Washington State Department of HEALTH

Children and Youth with Special Health Care Needs

Findings from the Youth Transition Needs Assessment: Community Feedback

Executive Summary:

The purpose of the needs assessment was to identify current gaps and needs in transition services and resources for youth with complex chronic health conditions in Washington state. The Washington State Department of Health (DOH) distributed an online survey through multiple children and youth with special healthcare connections. This included local organizations representing disability and community professionals such as The Arc, Parent to Parent (P2P), and Developmental Disabilities Community Services (DDCS, formerly Developmental Disabilities Administration). The survey also went to providers, caregivers, and school support.

DOH received 145 responses consisting of 9 respondent groups:

1. Parent/caregiver (69, 48.6%)
2. Public health/government (24, 17%)
3. Other – guardians, county programs, disability advocates, etc. (22, 15.5%),
4. School – K-12 transition services (18, 12.7%)
5. Pediatric healthcare providers (13, 9%)
6. Community-based providers working with adults (11, 7.75%)
7. Community-based providers working with children and youth (10, 7%)
8. Adult healthcare providers (7, 5%)
9. Young adult older than 18 years old (4, 2.8%)

The evidence from this survey suggests that respondents value printed materials that are accessible in multiple languages, clear, up-to-date, and tailored to both the individual and state-specific organization websites.

Overall, the survey suggests that having a provider or an individual with lived experience walk families through the resources is most effective. When asked about sharing or finding transition resources, the leading method was word of mouth through family and peer networks. Websites including YouTube, Google, and social media followed closely after.

The existing adult healthcare workforce faces shortages and is often unprepared to serve youth with complex or chronic health conditions. While transition services exist, they vary by county, and many families lack awareness and a warm handoff to adult care. Families and youth also struggle with late or limited planning, fragmented systems, poor communication, and the absence of a clear care coordination leader to guide the way for transition.

The following is a summary of key focus areas to explore to make the pediatric to adult transition more successful in Washington state for youth with chronic health condition(s). These are based on responses from individuals who participated in the survey:

- Understanding resources and accessibility
- Advocacy and awareness for planning ahead
- Collaboration through care coordination or improved navigation
- Partnerships among school-based interventions, healthcare systems, and familial involvement
- Provider support through education and training
- Services, resources, and county/community consistency

Key recommendations also included reviewing other state models like Texas, Maryland, California, and Oregon. It also included adapting or adopting best practice ideas, such as:

- Establishing cross-system communication by creating transition teams
- Utilizing a transition coordinator or navigator role
- Involving families and youth in decision-making with a transition advisory board

Background:

The transition from adolescence to adulthood is a critical period, especially for youth with complex and chronic health conditions. Many face significant barriers when navigating changes in medical care and non-health changes like education, employment, housing, guardianship, safety, transportation, financial planning, and benefits.

These challenges are more prominent for young people with disabilities who may need ongoing support across multiple systems during a time when many things change by the age of 18. According to the 2022-2023 National Survey of Children's Health, over 80 percent of youth ages 12-17 do not receive services to prepare for and move to adult care.

"It is more of an awareness issue. Everyone talks about 'transition' as employment. It is so much more than that. Pediatric docs are not good about preparing patients either."

-Caregiver/parent

Nationally, about 1 in 9 young people between the ages of 16 and 24 are disconnected from school or work. Often referred to as "opportunity youth," they are nearly twice as likely to live in poverty and have reduced access to healthcare compared to their peers (Mmari et al. 2018).

Additionally, neurodivergent youth are more likely to face long-term health and social challenges compared to their neurotypical peers. This only widens the gap for potential disconnection. Having consistent access to experienced adult healthcare providers, health insurance, and long-term support systems like community engagement are a few key areas of additional care. For these young people, preparing for life after high school may require tailored services that promote connection, independence, autonomy, and continuity of care.

Public health must lead the way in creating family and youth-centered, equitable systems that promote engagement and long-term well-being. Johns Hopkins Bloomberg School of Public Health identified adolescent health as 1 of its 5 public health focus areas. This recognizes adolescence as a formative life stage that influences lifelong health and development. This project aligns with that focus by assessing healthcare transition needs in Washington, a key issue affecting young people with disabilities, and elevating community voices in the process.

"Health care transition, or HCT, is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care."

-Got Transition

In Washington state, 1 in 5 children has special healthcare needs. DOH promotes connected systems of care for Children and Youth with Special Health Care Needs (CYSHCN) from birth through transition to adulthood. Our purpose is to ensure comprehensive, integrated, coordinated, family-centered, and culturally competent systems of care to ensure that CYSHCN can achieve the healthiest life possible and develop to their full potential.

Our vision is that all CYSHCN and their families belong, participate, and thrive in communities with accessible systems that equitably support their social, health, developmental, and emotional well-being. The CYSHCN program provides funding and technical assistance to providers across the state. This includes local public health jurisdictions, registered dietitians, neurodevelopmental centers, youth and family support organizations, behavioral health providers, schools, hospitals, and primary care providers.

DOH's Children and Youth with Special Healthcare Needs program, with funding from the federal Maternal and Child Health Block Grant, conducted a statewide needs assessment. The assessment focused on the pediatric to adult care transition for youth with disabilities in Washington state. Through survey responses of young people, caregivers, healthcare providers, school supports, and community organizations, the project explored the barriers and gaps that impact access to high-quality, family-friendly, transition services.

Background:

In April 2025, we began the transition needs assessment to understand the state of transition gaps for young people living with chronic health conditions in Washington state from the community's perspective.

