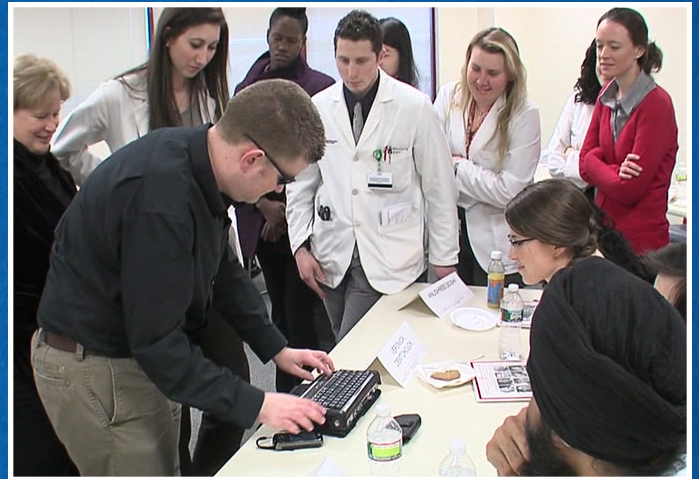


The New Jersey Action Blueprint for **TRANSITION** to Adult Health Care



The New Jersey Action Blueprint for Transition to Adult Health Care

A resource developed by:

THE BOGGS CENTER ON DEVELOPMENTAL DISABILITIES

New Jersey's University Center for Excellence in Developmental Disabilities Education, Research, and Service

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The Forum Process

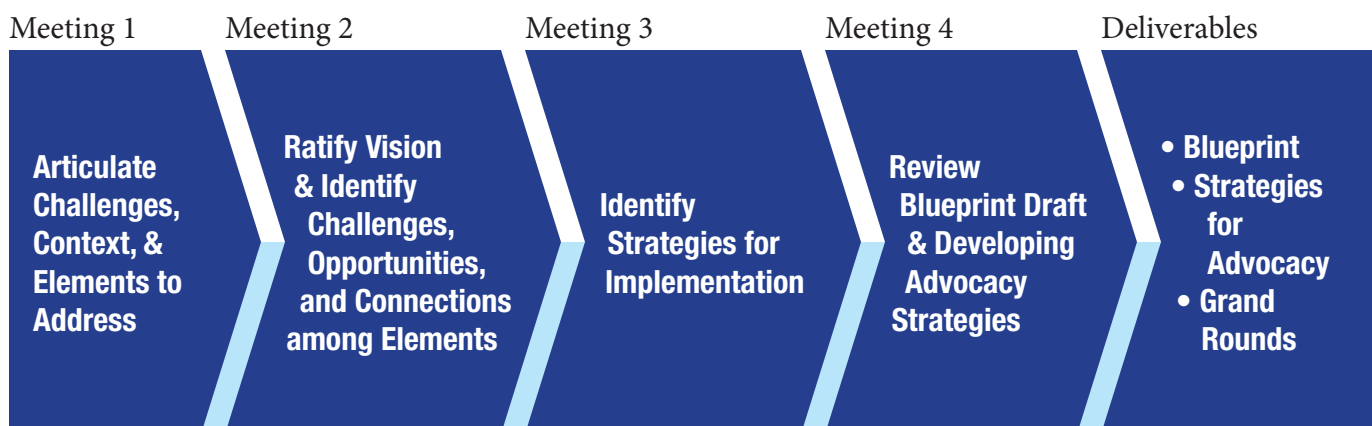
The *New Jersey Action Blueprint for Transition to Adult Health Care* is the culmination of the ideas and work of the stakeholder group, **The New Jersey Developmental Disabilities Transition to Adult Health Care Forum**. To build the capacity of New Jersey’s adult health care system to support the transition of emerging adults with developmental disabilities to age and developmentally appropriate health care, The Boggs Center, New Jersey’s federally designated University Center for Excellence in Developmental Disabilities Education, Research, and Service at Rutgers Robert Wood Johnson Medical School, with support from the Special Hope Foundation, convened a stakeholder Forum to address this pressing national problem. Defining transition age from 16 to 30 years of age, this project uniquely shifted the predominant paradigm in health care transition: from pediatrics being ready to “send” patients, to preparing the adult health care system to “receive” emerging adult patients.

