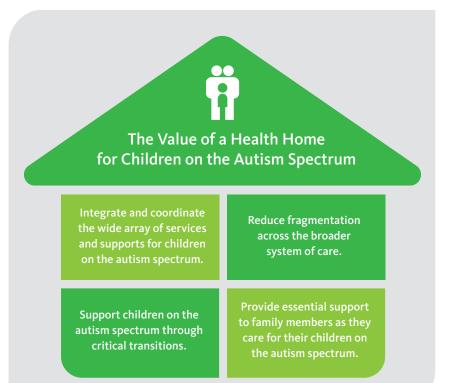
Veronica is a five-year-old girl recently diagnosed with autism spectrum disorder (ASD) who receives healthcare through her state's Medicaid program. Although Veronica and her family have been happy with the physical healthcare she receives, the opportunities to connect Veronica and her family to holistic and coordinated services and supports have been limited.

Veronica's providers have not been able to help the family access identified services and supports that will promote self-growth, quality of life, and her overall wellbeing, including her educational, behavioral, emotional, and social development needs.

Veronica's family wants to make sure she is receiving services and supports tailored to her individual strengths and needs, yet identifying and connecting with the right resources, and understanding their new world of special education and disability services, can be quite challenging. While Veronica and her family are learning to adjust to Veronica's diagnosis and her day-to-day needs, they are also trying to learn more about local, state, and federal programs that assist children on the autism spectrum. The family needs assistance finding providers specially trained in supporting children on the autism spectrum, identifying in-school supports that exist for Veronica, accessing appropriate childcare and respite, and coordinating all these different pieces.

Health homes help reduce the stress families and caregivers experience trying to navigate the delivery system. services and supports. For states, a health home approach can mean effective and efficient use of limited resources, while emphasizing a coordinated approach to the child's healthcare and supportive services.

This paper discusses the important role that health homes can play in supporting children and youth on the autism spectrum (collectively referred to throughout this paper as children) and their families. In partnership with MCOs, health homes can enhance the experience of children and their families by improving access to and coordination across the array of services and supports, implementing a child- and family-centered approach, and offering critical assistance to children and their families as they navigate multiple agencies and support systems. In particular, health homes can help reduce the stress families and caregivers experience navigating the complex system of care and instead let them focus on what is most important to them—raising healthy and happy families.



2,000,000+

individuals in the U.S. are affected by autism spectrum disorder.

Children on the autism spectrum		
Boys	1 in 42	
Girls	1 in 189	

Medicaid plays a critical role in serving children on the autism spectrum

State Medicaid programs provide healthcare to more than 74 million adults and children each year, including children on the autism spectrum.¹ Autism is a spectrum of developmental disorders, often diagnosed in early childhood, that manifest as a range of symptoms and levels of disability.

For many children on the autism spectrum, this includes significant social, communication, adaptive, and behavioral challenges.^{2,3} Over 2 million individuals in the United States are affected by autism spectrum disorder (ASD),⁴ and the number of children on the autism spectrum has grown from 1 in 110 children in 2006 to 1 in 68 children (1 in 42 boys and 1 in 189 girls) in recent years.^{5,6}

Due to the wide range of symptoms and characteristics associated with ASD, as well as other related health conditions, children on the autism spectrum are likely to have a variety of service and support needs. They often experience challenges related to multiple developmental domains (e.g., speech, language, cognitive, emotional, sensory, and motor development), communication, social interactions and social relationships, and adaptive behavior. In addition, children on the autism spectrum often experience co-occurring conditions such as epilepsy, attention-deficit disorder, sleep disorders, and gastrointestinal problems. Approaches for serving children on the autism spectrum typically include:

- Physical and behavioral health services (e.g., primary and specialist care, speech and language therapy, physical therapy, occupational therapy, medications)
- **Social and supportive services** (e.g., education, transition planning, independent living, adaptive skills)
- Behavioral and communication supports, including assistive technologies
- **Dietary services** (e.g., evidence-based feeding therapy services, special diets included in a care plan for co-occurring conditions)

As these children grow into young adulthood, many continue to need these supports and services. Some children may also experience changes in existing co-occurring physical and mental health conditions or develop new conditions. Consequently, coordinating current services and supports along with the addition of employment supports, transportation, personal assistance, and supportive housing options becomes paramount.

