

Supplementary Table 1: Barriers to Effective Pediatric to Adult Health Care Transition for Persons with IDD		
Health Care Transition Constraints ¹	Cause(s) ¹	Possible Ways to Remediate ^{1,2}
Inadequate availability of formal, structured pediatric to adult health care transition programs	<ul style="list-style-type: none"> • Low prioritization of transition programs • Inadequate number of primary care and specialist clinicians with expertise or willingness to care for those with IDD • Inadequate number of providers with expertise to address the unique needs of youth/young adults • Inadequate remuneration for providers' services 	<ul style="list-style-type: none"> • Integrate health care transition into routine primary, specialty and behavioral health care • Improve communication of the need for pediatric to adult transition programs • Increase programmatic investment • Increase the number of clinical providers • Improvement of all clinical curricula • Reform of clinical service reimbursement system • Region/country-specific legislation ensuring successful transfer of care • Further research on models/outcomes of transition programs
Delayed entry in transition planning for patients/caregivers	<ul style="list-style-type: none"> • Inadequate policy/function of transition programs • Variability of patients/caregivers in willingness to begin transfer • Variability between providers regarding age of transfer 	<ul style="list-style-type: none"> • Implement more and better programs • Standardized and enforced upper age for transfer of care by medical providers
Emotionally difficult transition from pediatric care for patients/caregivers	<ul style="list-style-type: none"> • Absent transition programs 	<ul style="list-style-type: none"> • Improve communication with family

	<ul style="list-style-type: none"> • Inadequate transition programs with disorganized communication among family and care team • Lack of specialized social work providers 	<ul style="list-style-type: none"> • Implement more and better programs • Develop/utilize peer and caregiver supports
Inadequate number of primary care and/or specialist clinicians in the adult medical system with expertise in caring for those with IDD	<ul style="list-style-type: none"> • Inadequate teaching regarding IDD in medical and nursing schools, residencies and fellowships 	<ul style="list-style-type: none"> • Improve all clinical curricula
Difficulty accessing primary care and/or specialist clinicians in the adult medical system with willingness to care for patients with IDD	<ul style="list-style-type: none"> • Ableism • Inadequate remuneration for services 	<ul style="list-style-type: none"> • Increase learning re: IDD and disability-related matters • Reform of clinical service reimbursement system
Difficulties for patients/caregivers in making appointments	<ul style="list-style-type: none"> • Ableism • Limited clinic resources 	<ul style="list-style-type: none"> • Ensure accessibility scheduling processes (e.g., improve websites and phone systems) • Make online chats or live help via phone available
Challenges for patients/caregivers regarding transportation to appointments	<ul style="list-style-type: none"> • Ableism • Poverty/income inequality • Geographic locale 	<ul style="list-style-type: none"> • Improve access to transportation services • Increased utilization of mobile clinical units, if available • Increased utilization of telemedicine, when appropriate
Difficulties in the transfer of medical information from pediatric to the adult medical practices	<ul style="list-style-type: none"> • Inadequate electronic forms and portals • Incompatible electronic communication systems • Lack of education for clinical providers on available tools 	<ul style="list-style-type: none"> • Develop improved electronic forms/portals • Increase use of 'Care Everywhere' or similar tools • Create written medical transfer summaries that are provided to patients/families

	<ul style="list-style-type: none"> • Insufficient time/reimbursement for discussion between pediatric clinicians and clinicians in the adult system 	<ul style="list-style-type: none"> • Use short, patient-centered ‘medical summary’ videos • Use short, patient-centered life interests/lived experiences videos • Reform the clinical service reimbursement system • Embed tools regarding health care transition in the EMR to prompt usage and track progress
Inadequate information about the transition process and related resources for patients/caregivers	<ul style="list-style-type: none"> • Inadequate transition programs 	<ul style="list-style-type: none"> • Develop paper- and web-based resources for patients/families • Create transition consult clinic to provide access to transition navigator • Consultation with Legal Aid or embedded legal representation and/or social work in transition planning • Utilization of peer supports
Inequitable access for patients related to the physical design of clinical spaces	<ul style="list-style-type: none"> • Ableism • Limited institutional resources 	<ul style="list-style-type: none"> • Follow ADA requirements (at a minimum) • Subsidization for increasing accessible spaces
Insufficient information for clinicians in the adult medical system about the transfer process and care for persons with IDD	<ul style="list-style-type: none"> • Inadequate transition program • Inadequate teaching in medical and nursing schools, residencies, fellowships • Absent or inadequate professional practice policies 	<ul style="list-style-type: none"> • Improve transition readiness materials for clinicians • Improve clinical curricula • New or improved professional practice policies