The year-long planning process undertaken by The New Jersey Developmental Disabilities Transition to Adult Health Care Forum included 37 diverse stakeholders representing all levels of the adult health and human services systems. The Forum brought together family members, practitioners, Managed Care Organizations, Medicaid as a payer, and state agencies as regulators and providers, with the medical education system and disability advocates, to address transition and adult health care for people with developmental disabilities. The Forum provided a unique opportunity for users of service to identify needs and engage in dialogue with payers and providers who can innovate and redesign practice.

Stakeholders were surveyed prior to meeting to gather data and information on issues and concerns, and to ensure the most practical and efficient use of time. The Forum planning process was structured around four in-person meetings, with much of the project’s organization, synthesis, and forward progression developed by project staff before and between meetings. At the first Forum meeting, the stakeholders articulated challenges related to the transition to adult health care, the contexts within which transition occurs, and significant areas around which to focus our efforts. The Forum created a vision for transition to adult health care: a shared ideal of what transition should be in New Jersey. This vision guided the work of the Forum throughout the year-long process.

Through this collaborative planning process, “Health Care Provider Education and Training,” “Care Coordination,” and “Whole Person Approach to Health” emerged as themes and became the organizing principles for Workgroups and the Forum’s efforts.

In the three subsequent meetings of the Forum, concrete challenges, opportunities for action, and strategies to implement change were identified around each of these themes. Strategies were organized to address goals, the context for which was provided by the Forum’s previous discussions.



The Forum Process

An Incremental Approach to Change while Working Toward The Long Range Ideal: Patient Centered Medical Homes

The Forum recognized and affirmed the Patient Centered Medical Home, or Health Home, as the ideal modality for addressing many of the challenges associated with the transition to adult health care for adolescents and emerging adults with developmental disabilities. By definition, the medical home is a complex model of care with many components. Implementation of this model represents a huge undertaking, involving substantial time and investment, and requiring actions across many entities- including Medicaid, private insurance, clinical practices and providers.

The Forum chose to take an incremental approach, concentrating on several components of the Patient Centered Medical Home model that could be more broadly and more immediately implemented. By focusing on more immediate and accessible goals and strategies which are not dependent on a complete overhaul of the health care system, **The Action Blueprint** is designed to provide practitioners, advocates and policy makers with achievable, meaningful recommendations and strategies that will move health care for transition age youth with developmental disabilities in New Jersey closer to the ideal expressed in the Forum's guiding vision and the Patient Centered Medical Home model.

Defining Health

The perspective of the Forum and The Action Blueprint is based upon the World Health Organization's definition of health as, "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."¹

The Structure of The New Jersey Action Blueprint for Transition to Adult Health Care

This **Action Blueprint** frames the **Context for Health Transition** for emerging adults with developmental disabilities, and enunciates a **Vision**. For each of the eight **Action Areas** identified by the Forum, a **Framework for Action**, including findings from the literature and the experience of the stakeholders and constituencies they represent, is presented. The **Goals** for each area are preceded by an **Imperative for Action**, and followed by a series of **Strategies for Action** to move the transition to adult health care agenda forward.

The Context for Health Transition

The developmental phase of moving from childhood to adulthood, now widely recognized as adolescence and emerging adulthood, is characterized by immense change in most areas of life. By typically held standards, successful transition to adulthood is synonymous with autonomy and independence in work, living, and social relationships. It is measured by one's achievements in planning for and attaining competitive employment, financial stability, friendships, and living outside of the family home.²

Adolescents and emerging adults with developmental disabilities may experience increased difficulty in achieving these transition outcomes, as they face additional challenges in finding, securing eligibility and obtaining supports from the myriad systems through which services are provided after leaving school. Though service and support needs vary among those with developmental disabilities - cognitive impairments, as well as impairments affecting daily living skills and communication, often necessitate some level of support throughout the life course.^{3,4} These supports are necessary for successful navigation through the multiple realms of the adult service system, many parts of which remain focused on individual action and responsibility, assume a certain level of self-management, and expect maturity and knowledge regarding one's own abilities and limitations.



Interdependence, through the establishment of natural supports (family, friends, and community) and formal, paid service systems, is critical in helping adolescents with developmental disabilities to achieve a successful transition into adult life, allowing adults to live as independently as possible.⁵ The majority of people with intellectual and developmental disabilities receiving formal services and other supports in New Jersey (71.3%) and nationwide (57.8%), continue to live within their family home well into adulthood.⁶ As service systems seek to rebalance and fiscal constraints have become commonplace, natural supports provided within the family home, and within one's local community, have become increasingly important.