This mixed-methods tool was developed on SurveyMonkey, with the help of Peggy McManus from Got Transition and the National Alliance organization. Additionally, the CYSHCN director, epidemiologist, and nutrition consultant contributed different viewpoints to create the survey. The survey uses a combination of multiple-select, Likert scale, and open-ended questions. Respondents reflected on their experiences and shared creative ideas for improving health care for adolescents and young adults in Washington.

We shared the survey through multiple outlets, including:

- CYSHCN and Washington Statewide Leadership Initiative (WSLI) newsletters
- Quarterly CYSHCN communication network meeting and the WA INCLUDE Collaborative
- Adult community centers, camps, Partnerships for Action, Voices for Empowerment (PAVE), The Arc, and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
- Organizations: Office of Superintendent of Public Instruction (OSPI), Developmental Disabilities Community Services (DDCS), and Division of Vocational Rehabilitation (DVR)
- DOH partners: Maxillofacial Review Boards (MFRB), Nutrition Network, Neurodevelopmental Centers (NDC), DOH Adolescent Health, DOH Genetics, and DOH Child Health
- Providers through the Washington Chapter of the American Academy of Pediatrics (WCAAP), DOH Power of Providers (POP), and Health Care Authority (HCA)
- Type 1 Diabetes (T1D) workgroup and Special Olympics of Washington (SOWA)

SurveyMonkey's built-in software provided quantitative analysis for all multiple-select and Likert scale questions. We used the qualitative analysis software Atlas.ti to code open-ended responses and categorized the data based on themes and subthemes.

This collaborative process, which brought together public health expertise and lived experience, identified strategies families are already using for transition and opportunities to strengthen them. One hundred and forty-five (145) individuals from across Washington completed the needs assessment transition survey.

Results

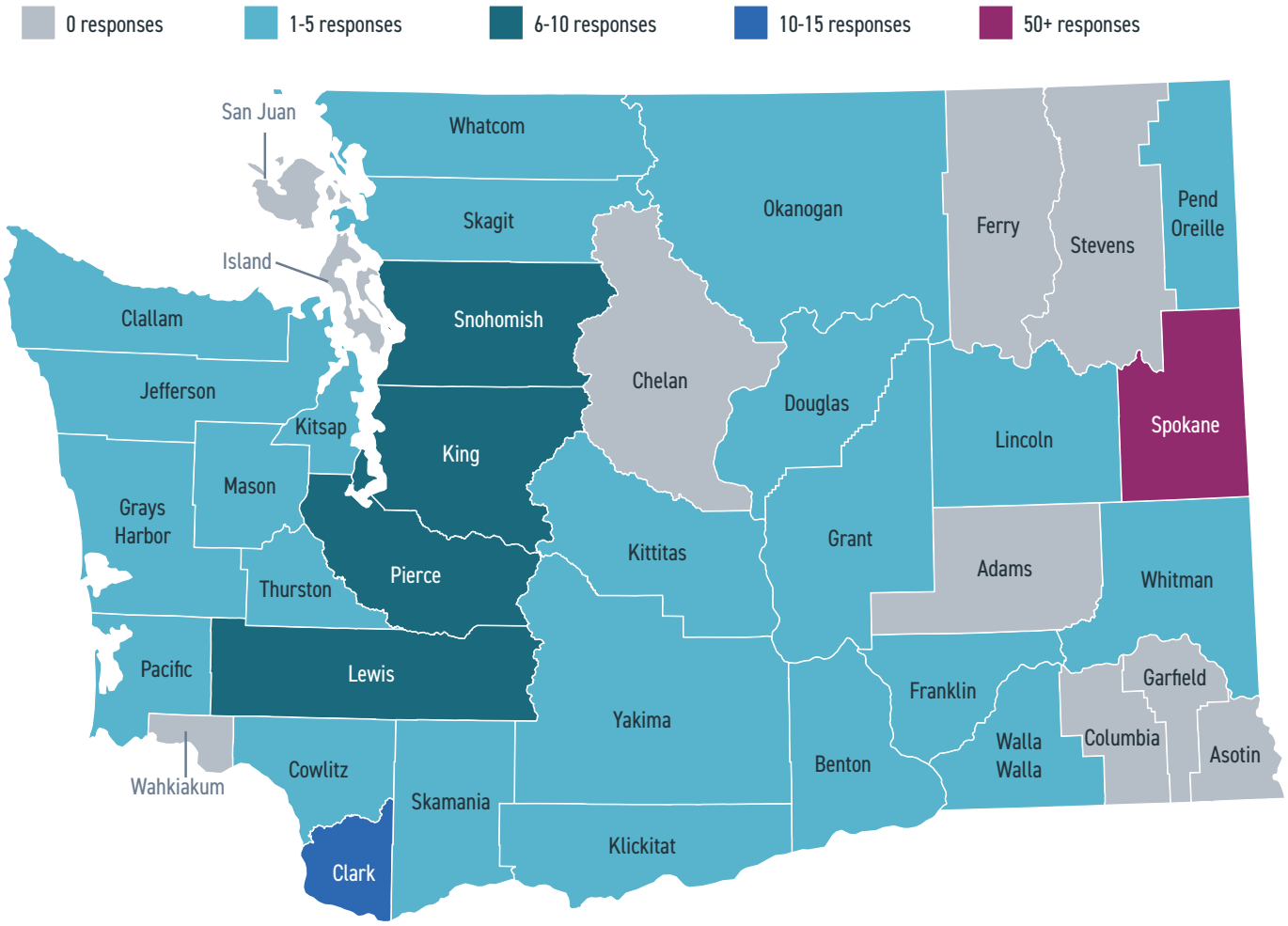
WHO: What role or settings do the participants play in the transition from pediatric to adult care?

