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Continuity of Mental Health Care from Adolescence to Adulthood (Transitional care)

Background & Scope of Problem (Monica):

While the National Survey on Children with Special Health Care Needs has previously reported that "the majority of youth with special health care needs are insured" (Crane, 2013, p.1), the challenges youth experience during transitions in healthcare services remain largely unaddressed. In addition to managing the complexities of their health conditions, they must navigate the intricacies of maintaining health insurance coverage, consider and secure a provider that will best meet their diverse needs, and acquire the appropriate support to independently manage their health care considering their change in status to legal adults (Crane, 2013).

Concerning mental health, the transition process from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) coincides with critical developmental milestones and a potential increased incidence of mental health conditions (Broad et al., 2017). The lack of transitional care support has forced transition-age youth to disengage from mental health service utilization without support to mitigate the negative effects of the pause in services during this vulnerable time. The long-term implications for the service gap and lack of support have "the potential for lasting functional impairment and development derailment" (Broad et al., 2017, p.2).

Partners/Stakeholders (Consumers, families, providers, payers, and more):

Mental health services are not as accommodating as they should be for individuals with neurodevelopmental disabilities. A recent national consumer study found that individuals with higher severity of mental illness had difficulty receiving appropriate care through their private insurance. Many individuals with these behavioral mental health conditions rely on the public behavioral health system to receive better care.

Among stakeholders, there has been a higher interest in school-linked services that provide access to these mental health services. Stakeholders continue to voice their needs for outpatient and intensive outpatient services delivered at school via telehealth, or in-home services. Below are some personal lived experiences from one of our authors, a self-advocate and stakeholder, to pressing policy needs:

"1. What resources have you been able to access in transitioning from adolescence to adulthood?"

My mother is a mental health professional, and I have been able to access resources through her. It would be hard to have these services if it weren't for her, as it is mostly independent.

2. What challenges or barriers did you encounter as you received mental health services, and what was helpful for you?"

A lot of therapists are super short-term. It feels right when I get a little bit better, services get cut, or the therapist changes. Since I have Borderline Personality Disorder, I don't do well with the change in people. Due to my abandonment issues, I can't differentiate between people

abandoning me and people not abandoning me. Personally, I like to keep in contact with previous or current therapists and caregivers. That's how I soothe myself.

3. What do you wish to see more support for through this transition?

I have to say there are times where I don't see a point in living and I ask myself all the time, "is it ever going to get better" or is this vicious cycle going to continue. I've found ways to cope with how you are feeling through therapy. I wish that more people were genuine with their care. One of the things I wish was better is consistency in providers. A couple of resources that really helped me are NAMI (National Alliance on Mental Illness) and Emotions Matter."

Previous Interventions:

The US Department of Health and Human Services Maternal and Child Health Bureau (MCHB) declared transition services as an area of focus for improving outcomes for children with special healthcare needs. Multiple existing organizations seek to facilitate the transition period for youth with disabilities by providing various resources and services. Examples include the Child Information Gateway, California Department of Developmental Services, Strategies to Empower People (STEP), Connections for Life, and Creating Behavioral and Educational Momentum (CBEM). However, the extent of support regarding mental health care continuity is inconsistent among these organizations. Some provide specific strategies for crisis management and connections to mental health resources, while others do not address mental health as a transition component.

The medical home model is one example of a comprehensive healthcare delivery approach that aims to optimize care coordination. A medical home comprises an interdisciplinary team of providers coordinating services to manage preventative health, acute illnesses, and chronic conditions. Individuals already established within a medical home are more likely to receive transition support services. A medical home can also overcome common barriers, such as a lack of timeliness of services and limited communication between providers. Although medical homes offer significant benefits, fewer than half of youth with special health care needs have a medical home, primarily due to challenges associated with reimbursement policies.

Policy Recommendation & Benefits and Costs:

In the United States, the challenges of providing timely healthcare transition (HCT) planning and quality mental health services for adolescents with developmental disabilities who are emerging into adulthood (AEA) persist. With one million adolescents transitioning to adulthood annually, and thirty-five percent of individuals with developmental disabilities (DD) having a co-occurring mental health condition, fragmented governance and public community-based health services contribute to delays in accessing mental healthcare providers for AEA with ID/DD, overutilization of emergency/hospital services, poor health outcomes, and high healthcare costs.

To address these challenges, recommendations have been put forward, including revising state medical plans to include reimbursement policies for "health home program" (HHP) services, expanding Medicaid eligibility, and providing educational efforts on transitional outreach programs for adult models of care. The experiences of individuals with ID/DD highlight the need to urgently address these challenges. Many have reported that gaps in healthcare coverage still persist despite these efforts and significant difficulties accessing mental health services.

An ID/DD Consumer's Voice: "When I turned 18, my Psychiatrist dropped me" " I was placed on a ten-month waiting list to receive my first appointment"I was in and out of the hospital a lot" (Nikita, 2022).

An additional aid to address this need may be psychiatric mental health nurse practitioners (PMHNPs) as they could be a potential resource to close this gap (Ramirez, 2016). PMHNPs can offer primary mental healthcare services, medication management, therapy, patient education, and care coordination to ensure continuity of care. With the recent removal of the supervisory requirement in the state of California for PMHNPs to work without physician supervision, PMHNPs can provide high-quality care and improve access to quality mental health services for this vulnerable population (California Association for Nurse Practitioners, n.d.).

Summary:

Access to quality mental health services remains a significant challenge for individuals with disabilities and those who are neurodivergent, particularly for emerging adults who risk losing services if they fail to transition to adult mental health care providers. While organizations and models like the medical home have been developed to aid in the transition process, the delivery of mental health services lacks consistency. Policy changes that support continuity of care from adolescence to adulthood are necessary. Recommendations have included amending state medical plans to provide reimbursements to providers after youth reach age 18, expanding Medicaid coverage for all adults below the federal poverty line, and educational efforts for families and providers on adult transitional mental health care. Improving mental health services in schools can also increase accessibility and facilitate the transition to adult care. Additionally, PMHNPs can serve as a valuable resource to close the gap in mental health services for individuals with disabilities and those reaching adulthood. With the recent removal of the supervisory requirement for PMHNPs to work without physician supervision in California, they can provide high-quality care and improve access to quality mental health services for this vulnerable population in the golden state.

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Nikita's journal

To whom it may concern:

My whole life I was in therapy and had caregivers. Nobody taught me how I should be treated. As a young child not being able to speak and not being able to communicate was a huge barrier on advocating for myself. I used to throw tantrums, scream, pull out my hair and bite people. Now I realize that I wasn't doing it for no reason; I was doing it because I was being bullied, abused, neglected and misunderstood by your staff. I've been called manipulative, lazy, and told that I was faking it. This caused me to have negative thoughts about myself and suffer from

mental health related issues. Physically, most of the staff put me through so much pain to the point where my legs were shaking. I could never forget the damage your staff caused me. In my journey I had an amazing physical therapist that I really felt safe and comfortable opening up to. He taught me a lot of valuable life lessons, like how to take care of my body and how to advocate for myself when I feel I'm being mistreated, disrespected and taken advantage of. Before him, I had no idea that I was being mistreated, disrespected and taken advantage of. I always thought I had to be nicer to be treated with dignity and respect and did not understand that what they were doing was wrong. I don't believe that I should remain quiet. Now that I am able to speak, I demand a change in the care system. I want to thank the select few therapists and caregivers who were attentive, loving, caring, affectionate and gentle. Keep doing what you're doing. Don't let people discourage you. You helped me see what real care looks like and should always be

Love, Nikita