Due to this interdependence, or “independence through support,”⁷ people with disabilities are now entering post-secondary education, competitive employment, and living in the community with assistance at rates that, while lower compared to those without disabilities, have been previously unheard-of. These improvements are also attributable to advances in medicine and health interventions, which have led to individuals with developmental disabilities living far longer than in the past.

Adolescents, emerging adults, and adults with developmental disabilities face the same health risks as the general population.⁸ Most are not chronically ill, nor do their disabilities predispose them to poor health.⁹ As adults with developmental disabilities live longer, they are experiencing higher rates of adult-onset health conditions than ever before.¹⁰ Age-appropriate care, from practitioners who are trained in adult health conditions and treatment, has become increasingly important. Despite this need, many adults with developmental disabilities remain with their pediatrician until much later in life than those without disabilities. The reasons for this range from attitudinal barriers among health providers and related professionals, to limited knowledge-base and inadequate reimbursement for quality care.¹¹

The Context for Health Transition *(continued)*

Pediatrics has long served as the locus of expertise in caring for persons with early-onset conditions. Few adult health care providers receive training about developmental disabilities, and even fewer are experienced in providing care to this population.¹² In addition, professionals in the adult health care system may hold erroneous assumptions about the capacity of people with intellectual and developmental disabilities to participate in their own health care. Individuals with developmental disabilities may encounter cognitive challenges in recognizing health concerns, communicating health needs to medical professionals, and independently complying with recommended treatments. However, with the appropriate assistance and support, many individuals are able to engage and participate in their own health care.^{13,14} While the efficacy of a health care advocate (often a family member or other caregiver), has been recognized as helpful to individuals with disabilities in navigating health services and maintaining good health, adult health care providers are typically unaccustomed to working collaboratively with persons other than the patient.¹⁵

Few resources are available to facilitate the necessary level of collaboration, which requires additional coordination and patient support within adult health services.¹⁶ Financial considerations, including limitations in reimbursement, further restrict the time practitioners are able to spend with patients.¹⁷ For patients with developmental disabilities, the need for accommodations, as well as additional administrative effort, coordination and treatment time required for the provision of quality care, may not be feasible for practitioners under reimbursement mechanisms in which payment is inconsistent with time demands in providing care.^{18,19}

“Emerging adults with developmental disabilities often lack access to: [1] health care by providers who are trained in competencies, including attitudinal ones, necessary to provide appropriate care to that population; and [2] services provided in systems that integrate outpatient health care and habilitation for persons with developmental disabilities.”

-Health Care Administrator

The New Jersey Vision for Transition to Adult Health Care

Vision Statement

Emerging adults have access to comprehensive, personalized, quality health care which emphasizes wellbeing and prevention. Health care is provided in a manner that is respectful, age and developmentally appropriate, patient and family centered, and culturally competent.

Considerations Supporting the Vision

- Access to care is physically, geographically, linguistically, and cognitively appropriate and available.
- Comprehensive care integrates primary care, behavioral, mental health, and substance abuse treatment, dental care, and specialty care, which are important determinants of health.
- Providers collaborate with each other, patients, and their support systems to deliver integrated, quality care.
- Accessible, integrated care is provided within the context of a Patient Centered Medical Home or Health Care Neighborhood.

Action Area: *Integrated & Coordinated Approach to Transition to Adult Life*

The Framework for Action:

A multitude of changes across all areas of life occur between the ages of 16 and 30 years. During this transition period, adolescents and emerging adults finish school, enter post-secondary education and/or seek employment, may begin to establish more independence, and think about living outside of their family home. Individuals with developmental disabilities may experience these changes in uniquely complex ways.



Emerging adults with developmental disabilities are more reliant on support or assistance from others to work toward these life goals. This support is largely provided by parents and other family members, as well as multiple formal systems of service. Under federal and state law, students with disabilities who are classified as eligible for Special Education, have an entitlement to all needed services specified in their Individual Educational Plan (IEP). As these young adults emerge from school, either through graduation or reaching age 21, the basis of their services shifts from entitlement to eligibility, based on program requirements and available funding for adult services. Service systems offer different services, utilize different terminology and eligibility criteria, require different information from and about individuals, and often address only one area of a person's needs. To ensure a smoother transition to adult life, common understanding, communication, and information gathering and sharing processes are necessary within and across these service systems.