Role		Responses	
Parent/Caregiver	48.59%	69
Public Health/Government	16.90%	24
Other*	15.49%	22
School (K-12, transition program)	12.68%	18
Pediatric Health Care Provider	9.15%	13
Adult Community Based Provider	7.75%	11
Child/Youth Community Based Provider	7.04%	10
Adult Health Care Provider	4.93%	7
Young Adult (>18)	2.82	4

Total Respondents: 142

*Other category includes: parent advocates, disability advocates, grandparents, guardians, mental health providers, medical assistants, board members, and county programs.

WHERE: What counties did participants reside in or practice in?

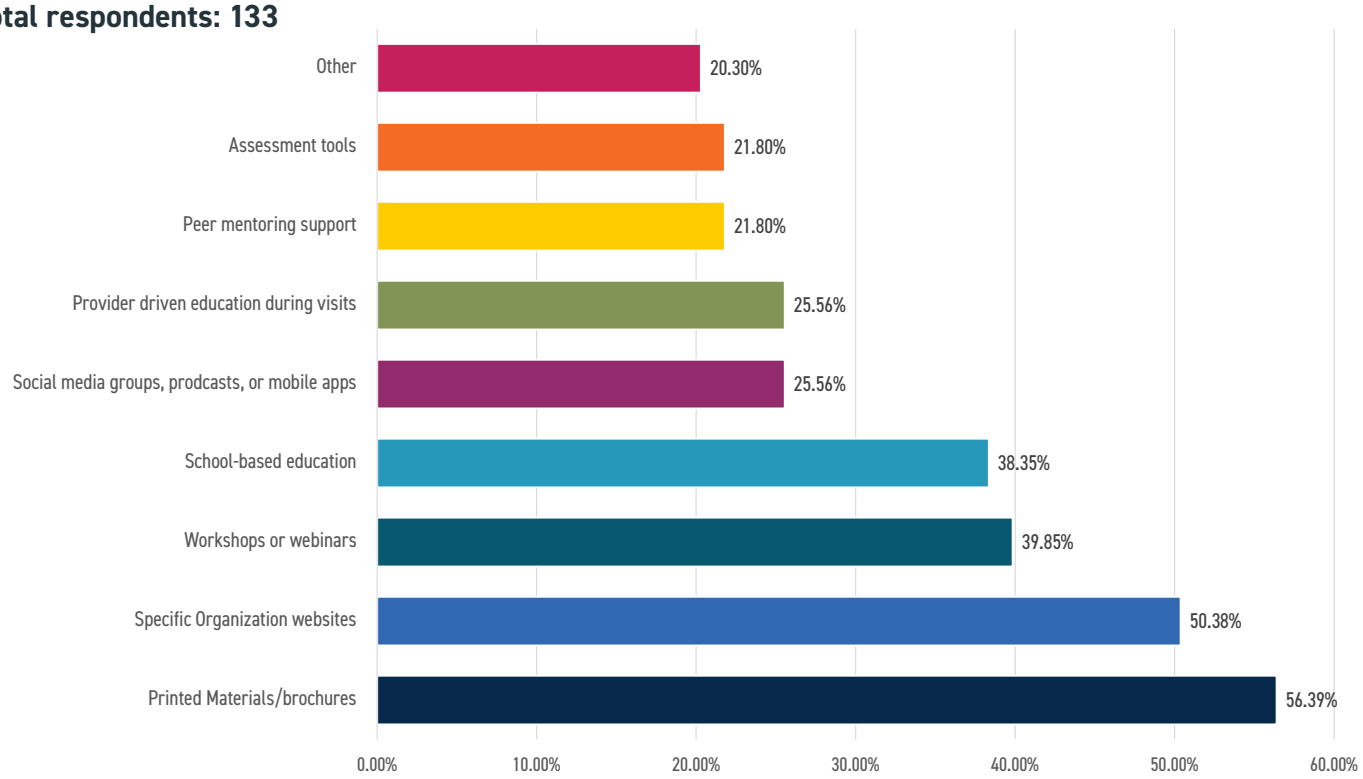


County	Responses	County	Responses	County	Responses
Out of State	1	Grays Harbor	3	San Juan	0
Adams	0	Island	0	Skagit	4
Asotin	0	Jefferson	1	Skamania	1
Benton	5	King	9	Snohomish	8
Chelan	0	Kitsap	1	Spokane	53
Clallam	1	Kittitas	4	Stevens	0
Clark	13	Klickitat	1	Thurston	3
Columbia	0	Lewis	6	Wahkiakum	0
Cowlitz	1	Lincoln	1	Walla Walla	1
Douglas	1	Mason	1	Whatcom	4
Ferry	0	Okanogan	2	Whitman	1
Franklin	1	Pacific	1	Yakima	4
Garfield	0	Pend Oreille	2	Statewide	0
Grant	2	Pierce	6	**Total**	**142**

Thoughts and Feedback on Services and Resources:

What resources do you use (or provide) to prepare youth and their families for pediatric to adult transition planning?

Total respondents: 133



*Other category includes: behavioral therapy, DDCS, informing families, self-online searches, School-to-Work programs or workshops, community outings, social worker referrals, and multidisciplinary care.

Key Takeaways:

- Families and providers use a variety of resources, including pamphlets, brochures, flyers, snail mail, handouts, and FAQ sheets. They see the most value when these **resources are tailored** to their specific needs instead of a "one-size-fits-all" approach. According to one caregiver, "least effective is hands-off materials 'brought home' that have no personal connection point." This shows that having an experienced individual walk families through the resources is most effective.
- Providers see strong potential in pairing online tools and assessments with **human connection**, especially lived experience and follow-up support. This makes transition resources more effective and meaningful. A pediatric healthcare provider said, "I think these services work best when families have a person to explain the process rather than just give them a website alone."
- Community-based providers and public health supports recognize the importance of making resources available in multiple languages. This creates opportunities to expand **inclusiveness**.
- **Accessible formats** like written material that can be revisited, or videos where information is shared aloud, were identified as helpful tools for reinforcing learning and supporting retention. According to a grandparent/guardian, "for me, it helps that I can review things repeatedly. Written materials, as well as websites I can access, help with this. I know sometimes the reading level can be a challenge for some to understand, or not being able to have the information read aloud to them."