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State Medicaid programs address the important needs of children through state plan benefits, waiver services, and EPSDT.



Uncoordinated care can lead to duplication or even an absence of critical care.

State Medicaid programs offer an array of resources, services, and supports that help children on the autism spectrum thrive in life and in the community. Medicaid covers these through several statutory authorities: state plan benefits,⁷ waiver services,⁸ and Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefits.⁹ Every state and the District of Columbia offer some level of services and supports for children on the autism spectrum.¹⁰ However, given the variation across state Medicaid programs with respect to coverage of optional services and the scope of waiver services, the array of Medicaid services available differs by state. While Medicaid covers a number of formal (i.e., "paid") services and supports for children on the autism spectrum, it is important to note that parents and family members provide a significant amount of informal (i.e., "unpaid") caregiving support in lieu of formal paid services.¹¹

Children on the autism spectrum and their families also have access to and receive services and supports from a number of local, state, and federal programs, including school districts/education systems, child welfare agencies, and Social Security. They receive support from other programs such as early intervention for infants and toddlers, family support initiatives, and vocational rehabilitation; some access home and community-based services through Medicaid waivers.

Most significantly, these children have a federal entitlement to special education services, including individualized supports to help them learn, participate in the general education classroom, and thrive. Given the number of different service systems that engage children on the autism spectrum, their services and supports can often be uncoordinated and fragmented. The lack of coordination can lead to duplication, absence of critical services, and challenges for families as they try to navigate across multiple complex systems. As Veronica's experience illustrates, this dynamic can create added stress and hurdles for families as they try to identify and connect their children to the most appropriate services and supports.

Coordination across programs and funding sources is essential to maximize resources and make sure that children and their families have continuity of services and supports as well as a seamless experience. Children on the autism spectrum enrolled in Medicaid receive services through either fee-for-service (FFS) or Medicaid managed care. In managed care, the MCO is responsible for coordinating and paying for services covered by the state Medicaid program. Managed care can enhance coordination of these Medicaid services and supports and can, at times, offer coordination of supports beyond what is available through the Medicaid state plan and FFS programs. However, MCOs are exploring a more seamless approach across all the various systems of care support that improves health, wellbeing, and the achievement of personal outcomes and goals.



The health home performs a much-needed one-stop navigation and coordination function.

Enhancing Medicaid services and supports for children on the autism spectrum through a health home

As MCOs continually strive to identify new ways to improve coordination and delivery of services and supports for children on the autism spectrum and their families, one of the emerging approaches is a health home.

Health homes represent a unique collaboration that joins the comprehensive approach of Medicaid MCOs with the knowledge of the community-based provider or organization that serves as the health home lead. This health home lead entity has years of experience working in the local delivery system—establishing and continuing to develop relationships with many of the children and their families. Combining this on-the-ground experience with the managed care model creates a unique approach for serving children on the autism spectrum.

Seamless coordination and integration of benefits through the health home approach enhances access to the services and supports that children receive, reduces fragmentation, and improves outcomes and the experience of children and their families as they engage with the healthcare delivery system. MCOs serve as valuable partners in designing and facilitating access to these solutions.

Health homes integrate and coordinate the full array of services and supports for children on the autism spectrum

Children on the autism spectrum have lifelong health and social support needs. They may also have co-occurring physical health and/or mental health conditions.¹² As a result, these children and their families interact with diverse provider types across the physical healthcare, mental healthcare, and education systems, among others. A health home aims to pull together a child's full array of services and supports into a comprehensive person-centered service plan; this plan makes sure that children and their families are receiving the care, services, and supports they need, regardless of the services system or who pays for the service. The health home performs a much-needed one-stop navigation and coordination function, giving families reliable and consistent assistance when they need it most.