The Imperative for Action:

To support emerging adults with developmental disabilities in achieving a successful transition to adult life, all systems must recognize health and wellbeing as crucial underpinnings in preparing for adulthood.

“In addition to actually finding qualified practitioners there is the question of medical benefits and government services which also change over at the transition. The system is confusing and often hard for parents to navigate yet it must be done in order to access healthcare services.”

*-Family Member &
Health Care Provider*

Action Area:

Integrated & Coordinated Approach to Transition to Adult Life

Action Goal: To develop capacity in New Jersey to implement an integrated and coordinated approach to supports and services for the transition to adult life, which addresses the importance of health and wellbeing in all planning.

Strategies for Action:

- Enhance the recognition of health and wellbeing as an underpinning for achievement of goals across life domains, including work and career, housing and living arrangements, and community participation.
- Support and include health and wellbeing as critical elements in planning for, and providing services across systems, including the Department of Children and Families, Special Child Health Services, Department of Education, Division of Vocational Rehabilitation Services, and Division of Developmental Disabilities.
- Identify health outcomes for emerging adults as part of all transition planning processes, including the IEP (Individual Education Plan) process in school districts.
- Develop and promote cross-systems training, which includes the Department of Education, school districts, Department of Children and Families, Special Child Health Services, Division of Vocational Rehabilitation Services, Division of Developmental Disabilities, and Managed Care Organizations, to facilitate a shared understanding of the importance of health within all life domains.
- Facilitate understanding and knowledge of health care providers about the other services and systems that serve emerging adults with developmental disabilities.
- Utilize technology, including the Electronic Health Record (EHR) and other electronic record keeping systems, to promote communication and information sharing across schools and service systems, and between acute care and long term services and supports, while protecting individual confidentiality.
- Identify transition champions within service systems who will promote collaboration and cross-system partnerships.

Action Area: Available & Effective Health Care Coordination

The Framework for Action:

Care coordination has long been considered an essential set of processes for addressing the health care needs of individuals with developmental disabilities, and one of the central underpinnings of Patient Centered Medical Homes.²⁰ Care coordination, or care management or case management, as it may sometimes be labeled, typically involves assessment of service need, the development of a plan, linkage and brokering of services, follow-up and monitoring, and evaluation to ensure that services are being delivered and are effective. Through care coordination, health care can be synchronized across settings and services, linking individuals not only to health care providers, but to community organizations and other entities outside of the health care arena. The challenges in transitioning from pediatric care to adult health care, the nature of life span disabilities and the complexity of multiple service systems highlight the need for comprehensive care coordination for emerging adults with developmental disabilities.



Care management, the term for health care coordination within Medicaid, is provided by contracted Managed Care Organizations (MCOs) for Medicaid-eligible beneficiaries with developmental disabilities. While critical in helping to meet the health care needs of people with developmental disabilities, care coordination benefits are neither required nor available for individuals with developmental disabilities whose health insurance is private, third party insurance. This disparity becomes particularly important during the transition to adulthood as emerging adults who had not previously been on Medicaid may continue to be covered by their parent’s health insurance.

For eligible individuals, the Medicaid contract identifies the elements of Care Management as including “Comprehensive Needs Assessment, development and implementation of a Care Plan, referral, coordination of care, continuity of care, monitoring, and follow-up and documentation.”²¹ The Medicaid contract also specifies “Coordination with Essential Community Programs”²² as well as “methods for coordinating care and creating linkages with external organizations.”²³ Though these identified components provide a model of the type of coordination of services and systems that need to be engaged in the transition to adulthood, communications with external organizations remains challenging.

In addition to a Care Manager from a Managed Care Organization, an emerging adult under 21 years of age may have a Case Manager as part of their special education services, a Case Manager through Special Child Health Services, and be served through a County-Based Case Management Organization through the Children’s System of Care of the Department of Children and Families. An emerging adult over 21 years of age may have a Support Coordinator or Case Manager through the Division of Developmental Disabilities, and a Vocational Counselor through the Department of Vocational Rehabilitation. Communication across these coordinative functions is vital to ensuring continuity of care, in health and all other areas of life for which people with developmental disabilities receive support.