- **Online searches** like Google, national websites, and YouTube are common starting points for families. Enhancing these points with more individualized, up-to-date, and practical resources, can further support the transition learning process.

"We only learned of my daughter's diagnosis 2 years ago at the age of 16. Her provider gave materials/brochures, and we have looked online for resources. That's been about 30% effective compared to what I think we need to know."

-Got Transition

"If we have a family that still has a need, we support them whether it's another team visit or remailing a copy of the treatment plan letter with recommendations for care (including provider/clinic and their phone numbers)."

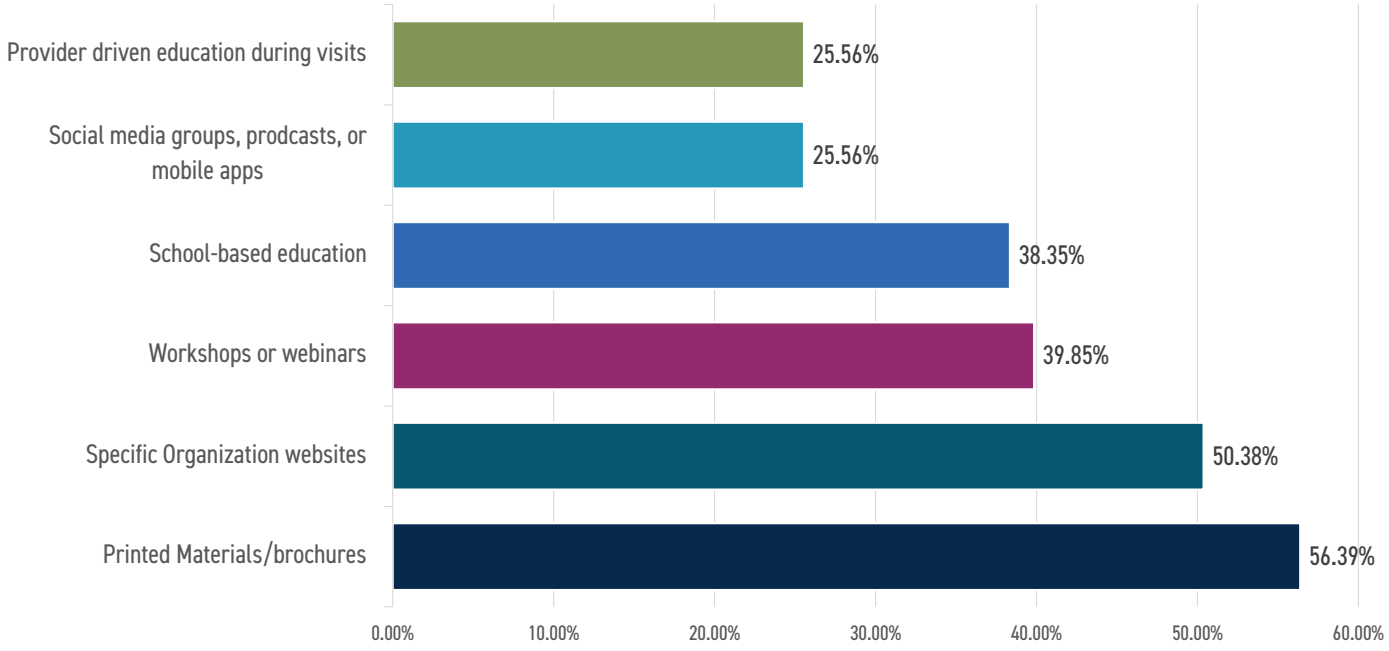
-Healthcare provider (pediatrics)

"Organizational websites, such as PAVE and Informing Families have been the best; along with workshops on various topics."