The comprehensive framework of the health home approach allows for an array of functions for children and their families—from intake and assessment all the way through to transition planning. For example, a health home care coordinator:



The health home integrates Medicaid benefits with supports provided by the education system and other communitybased resources.

- Conducts a holistic needs assessment when a child enrolls in the health home
- Works in partnership with the child and family to develop, monitor, periodically reassess, and adjust the person-centered plan to help the child achieve his or her goals
- Reviews the details of a child's school-provided services and individualized education program (IEP)
- Helps the child and their family navigate the system of care, including physical health, behavioral health, and social supports

One key function is the development of a comprehensive person-centered plan. The person-centered plan is dynamic in order to respond to evolving preferences, strengths, support needs, and personal goals. The plan considers each child holistically to make sure physical health, mental health, social, and educational supports and services are addressed to maximize health, wellbeing, achievement of key milestones, and independence. The personcentered planning process is essential to optimize coordination and delivery of needed services and supports so that they are complementary and not duplicative. To achieve this objective, the child's plan may include:

- Establishing clear goals and expectations for the child's services and supports
- Identifying the providers working with the child and the family, and the role of each in addressing the child's needs
- Scheduling regular meetings among the child, the family, and the health home care coordinator to share updates and assess progress towards plan goals

Central to this team is the health home care coordinator. The care coordinator is responsible for implementing all aspects of the person-centered plan making sure providers and other supports are meeting the child's needs in accordance with goals and expectations. The care coordinator also works closely with the child, their family, and providers to make sure the personcentered plan includes a crisis plan—outlining the appropriate resources that can stabilize the child in a time of emergency. As crises arise, the care coordinator plays a critical role connecting the child and their family to the emergency services and supports that they need. Thoughtful and deliberate crisis planning and timely services are critical to ensuring the wellbeing and continued community integration of the child and the family.

The care coordinator is also responsible for addressing any areas of concern that the family may raise in their regularly scheduled meetings and making adjustments to the person-centered plan as the needs or goals of the child and their family change. For example, the care coordinator helps children and their families transition between providers, programs, and service systems—such as helping the child transition home after a hospitalization or crisis stabilization episode. Importantly, the care coordinator also provides specialized coordination to make sure the family receives services and supports that meet the specific needs of their child. For instance, the care coordinator can work on environmental modifications and adaptations that can help the child thrive in the home and community. The care coordinator can also help the family manage dietary restrictions, identify and manage gastrointestinal issues, and secure respite services and in-home supports that address co-occurring behavior needs. Overall, the health home care coordinator ensures accountability to the person-centered plan and helps the family members problem-solve across systems and providers as they care for their child.

MCOs are a crucial partner for the health home when it comes to coordinating a child's Medicaid benefits. MCOs work closely with the health home to establish eligibility and enrollment requirements for the health home program. Based on these determinations, MCO care managers provide referrals to and enroll children in the health home. While the health home is the lead entity for coordinating the child's full array of health and supportive services, the MCO's care managers remain engaged with the health home and are responsible for coordinating and monitoring the Medicaid benefits received through the health plan. In addition, all determinations of eligibility for Medicaid services are made by the MCO, not the health home.

Coordinating resources through the health home provides seamless coverage for the child but without the need for families to engage with multiple payers or agencies. As part of this dynamic, the roles of MCO care managers and health home care coordinators are complementary and collaborative not duplicative. The MCO care managers work with the health home care coordinators to support the integration of Medicaid services and supports with non-Medicaid services and supports provided through the education system, community resources, and other entities. This can include working with the health home care coordinators to identify and connect members to the right physical health, mental health, and other supportive services covered by the state's Medicaid plan.

The health home care coordinator ensures that healthcare services are coordinated with other services and supports. Health home coordinators know and understand the local care delivery network and can identify the resources and supports an individual needs in that community. They also function as the system navigator on behalf of families.