Action Area: ***Available & Effective Health Care Coordination***

The Imperative for Action:

To comprehensively address the health care needs of emerging adults with developmental disabilities, effective care coordination must be made available to: assess, plan for, obtain, and evaluate the combination of supports and services necessary for improving outcomes in health, and other areas of life.

Action Goal 1: To increase the availability of and access to health care coordination that is supportive of emerging adults and their families.

Strategies for Action:

- Collaborate with Medicaid MCOs to ensure that health care transition is addressed in care coordination for emerging adults with developmental disabilities.
- Develop mechanisms to link emerging adults who have 3rd party insurance to care coordination services.
- Address health care transition in services and supports provided to emerging adults under New Jersey's Comprehensive Medicaid Waiver, including the Supports Program for emerging adults over 21 years of age (provided through Division of Developmental Disabilities, New Jersey Department of Human Services) and for emerging adults under 21 years of age through the Developmental Disabilities/Mental Illness Pilot (provided by the Children's System of Care- New Jersey Department of Children and Families).
- Advocate that planning for the transition to adult health care become an explicit requirement within the Medicaid Managed Care contract.

Action Goal 2: To increase the quality and effectiveness of health care coordination for emerging adults with developmental disabilities.

Strategies for Action:

- Encourage the use of a comprehensive individual and family health history in forming the basis for care.
- Promote relationship-centered care coordination.
- Focus health care coordination geographically to ensure knowledge and linkage with local resources.
- Provide training and education to health care coordinators on community resources and evolving service and support models.
- Strengthen connection and communication between care coordination at the MCOs, community providers, and practitioners to integrate health care planning at the practice level.
- Explore options for in-person or on site models of care coordination.
- Develop practices and protocols to promote collaboration across care coordination, case management, and support coordination functions and roles across delivery systems.
- Educate individuals performing care coordination about resources, responsibility, and roles related to health care and transition to adult health care.
- Develop mechanisms for coordination between physical health, behavioral and mental health, and long-term services and supports, as delivery systems evolve under the Comprehensive Medicaid Waiver, including the Administrative Services Organization and the DDD Supports Program.
- Utilize information from care coordination for planning to improve and predict physical health and mental health needs of adults with developmental disabilities.

Action Area: Knowledgeable Health Care Consumers & Advocates

The Framework for Action:

Emerging adults, their families, and other caregivers often lack information about health and health care and report their participation in health promotion activities as minimal.²⁴ Emerging adults with intellectual and other disabilities may have limitations in understanding and/or recognizing their own health problems, limited capacity to communicate their health needs to a health care professional, and inconsistent adherence to recommended treatment plans without assistance and support.²⁵ Parents and other caregivers may need to serve as sources of information, guidance, and support to health care professionals during the health care encounter. With the help of a family member or other caregiver as an informed health care advocate, access to quality health care is improved for individuals with intellectual and developmental disabilities.²⁶



The Imperative for Action:

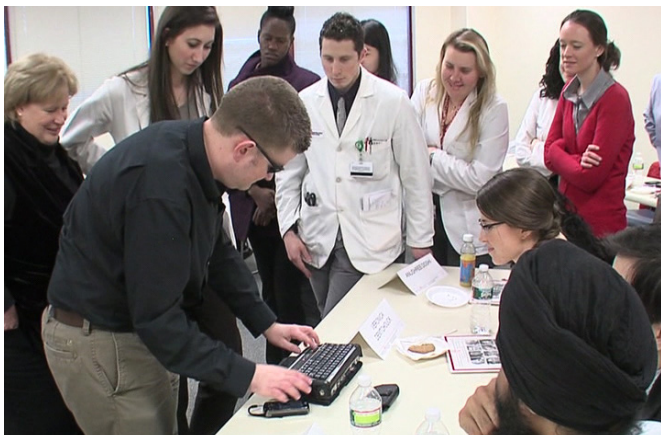
There is a clear imperative for information about health and health care to be made accessible to emerging adults with disabilities, their families, and other caregivers in order to achieve optimal access to health care and improved health and wellbeing. This information must consider cultural and linguistic diversity, and access to technology among emerging adults, their families and caregivers.

Action Goal: To support emerging adults, their families, and other caregivers in identifying health concerns, becoming knowledgeable health care consumers, and engaging in behaviors which promote health.