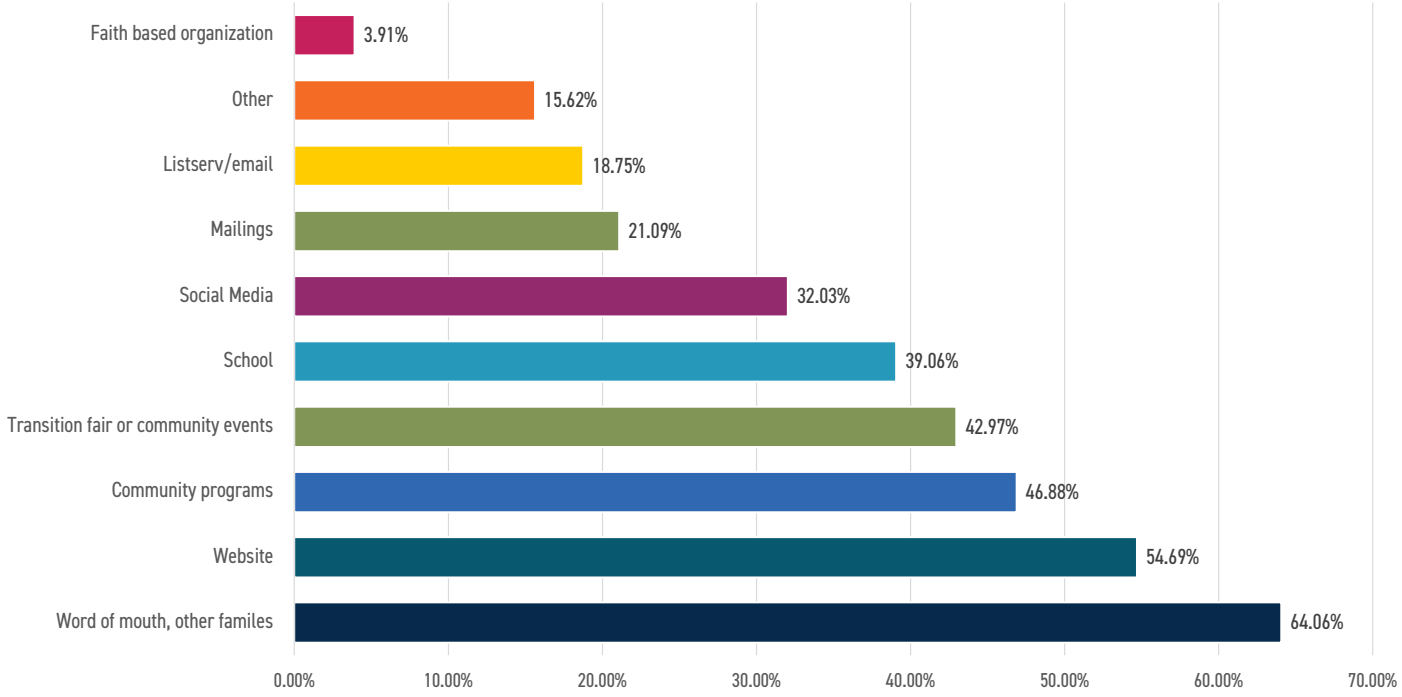
-Public Health/Government

How effective have these pediatric to adult transition resources or programs been in preparing youth for adulthood in Washington state?

Total respondents: 133



What methods are used to share information as a provider or how did you find these resources as a caregiver?



*Other category includes: DDCS case manager, client-specific referrals, family conversations, local radio or newspaper, and handouts/Google documents.

Caregivers primarily find and share resources through personal connections rather than formal systems. The leading method was word of mouth, family and peer networks, followed closely by websites, community programs, and social media. Across all responses, a key theme is that relationships drive awareness and support.

Key Takeaways:

- **Families are the strongest source of support**. Word of mouth and family-to-family sharing were the most common ways caregivers found resources. This highlights the power of lived experience and peer support.
- **Technology and community connections expand access**. Caregivers also relied on websites, social media, schools, and community programs. This shows that both digital platforms and local networks help bridge resource gaps.
- **Events and structured supports add value**. Transition fairs, providers, and listservs provided additional avenues for information, particularly for families navigating complex systems.
- **Multiple entry points matter**. Caregivers identified diverse ways of learning from DDCS case managers to local radio. This shows that a variety of touchpoints help families access what they need.
- **Relationships drive resilience**. Across all methods, connection and collaboration were foundational to caregiver awareness. This suggests that investing in community-building is a key strategy for strengthening supports.

"Parents with kids with disabilities need a social worker to help navigate what is best for the teen going into adulthood. It is exhausting trying to track down info and having a hard time even finding resources. Our resource center doesn't even know how to help us. We so need help for mental health. We need a support group for not only the youth but their parents. We could learn from each other if those were available."

-Got Transition

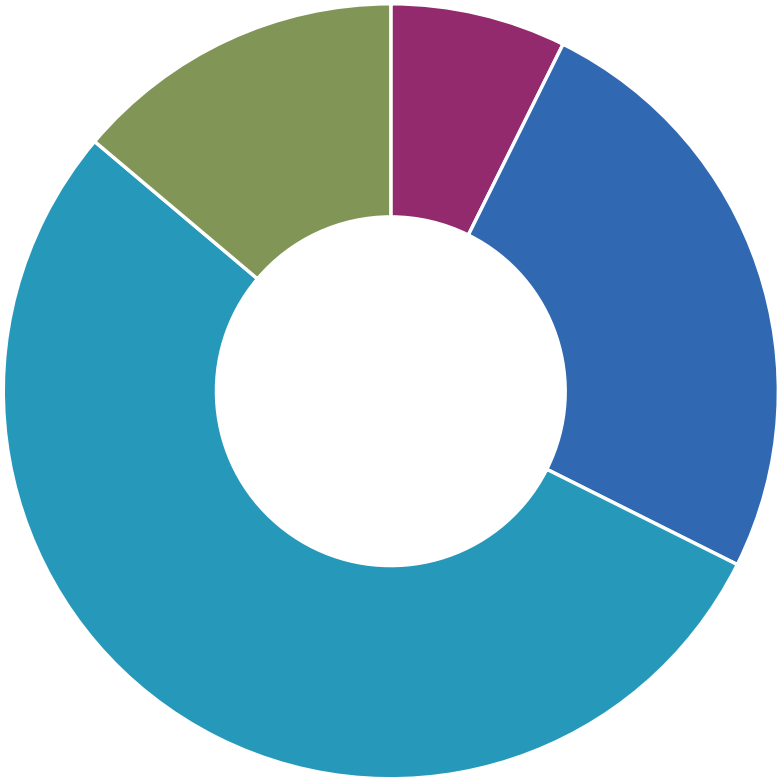
"We need awareness and funding. We also need to be able to collaborate with other providers to build a comprehensive support network. Providers and parents are burned out and isolated. If we had a hub where we all networked and helped each other, maybe we could get more traction."

-Parent and healthcare provider (all ages)

"Social media and connecting with other families has been helpful."

-Caregiver/parent

How accessible are these transition services and resources to all youth and their families in Washington?



Level of accessiblity		Responses
Very accessoble	7.2%	9
Mostly accessible	26.4%	33
Somehwat accessible	52.8%	66
Not accessible	13.6%	17

Total Respondents: 125

What the community had to say about accessibility:

"Most are not free or covered by a lot of insurance companies, leaving difficult access. Sometimes, they're not accessible to minors without parental consent, which is also not always easy to obtain."