MCOs are a crucial partner for the health home when it comes to coordinating a child's Medicaid benefits. The health home care coordinator, in close partnership with the MCO care managers, can take the lead in resolving coordination issues that arise across providers or systems. For example, many families often struggle to get pediatricians, mental health supports, and behavioral supports providers to communicate and coordinate to resolve problems that the child may encounter. The care coordinator can help overcome this fragmentation by facilitating communication across the child's providers and other supports to make sure there are no gaps or delays in care. The care coordinator can work closely with the MCO care manager to help improve and expedite the flow of information between the MCO and the health home and between the health home and the child's providers.

This collaborative relationship between the health home and the MCO promotes a seamless experience by reducing the need for the child's family to interact with two separate care coordinators, which in turn helps avoid disruptions and delays in services.

Coordinating Veronica's services through a person-centered plan

After reflecting on Veronica's new diagnosis of ASD and the services she will need moving forward, Veronica's family decided to enroll her in the health home available through their health plan.

Once Veronica was enrolled, her MCO care manager, Jenny, introduced her and her family to the health home care coordinator, Debbie. Veronica and her family's first visit with Debbie focused on learning what was important in order for Veronica and her family to be happy and healthy and to feel safe. In addition, Debbie completed the holistic needs assessment.

The needs assessment, including input from Veronica's family and other people important to her, was used to develop a comprehensive person-centered plan reflecting Veronica's preferences, strengths, and goals, along with her family's goals for her. It also detailed the services and supports needed to achieve those goals, including mental health services and education supports.

To execute Veronica's plan, Debbie and Jenny stayed in close communication to

ensure service authorizations and continuity of care. For instance, Jenny made sure that Veronica was referred to the mental health services included in her plan and Debbie worked with Veronica's mother to follow through on finding an appropriate provider and scheduling.

Debbie worked closely with Veronica's school, the MCO, and Veronica and her family to confirm that in-school services and supports—consistent with her IEP —were in place to support Veronica's success in school. For example, when Veronica began demonstrating some challenging new behaviors in school on certain days, Debbie assisted Veronica's mother in engaging with the school staff, mental health provider, and pediatrician to try to determine the cause.

After bringing the team members together to think through the issue, they realized that a change in the school lunch menu on those days had exacerbated an underlying gastrointestinal problem for Veronica. Eliminating the dietary irritant reduced the gastrointestinal issues, and Veronica's adverse behavior decreased significantly. Debbie made sure that the person-centered plan was updated, and supported Veronica's mother and the school to update the IEP to reflect the dietary accommodations.

To stay on top of potential incidents like these, Debbie and Jenny meet with Veronica and her family each month to reassess and adjust the personcentered plan, as needed, to make sure the services and supports are responsive to any evolving needs and help Veronica achieve her goals.

By coordinating all of Veronica's services through a comprehensive person-centered plan, the health home and MCO eliminated gaps in care that Veronica and her family may have otherwise experienced. Through this approach, Veronica and her family have more family time, experience the support needed to reach their goals, and have the opportunity to celebrate positive milestones as she moves through childhood into adulthood.



Multidisciplinary teams create an environment where a child's team members "talk" to each other across the traditional silos.

Health homes reduce fragmentation across the broader system of care

There are a number of disparate entities, programs, and resources (e.g., doctors, therapists, schools, childcare providers, community agencies) that serve children on the autism spectrum, and they are rarely coordinated. Even within a single program such as Medicaid, the available services and supports may not be closely coordinated or integrated. The health home can improve integration, collaboration, and coordination across a diverse and comprehensive array of services and supports. The health home also works with children and their families as they engage with multiple systems or entities to access needed services and supports.

For most families whose child is diagnosed with ASD, finding their way to the right combination of services and supports is often hit-or-miss and can take a substantial amount of time. Upon diagnosis, families are frequently overwhelmed with information, "to-do" lists, and questions and concerns. They often do not know how to find the right resources and may need assistance getting connected to local community services, as well as accessing peer-to-peer family networks and other important supports that can help their children thrive. Health home care coordinators can facilitate communication and collaboration among the various agencies, providers, community resources, and service systems.