Strategies for Action:

- Advocate for and monitor that all outreach strategies and health education materials are culturally and linguistically competent.
- Implement technology-based strategies for health literacy and health promotion that empower emerging adults, their families, and other caregivers to become knowledgeable healthcare consumers and advocates.
- Advocate that technology utilized in patient communication takes into account individuals' and families' access to technology and levels of literacy.
- Develop new and promote existing materials to ensure that individuals and families have access to information on health promotion, issues of rights including supported decision making and guardianship, and interacting with health care providers and systems.
- Encourage the development of training for adolescents and emerging adults around managing their own health and health care services, as exemplified by *Being a Healthy Adult*²⁷ and *Health Matters*²⁸ curricula.

Action Area: Qualified & Competent Health Care Workforce



The Framework for Action:

Historically, training to provide care to individuals with developmental disabilities has been limited in health professions curricula, particularly related to providing care for adults.^{29,30} Pediatric medicine and pediatricians have typically served as the locus of expertise in caring for this population.

With medical advances, people with disabilities are living longer and are experiencing higher rates of adult-onset health conditions than in the past.³¹ Care from practitioners who are trained in adult health

care has become increasingly important. One of the major barriers to accessing adult health care has been a lack of knowledgeable providers who are willing to accept patients with developmental disabilities.³² Underlying this may be the view of people with disabilities as a distinctly separate population, rather than disability as a condition or characteristic of an individual. Additionally, recognition of the adult status of individuals with disabilities has been overshadowed by outmoded notions of mental age and undue emphasis on limitations in functional capacity.

The Imperative for Action:

In preparing the next generation of health care professionals, as well as existing practitioners, student and continuing education must build the awareness, attitudes and skills necessary to provide accessible, quality healthcare to adults with developmental disabilities.

Action Goal: To develop a qualified and competent health care workforce prepared to provide health care to emerging adults with developmental disabilities.

Strategies for Action:

- Identify and cultivate champions within health professions education who have the authority to effect curricular change and secure institutional educational commitment to expand educational opportunities and focus.
- Create faculty development opportunities to embed a broader understanding of disability in health professions training programs.
- Advocate that education for all health professionals includes a broad, comprehensive exposure to disability, including experiential learning opportunities.
- Address attitudinal barriers about disability through structured and supported awareness-building opportunities.

“Access to needed healthcare is the biggest challenge - both from a physical accessibility standpoint and one of finding doctors who are qualified and willing to treat adults with “pediatric on-set illnesses.”

*-Family Member/
Health Care Provider*

Action Area: ***Qualified & Competent Health Care Workforce*** *(continued)*

Strategies for Action:

- Infuse disability content into curricula on the full range of common health conditions in training across health professions and disciplines.
- Include disability as a form of diversity in health professions education.
- Promote curricular strategies which incorporate the experience and expertise of emerging adults with disabilities and their families into health professions education about the full range of health conditions, prevention, and health promotion strategies.
- Embed information about the life course of people with disabilities, including services, benefits, and the role of family members, into curricula across health professions and disciplines.
- Utilize inter-professional educational programs and strategies to enhance competency in addressing the health needs of emerging adults with disabilities.
- Create a directory of disability-related educational opportunities/experiences/sites for meeting curricular requirements across health professions and disciplines.
- Evaluate student experiences across professions and disciplines to design effective educational opportunities.
- Advocate inclusion of disability content on licensing exams.

“The greatest need in increasing capacity is a cadre of health care providers educated in the area of IDD and willing to meet the unique needs of the population. An awareness of the prevalence of secondary/comorbid diagnoses; possible alteration in communication and communication modalities; and the need for individualized person-centered care would all add to the effectiveness and capacity to address the needs of the population new to the adult world.”

-Health Care Provider - Nurse

“...consideration should be given to the added component of IDD; it is not a complicating aspect of the patient, rather another factor to be considered in the whole.”

-Health Care Provider - Nurse

Action Area: *Qualified & Competent Direct Support Professional Workforce*



The Framework for Action:

During adolescence and emerging adulthood most of the provision of support and caregiving rests with the family, and continues to do so well into adulthood. As individuals with developmental disabilities move into adulthood and adult roles, formal services and supports are delivered across multiple systems, and are increasingly provided by paraprofessionals and Direct Support Professionals. As service systems evolve, Direct Support Professionals will be providing personalized services within the family home. They may be

tasked with some of the caregiving that has typically been provided by families, for example administering medication or accompanying individuals to medical appointments.³³ Direct Support Professionals will need to have the skills to interact with family members, health care providers, as well as other professionals and paraprofessionals from multiple service systems, who are supporting the young adult.