Variable self-advocacy skills of patients	<ul style="list-style-type: none"> • Inadequate individualized transition plan 	<ul style="list-style-type: none"> • Improve transition program • Utilization of peer supports, when possible • Utilization of clinical psychologists or specialized social work providers
Inadequate duration of many appointments from patients'/caregivers'/clinical providers' perspectives	<ul style="list-style-type: none"> • Biased medical compensation practices (oriented to RVUs and productivity goals vs. medical education, preventive care, collaborative care, care for those with medical complexity) 	<ul style="list-style-type: none"> • Improve receipt/review of patient/family information prior to clinic visits • Use of scribes (actual person or AI) • Extend clinic hours (evenings, weekends) • Improve collaboration with medical system administration • Reform of clinical service reimbursement system
Competing family and work obligations faced by caregivers during the transition process	<ul style="list-style-type: none"> • Excessive demands on caregivers • Inadequate provider availability • Scheduling conflicts between caregivers and needed services • Child care needs 	<ul style="list-style-type: none"> • Improved transition program with better navigation, coordination and services • Provide childcare • Adjust schedules of day programs to that of full-time workers
Negative impacts on caregivers' health related to the demands of managing their children's health needs	<ul style="list-style-type: none"> • Excessive demands on caregivers' time due to inadequate transition program • Inadequate time for self care 	<ul style="list-style-type: none"> • Improved transition program with better navigation, coordination and services • Novel medical practice design to provide care to young adult and the adult caregiver(s) at the same visit
Challenges in handling issues relating to relinquishing or sharing	<ul style="list-style-type: none"> • Inadequate information for all parties 	<ul style="list-style-type: none"> • Increase resources (legal, social work, psychol.)

medical decision making with patients	<ul style="list-style-type: none"> • Inadequate time for quality discussions • Inadequate resources 	<ul style="list-style-type: none"> • Reform of clinical service reimbursement system
Difficulties in communication between pediatric clinicians and clinicians in the adult system	<ul style="list-style-type: none"> • Biased medical compensation practices • Inadequate time for quality discussions • Incompatible electronic communication systems 	<ul style="list-style-type: none"> • Reform of clinical service reimbursement system • Increase allowance of time in clinical encounters • Increase utilization of ‘Care Everywhere’ or similar tools
Difficulties in communication between clinicians in the adult medical system	<ul style="list-style-type: none"> • Biased medical compensation practices • Inadequate time • Incompatible electronic communication systems 	<ul style="list-style-type: none"> • Reform of clinical service reimbursement system • Increase allowance of time for this purpose • Increase utilization of ‘Care Everywhere’ or similar tools
Inadequate or insufficient supplies or equipment for patients after transfer to the adult medical system	<ul style="list-style-type: none"> • Ableism • Limited clinic resources • Lack of clear transfer plan 	<ul style="list-style-type: none"> • Follow ADA requirements (at a minimum) • Implementation of improved transition plan
Inadequate assistance for patients/caregivers in navigating the health care transition process and in navigating the adult medical system	<ul style="list-style-type: none"> • Inadequate ‘navigation’ support of the transition team 	<ul style="list-style-type: none"> • Implement a navigator or navigation team • Utilization of peer/caregiver supports
Financial challenges for patients/caregivers related to clinical care and related services	<ul style="list-style-type: none"> • Expensive medical care 	<ul style="list-style-type: none"> • Health insurance reform, incl. more emphasis on preventive and continued care • Transition call number to triage need for seeing provider vs. resolving clinical matter at home
Inadequate reimbursement for clinical providers for their medical services	<ul style="list-style-type: none"> • Inadequate insurance coverage for preventative care and education 	<ul style="list-style-type: none"> • Expand coverage of transition services

		<ul style="list-style-type: none"> • Educate providers regarding coding/billing for transition services • Implement funding and payment models that are flexible regarding age cut-offs and shared among pediatric and adult health services • Develop payment approaches to encourage collaboration between pediatric and adult care clinicians in the health care transition process
Inadequate financial and administrative support by institutions for their transition programs	<ul style="list-style-type: none"> • Low prioritization of transition programs • Challenges in defining metrics for measurement of success in transition 	<ul style="list-style-type: none"> • Improve allocation of resources by administrators • Improve communication of value of transition programs • Research on models and outcomes of transition programs.
Inadequate integration of education system, social and recreation needs, employment considerations, community systems/supports and legal considerations with the medical system	<ul style="list-style-type: none"> • Siloed operation of different systems • Lack of coordination between public service agencies • Lack of specialized social work providers 	<ul style="list-style-type: none"> • Co-participation of pediatric and adult medical leadership, social work and others in transition program steering committees • Inclusion of transition process in the education system, including IEP goals • Integrate health care transition supports in legal discussion (eg, guardianship, power of attorney) • Collaboration across sectors, such as health, education and social domains, that includes

		<p>integration with local government services</p> <ul style="list-style-type: none"> • Train increased numbers of specialized social work providers • Utilization of ‘capacity building’ model for transition program • Increase employment options and the number of day programs for those unable to work
Inequitable access to quality pediatric to adult health care transition services	<ul style="list-style-type: none"> • Poverty/income inequality • Discrimination based on race/ethnicity • Ableism/discrimination based on diagnosis • Maldistribution of health care resources and access related to geographic locale of the patient/family 	<ul style="list-style-type: none"> • Equitable access of health care regardless of income/race/ethnicity/gender • Include equity as an outcome measure of transition programs • Include disability-related learning in clinical curricula, as well as in continuing education • Increase use of telemedicine, mobile units and incentives to work in underserved areas • Develop accessible health care facilities that includes input from disabled persons • Provide ongoing disability training to health care workers
<p>1) It should be noted that not all of the listed barriers, their causes or the proposed interventions are universally present or applicable.</p> <p>2) Quality assurance/quality improvement processes are necessary aspects of most of the listed remediation efforts</p>		