One of the health home's core functions that makes the comprehensive approach possible is the use of multidisciplinary care teams. Multidisciplinary teams create an environment where a child's team members "talk" to each other across the traditional silos. The multidisciplinary team is composed of individuals with expertise across the child's array of services and supports (e.g., nurse practitioner, speech-language

Helping Veronica and her family navigate the broader system of supports

The health home care coordinator goes beyond healthcare to help children and their families secure needed social supports that ultimately improve children's health and ability to achieve their goals.

Debbie worked closely with Veronica's family members—helping them work through the stress of the initial diagnosis; helping them learn about programs, community resources, and support options; and participating in three-way calls with various entities, including local providers specializing in assistive technology, school staff, child care providers, and family support groups. In addition, the health home and MCO worked together with Veronica's family to connect them with transportation to improve her access to needed services.

Recently, Veronica's mother needed to find more stable and affordable housing for the family. The health home was there to help. Debbie helped Veronica's mother locate and apply for public and subsidized housing in her area. Debbie walked her through the website and application process and identified a contact person at the housing agency whom Veronica's mother could call with any follow-up questions.

Overall, Veronica and her family have benefited from the enhanced coordination and collaboration available through the health home. pathologist, occupational therapist, school-based specialist) to make sure there is coordination across the system of care. All of the child's service needs are met through ongoing coordination and support through this multidisciplinary, cross-system team.

Importantly, the health home approach also emphasizes quality-driven care, services, and supports for children and their families. The MCO, in collaboration with the health home care coordinator, tracks services and monitors outcomes to ensure that children on the autism spectrum are receiving the appropriate care and services they need and are achieving their goals. The MCO shares child-specific utilization and quality information (e.g., encounters, authorizations, gaps in care) with the health home care coordinator to help identify and address any unmet needs. Should there be any gaps in care or supports identified by the MCO, the care coordinator, the family, or other members of the child's team, the health home works with the provider, agency, and/or community resource to improve service coordination and delivery. This collaboration to ensure ongoing quality of care reinforces the accountability of the health home care coordinator when it comes to implementing the child's person-centered plan. It also demonstrates improved communication and flow of information within a health home approach that can help drive quality and enhance services and supports.

Overall, the health home's person-centered approach, better alignment of services and supports across the system of care, coordination of entities and resources through multidisciplinary teams, and focus on high-quality service delivery ensure that critical needs do not go unmet. Importantly, the health home's comprehensive role in coordinating and navigating the system of care helps relieve parents and caregivers of the stressors of those long "to-do" lists and instead lets them focus on what is most important raising healthy and happy families.

Health homes support children on the autism spectrum through critical transitions

Given the lifelong needs of children on the autism spectrum, it is inevitable that children and their families will experience transitions in their care and services. Therefore, having transition supports in place is integral to the health home approach. During periods of transition, children on the autism spectrum may need extra assistance to make sure their healthcare and service support needs are met without disruption. Young adults transitioning into adulthood may need assistance as they transition to self-directed care and having more control over their own healthcare decisions.¹³ Health home care coordinators work closely with children and their families as transitions occur between early intervention and school-based services, through changes in family or caregivers, when provider relationships start or stop, and as youth move from adolescence into adulthood. The health home also supports the children and their families as they transition between service settings, such as from the hospital back to the home or community.



Health home care coordinators provide continuity and support during critical transitions, such as changes in providers or moving between service settings.

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The health home prevents children and their families from experiencing any gaps in care or supportive services. Health home care coordinators conduct periodic reassessments of the person-centered plan to make sure the child's needs are being met and that any new or changing needs are addressed. For instance, as school-based supports are phased out and youth transition into adulthood, the health home can provide college or employment preparation and help identify new sources of services and supports in preparation for changes in benefits. Health homes also facilitate coordination between the child's primary care physician and other providers, particularly as children on the autism spectrum transition from pediatric to adult providers. And if a child leaves the health home, the health home care coordinators can help the family develop a transition plan to promote ongoing services and supports.