The Imperative for Action:

As service provision shifts to focus on individualized supports and services, it is essential for direct support professionals/paraprofessionals to understand and communicate the indicators of physical, mental, and behavioral health status of the individuals they serve.

Action Goal: To develop a qualified and competent direct support workforce prepared to address the health and wellness needs of emerging adults with developmental disabilities.

Strategies for Action:

- Institute training for Direct Support Professionals around appropriate interaction and clear communication with health care providers, professionals, other paraprofessionals, and families, about the health status and needs of emerging adults with developmental disabilities.
- Increase awareness among Direct Support Professionals about the expression of health conditions and symptoms in emerging adults with developmental disabilities, including pain, illness, and trauma.
- Promote the development and use of health history templates among Direct Support Professionals.
- Empower Direct Support Professionals to work in partnership with families to support the health and wellbeing of emerging adults with developmental disabilities.
- Educate community provider agencies about the importance of the Direct Support Professional's role in communicating with health care providers and supporting health and wellness.
- Enhance recognition of Direct Support Professionals as a valuable resource for information about individuals' physical, behavioral and mental health needs, including side-effects of medication.
- Encourage and support Direct Support Professionals to empower emerging adults to plan for and address their own health and wellbeing needs.
- Provide health promotion and prevention information and resources to Direct Support Professionals, enabling them to model and encourage healthy lifestyle and nutrition choices.

Action Area: Continuous & Coordinated Health Care Delivery

The Framework for Action:

Transition to adult health care typically entails movement from a centralized, interdisciplinary, team-based approach in the pediatric realm to an adult care model emphasizing individual action and responsibility, with providers often dispersed geographically, and fewer resources allocated to coordination and patient support.³⁴ Financial and health insurance considerations, including limitations in reimbursement, may also restrict the amount of time that practitioners are able to spend with adult patients.³⁵ The need for accommodations, coordination, and additional administrative and treatment time for patients with developmental disabilities may not be feasible for practitioners under reimbursement mechanisms in which payment is inconsistent with time demands in providing care.³⁶



Characteristics of intellectual and developmental disabilities may also create barriers to the successful navigation and utilization of adult health care services for emerging adults. For example, adult health care often assumes that the patient can communicate health status and concerns and coordinate care on their own behalf, though many emerging adults with developmental disabilities will require assistance or support with these tasks.^{37,38} Parents or other caregivers may be involved as proxies for communication throughout the life course.

Access to primary care providers, from both internal medicine and family medicine, and specialists who are receptive to and knowledgeable in providing care for individuals with developmental disabilities is another challenge in transitioning to adult health care.³⁹ Adult health care is also less likely to include primary care and specialty care in one physical location. Physical separation between primary and specialty providers, as well as pediatric and adult treatment spaces affects communication between practitioners and limits sharing of information, resources, and continuity of treatment.⁴⁰

The Imperative for Action:

Individuals with developmental disabilities have a pressing need for enhanced access to adult health care practitioners who engage in open communication, share knowledge and information, and have access to specialty centers and experienced providers as resources.

“...allowing more appointment time for an individual with IDD may enable the practitioner to focus on and listen to the person, the communication style, the individual’s comfort level, and appropriate physical assessment.”

-Health Care Provider - Nurse

Action Area: ***Continuous & Coordinated Health Care Delivery***

Action Goal: To improve continuity and coordination within existing health care delivery structures.

Strategies for Action:

- Develop and implement a system for coordinated communication among providers.
- Utilize care management in Managed Care Organizations to enhance communication between primary care, specialists, sub-specialists and other health care providers.
- Support and utilize specialty centers – health care facilities with multi-disciplinary expertise around specific populations - as a resource in providing care to emerging adults with developmental disabilities, and in developing strategies to support other adult health care providers.
- Make incentives available to adult practitioners who serve individuals with developmental disabilities to enhance care coordination and promote consultation with specialty centers and other experienced practitioners.
- Explore strategies for expanding Managed Care Organizations’ network capacity to include broader availability of adult health care providers, including specialists, to serve emerging adults with developmental disabilities.

“...the challenge to the adult health care system is to not only become intimately familiar with the physical needs of this population, but appropriate ways in which to interact with them as well.”