-Certified Medical Assistant in family medicine

"Services are inconsistent across the state; rural communities do not have transitional supports available."

-Public Health/Government

"Information is very difficult to find. Advocacy is critical yet many families are not aware. Once these resources are found, they are confusing to decipher and many of the best services are not always accessible."

-Parent/Caregiver

"Knowing about what services are available is just the first step. Navigating through the maze of paperwork, waitlists, and getting a provider to accept to patients is a complex and long process."

-Parent/Caregiver, School (K-12, transition programs)

"The resources are only accessible if you know how to navigate them and who to turn to for assistance."

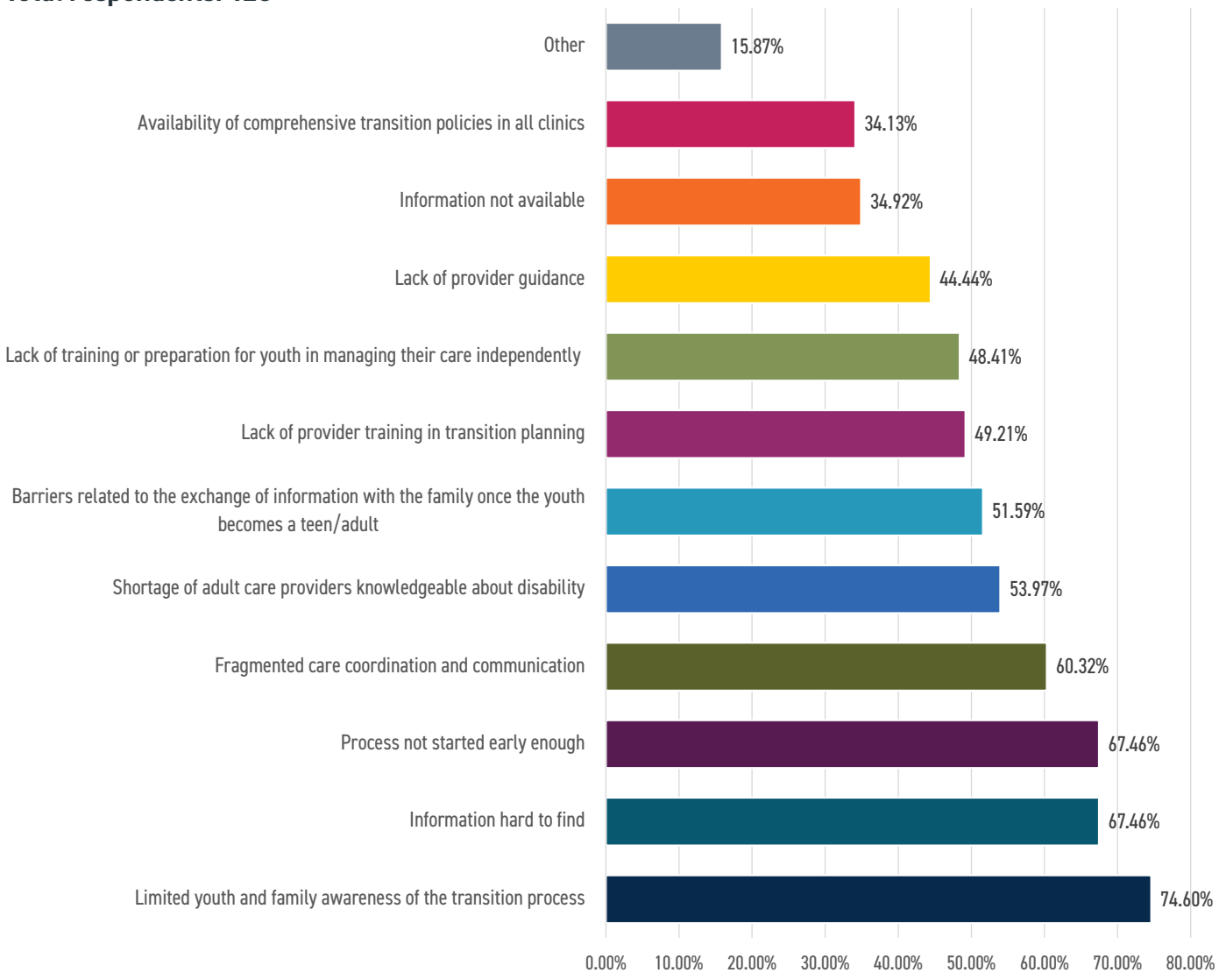
-Community Based Provider working with all ages

"School-to-Work is not statewide, some counties are not offering job foundations, schools do not know about/promote these options, DVR outreach and understanding of programs is limited, leaves out rural areas."

-Community Based Provider working primarily with adults

What are the common challenges or specific systemic barriers that hinder a smooth transition for youth with disabilities?