The health home has the flexibility to put greater focus on certain services and supports at key milestones. For instance, for Veronica, this may include strengthening proactive strategies and behavioral health supports when she moves from elementary school to middle school, or even at the start of each school year as she transitions into a new classroom. The health home will work to identify the specific resources she needs to smooth each transition. For example, the health home can reassess the educational, social, and health supports that Veronica needs in her new school setting and facilitate collaboration across Veronica's team to assist in the implementation of any changes to her IEP and at home.

Overall, by fostering continuity of care and supports during critical times in a child's life, the health home prevents the member from experiencing any gaps in care, supportive services, or both. Families also benefit from access to a multidisciplinary team that understands their needs and with whom they have a long and trusting relationship. For states, greater continuity and seamless connections across the system of care lead to more effective and efficient use of limited resources.

Health homes provide essential support to family members as they care for their children on the autism spectrum

The health home approach incorporates a family-centered approach into all its activities. Health home care coordinators take into account the physical health and emotional wellbeing of the family, in addition to those of the child. The person-centered plan implemented by the health home incorporates strategies that promote the health and wellbeing of family members, since the challenges of long-term caregiving often go unrecognized or unaddressed.

Although coordinating the person-centered plan and ensuring continuity of care is a core responsibility of the health home care coordinator, the coordinator's relationship with the child's family goes beyond this. The health home can offer ongoing education and resources in support of families. For instance, health home care coordinators might work with families to:

- Increase their awareness of available services and supports
- Connect them with peer-to-peer supports
- Educate them on the relationship between ASD and other commonly co-occurring conditions such as attention deficit disorder, intellectual disability, and epilepsy
- Help them stay on track with preventive care services (e.g., well-child visits and prescription drug regimens)

Given the care coordinators' local knowledge and ties to the community, they also help their family connect to quality, knowledgeable providers who get to know the child and the family. The care coordinator facilitates regular dialogue between the child's family and the child's providers so the family grows confident that the providers understand the needs and preferences of the child. The lifelong needs of children on the autism spectrum require consistent, stable, and ongoing relationships among children, their families, their MCOs, service providers, and other community-based social supports. Health home care coordinators can help cultivate and maintain these relationships for children and their families.

Another way in which the health home, in close partnership with the MCO, facilitates support for the family is through respite services. MCOs can provide access to necessary respite even above the limits available through the state Medicaid program to support family caregivers. Many MCOs monitor the family caregivers' ability to continue providing care, housing, and natural supports, and the barriers that may exist to their capacity to do so. The health home care coordinator can also evaluate caregiver strengths and needs for support, offering information, education, training, communications, and problem solving, where appropriate. These supports offered by the health home can help alleviate caregiver stress and can support the employment, economic, and social stability of the family.

Health homes can also serve as a clearinghouse of information on sources of support for families in the community (e.g., advocacy, support groups). For Veronica's family members, the health home proved to be an indispensable source of information as they learned more about ASD and available resources.

Most importantly, the health home is a coordinated approach to the delivery of quality healthcare while supporting and strengthening families to become independent, confident, and self-directed in their efforts to ensure their children's growth and development.



Care coordinators' local knowledge and ties to the community help families connect and develop relationships with quality, knowledgeable providers.



Health homes help children live meaningful, self-determined lives and achieve their full potential.

Conclusion

Children on the autism spectrum often have numerous health and supportive service needs. However, with the right services and supports, children on the autism spectrum have increased opportunities to live meaningful, self-determined lives and achieve their full potential.

Medicaid and other service systems provide a range of healthcare services and social supports to help children and their families thrive. Emerging approaches such as the health home can improve coordination and enhance the system of care surrounding a child—helping the child achieve his or her goals.

For states exploring innovative ways to enhance care for children on the autism spectrum, establishing a health home in partnership with an MCO is an effective way to improve the system of care. The health home approach builds on the strength of the managed care framework and the local knowledge of the community-based entity serving as the lead health home entity. Through this partnership, a health home brings considerable value to the state's delivery system while also providing children and their families with a family-centered option to manage all of their health and support needs.

Endnotes

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