-Family Member

Action Area: Evolving Health Care Models

The Framework for Action:

Consistent with adults in the general population, the major determinants of health among adults with developmental disabilities include a combination of genetic composition, social circumstances, individual behaviors, and access to health care.^{41,42}

Adults with developmental disabilities tend to be disproportionately poorer, have higher rates of unemployment, less access to preventive care and lower rates of health promotion practices than the general population.^{43,44} Poverty is an often unnoticed risk factor for poorer health in individuals with intellectual and developmental disabilities, as exemplified by higher rates of chronic health conditions such as obesity and hypertension.⁴⁵ Poorer health is a function of disparities in access to care, and can be improved with coordinated approaches to health care that are responsive to the acute and ongoing needs of this underserved population.



Transformative changes, driven by the Affordable Care Act and the emergence of more efficacious patient-centered approaches, have driven the development and implementation of innovative strategies to improve health care and coordination for traditionally underserved populations receiving public benefits through Medicare and Medicaid. Patient Centered Medical Homes, and other delivery models which utilize coordination of health and social services in collaboration with patients, have been used to address the needs of those dually-eligible for Medicaid and Medicare. Accountable Care Organizations, partnerships forged between groups of practitioners, hospitals, and other health care providers, can deliver coordinated care aimed at maintaining health among Medicaid beneficiaries while allowing practitioners to share in the savings achieved by spending health care dollars more efficiently.^{46,47}

The Imperative for Action:

In the continuing movement to more responsive and coordinated models of health care delivery, it is essential that individuals with developmental disabilities are included in innovations in models of care, including pilot programs.

Action Area: ***Evolving Health Care Models***

Action Goal: To advocate that evolving health care models are responsive to the needs of people with developmental disabilities, including the transition to adult health care.

Strategies for Action:

- Expand the availability of Patient Centered Medical Homes for emerging adults within the adult health care system.
- Advocate that innovations in health care delivery, including the development of Accountable Care Organizations (ACOs), address transition to adult health care.
- Support and utilize specialty centers – health care programs which include multi-disciplinary expertise that may be population-specific – to serve as a resource in providing care to emerging adults with developmental disabilities.
- Utilize the Medicaid Managed Care contract as a mechanism to promote and require age and developmentally appropriate health care for emerging adults.
- Advocate for the designation of people with developmental disabilities as a medically underserved population by the Health Resources and Services Administration (HRSA) to facilitate enhanced care and reimbursement models, encourage the development and use of health indicators, and promote a research agenda.

Action Area: Data, Information, & Technology

The Framework for Action:

Despite widely recognized health disparities and continually poorer post-school outcomes for emerging adults with disabilities compared to those without disabilities, little data is available to plan for supports and services that will make possible a meaningful transition to adult life in general, and adult health care more specifically. Most states and localities do not track or report data on health status and care needs for people with developmental disabilities, making comparison with the general population difficult and rendering the identification of unmet health needs unfeasible.^{48,49} Moreover, where this data is collected, it is limited to those receiving services from state or local agencies, though a substantial portion of people with developmental disabilities may be unknown to service systems.⁵⁰ Confidentiality-related restrictions within the educational system, which limit the sharing of information, further complicate the identification of students receiving special education services as they move into adulthood with or without continued supports and services.



The Imperative for Action:

The need to respond to growing generations of emerging adults with developmental disabilities with data-driven and evidence-based approaches to planning and services necessitates a coordinated and shared commitment to identifying health needs and addressing disparities.

Action Goal: To enhance data, information, and technology that will support successful transition to adult health care.

Strategies for Action:

- Identify health indicators for emerging adults with developmental disabilities and the transition process.
- Generate health services utilization data on emerging adults with developmental disabilities.
- Utilize information from care coordination to expand system capacity, address health care gaps, and support the physical and behavioral health needs of adults with developmental disabilities.
- Generate demographic data to predict the number of adolescents and emerging adults with developmental disabilities who will require health care services from adult practitioners.
- Promote the sharing of electronic records between health care systems and long-term services, to provide longitudinal data on the transition to adult health care and other adult services.
- Advocate for shared access to comprehensive data records across delivery systems through compatible electronic information databases, in a manner that addresses legal and regulatory barriers and facilitates budgetary and service planning for supports to adolescents and emerging adults with developmental disabilities.
- Incorporate information and resources on transition to adult health care into existing information and referral databases, including those of the Aging and Disability Resource Centers and the New Jersey Division of Disability Services.

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