Total respondents: 126



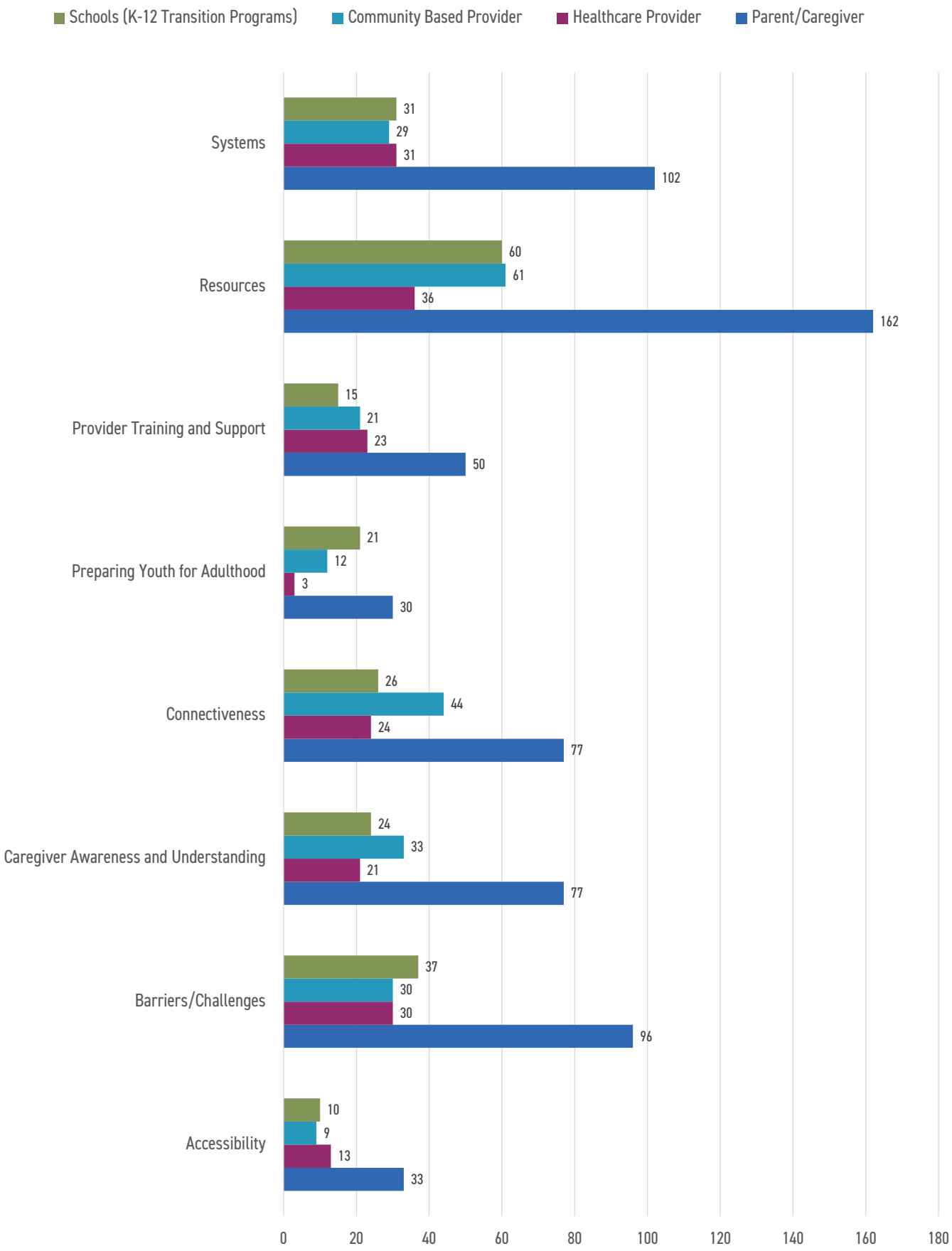
The data shows that youth with disabilities and their families face a wide range of systemic barriers when navigating the transition from pediatric to adult healthcare. The most common challenges include:

- limited awareness of the transition process,
- difficulty finding reliable information,
- and not initiating transition conversations early enough.

Respondents shared the lack of awareness and support, especially early in the process when the first stage of transition should be discussed. Many respondents also mentioned gaps in provider guidance, training, and finding knowledgeable adult providers to transition to. Overall, weak communication across systems was a recurring theme. Finally, youth often lack adequate preparation to manage their own care, while persistent barriers to information exchange make it harder to build continuity.

The story these findings tell is one of fragmentation, where strong intentions and available resources exist. But without earlier preparation, coordinated communication, and more trained and available providers, youth and families struggle to achieve a smooth and confident handoff into the adult world.

What else does the data story tell us?



Parent/Caregiver:

Parents and caregivers are overwhelmingly focused on **resources**, specifically, clear information, supports, and tools to navigate transition. They also emphasize **systems**, reflecting frustrations with fragmented care, eligibility barriers, and lack of coordination. **Barriers/challenges** reveal the real-world obstacles families face, like insurance, transportation, and service gaps.

According to one caregiver/parent, they said, "mainly it is challenging to get all the information needed from one avenue. Have to piece together info that is received from multiple agencies."

Healthcare Providers:

Providers also identify **resources** and **systems** as priority focus needs, but the emphasis is smaller compared to that of caregivers. Their highest concern is **barriers/challenges**, often tied to time constraints, insurance mandates, lack of transition training, and difficulty coordinating pathways across pediatric and adult systems.

Community-Based Providers:

Community providers focus heavily on **resources** but uniquely elevate **connectiveness**, like building networks, collaboration, and partnerships. **Barriers** also emerge, but their perspective centers more on community linkages and relational support rather than medical systems gaps alone.

According to a community-based provider who primarily works with adults, "the School-to-Work model in some counties, such as King, is successful and collaborative. The schools, counties, vendors, DVR, and DDCS are all involved, promote it, know the why, and encourage participation. Other counties rely on DVR to get the word out to schools, and they do not. Not sure what the accountability is. And DVR in the counties without School-to-Work is not the best entity to talk to schools and transition students about their options."

Schools (K-12, Transition Programs):

Schools also emphasize **resources**, especially tools and structured programs to support transition. Like providers, they also see **barriers/challenges** and **systems** issues. These are often related to communication between education and healthcare systems, or gaps when students exit school-based supports.

An enthusiastic parent who also works in the school systems shared the following: "I have always thought there needs to be a family resource coordinator in each school or district to help families navigate disability services, including transition services. There really is nowhere else in life where families have someone to help them. Current school staff are not educated in navigating these services. I want this job!"

Why this matters for pediatric to adult transition:

The differences illustrate where each role (or setting) sits in the transition ecosystem:

- Families live with the systemic burden and seek more navigation support.
- Providers feel constrained by systemic and structural barriers.
- Community programs act as connectors, prioritizing relationships.
- Schools lack system alignment and healthcare connection.

Together, these insights suggest that effective transition work requires:

1. Building accessible, family-friendly resources that are easy to find.
2. Strengthening system-level coordination between pediatric and adult care, especially in school networks and healthcare.
3. Investing in provider training to reduce barriers and improve support.
4. Leveraging community and county consistency to build connectiveness and continuity.

It's not just about exchanging information, but also about ensuring accountability. It's about creating community-based solutions that connect youth, caregivers, providers, and schools to make the transition process less overwhelming and more equitable. Strong system communication can be a powerful driver of smoother healthcare transitions when agencies, schools, and providers work in partnership.

According to participants, these best practices or models in other states should be considered for Washington:

Improving collaboration between pediatric and adult systems during the transition process for youth with disabilities requires both structural coordination and cultural shifts in how care is delivered across age-based service boundaries.

Below are just a few evidence-based strategies and approaches that communities, especially in Washington state's rural regions, can adopt or adapt:

- Locally, in **Clallam County**, "we are told by DDCS that we have the best transition program in the state. We are very involved with each school district in our county in promoting and educating the students, families, and staff about our transition program. We also present resource fairs at each of the high school campuses highlighting our transition program and all the other services available to students."
- **Texas Transition Toolkit (Statewide Resource) Lead Agency**: The Texas Department of State Health Services has the STAR Kids contract. This contract requires MCOs to employ transition specialists who assist members and service coordinators with ongoing transition planning beginning at age 15. Washington state could model a similar central website.
    - Key Features: Comprehensive resource hub for families, educators, and health care professionals. This includes training modules, timelines, interagency collaboration checklists, and culturally and linguistically adapted materials.
- **Vermont's Youth Transition Services Initiative Lead Agency**: Vermont Agency of Human Services Funding: Medicaid and vocational rehabilitation that pairs youth with Transition Case Managers trained in developmental disabilities and employment readiness. Connections between health, housing, and job support systems. Actively incorporates youth voice and self-advocacy in planning.
- **Oregon's Transition to Independence Process (TIP) Model Lead Agency**: Oregon Health Authority and partnering youth-serving systems population: Youth and young adults with behavioral health needs and disabilities.
    - Key Features: Uses Transition Facilitators to support coordinated transition planning. Emphasizes self-determination, life skills, and cross-agency collaboration. Integrated into both Medicaid and education service delivery.

- **Ready, Set, Go! (Maryland) Lead Agency**: Maryland Department of Health and Developmental Disabilities Target Group: Youth with intellectual and developmental disabilities. Washington state could adapt this to embed in IEP transition planning supports or Family Resource Navigator roles. Practical for school-community-medical partnerships in smaller districts.
    - Key Features: Interactive toolkit to prepare youth, families, and providers for adulthood. Structured around individualized planning starting at age 14. Strong connection with education, employment, housing, and health supports.

Discussion:

A clear takeaway from this needs assessment was that current resources or programs are only somewhat effective in meeting the needs of preparing CYSHCN for adulthood in Washington state.

Respondents highlighted many ways that families and young people navigate their care. This included the use of printed materials, online searches, national websites, and school-based support. They emphasized the importance of human connection throughout the transition process, from direct provider support to peer mentoring.

The ability to access transition services was a consistent barrier. Most respondents found these services only somewhat accessible or not accessible at all. Other reported barriers that prevent a smooth transition include a lack of awareness from both familial and provider perspectives or difficulty navigating the complex and fragmented systems of care.

We learned there is work to be done, particularly with awareness, care coordination, and system communication. The survey input helped identify gaps, needs, and priorities to improve the transition process.

This report summarizes key findings from that assessment and offers recommendations for improving healthcare transitions in Washington. At its core, this work is a call to action to ensure youth with disabilities in Washington state are supported, connected, and empowered as they enter adulthood.

"Individuals with developmental and intellectual disabilities, especially those with mental health needs, as well as their DD/IDD Diagnosis, often have complex needs. The WA state health care system is currently not equipped, nor has accountability mechanisms in place to increase competency from health care providers to serve this population overall. Individuals with DD are often declined to be served by all provider types and struggle to have equitable, quality services to meet their needs in both the physical and behavioral health realms. Medicaid reimbursement rates also affect providers willing to serve the DD/IDD population."

-Healthcare provider

Practice Ideas for Washington:

Establish cross-system transition teams that include pediatricians, adult care providers, CYSHCN coordinators, educators, and social service staff who meet to coordinate transitions.

Co-develop shared transition protocols and utilize a Transition Coordinator or Navigator Role who walks families through the transition, helps them access adult systems, and reduces fragmentation.

Crosstrain providers in youth-friendly and developmental disability-aware practices by offering joint continuing education or webinars for pediatricians and adult providers.

Provide families with **direct transition planning** and coordination support (e.g., referral and connection to new providers).

Extend age limits on pediatric coverage and benefits to include young adults with chronic and complex needs.

Select health care transition as a **national performance measure** to assess, monitor, and focus on activities funded by the federal Title V Maternal and Child Block Grant.

Involve families and youth in transition governance by including caregivers and young people in our Youth Advisory Council (YAC) or LEND self-advocates. Involve those who've recently transitioned to serve as transition ambassadors on transition planning advisory boards.

Incorporate transition-specific services into **Medicaid managed care programs.**

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