

The Indian Academy of Pediatrics and Directorate General of Health Services, Government of India White Paper on Transition of Care for Youth with Special Health Care Needs

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ABSTRACT

Over the years, survival of children with chronic diseases has significantly improved and a large proportion of them now are entering into adult hood. Transition of Care (ToC) of such patients with having childhood onset of chronic diseases to the adult health care system is well organized in developed countries, although it is an emerging concept in India. In situations where the systems for ToC are not in place, such cases are fraught with unsatisfactory health outcomes. With proper ToC in place, these patients are likely to receive uninterrupted care by the adult care physicians and hence reach their full potential. This document highlights the need, rationale and way forward for ToC of youth with special health care needs (YSHCN) across the country. It also describes the standard operating procedures to develop the ToC at a hospital level for clinicians and administrators.

Keywords: Adolescent, Chronic, Self-care, Therapy, Young adult

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PREAMBLE

The Maternal and Child Health Bureau (MCHB) of the United States of America (USA) defines Youth With Special Health Care Needs (YSHCN) as “Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” Hence, a proper transition (transition of health care) to adult care system is required for these patients once they attain adulthood.

Over the past two to three decades, significant improvements have taken place in the care of children with chronic diseases. As these patients reach their adolescence,

their specific needs for the underlying medical conditions get compounded by the challenges specific to this age-group (**Box 1**). It is a common trend, especially in public sector hospitals, to direct the adolescent and young adult patients to the Medical rather than the Pediatric out-patient services, when they are beyond the cut-off age for pediatric services for that particular hospital. This method works well for otherwise healthy people attending the hospital for intercurrent illnesses; however, it can be challenging for patients with chronic illnesses needing a continuum of care. Transition of Care (ToC) is a crucial aspect of health care which can smoothen this process.

Currently, there are no guidelines in place for such a transition of care in India. Taking cognizance of this fact, in early 2023, Indian Academy of Pediatrics (IAP) approached the Directorate General of Health Services (DGHS), Ministry of Health and Family Welfare (MoHFW), Government of India, for framing a ToC policy

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Box 1 Special Health Needs Adolescents with Chronic Illness

- Nearly 30% of adolescents and young adults have one or more chronic illness
- Nearly 25% of these youth with special health care needs (YSHCN) have at least one unmet need which may affect their physical and psychological well-being
- With improved survival of YSHCN, newer complications are being encountered
- Poor adherence to treatment is a problem among adolescents resulting in poor health outcomes
- With proper ToC, better satisfaction is seen among YSHCN which leads to improved treatment adherence
- Proper ToC leads to improved self-care
- Without proper ToC, control of chronic diseases goes haywire resulting in increased emergency room visits and other poor health outcomes

that could be uniformly implemented across the country. A meeting of experts from pediatric and adult care teams of central government teaching hospitals and All India Institute of Medical Sciences, New Delhi, was organized by the DGHS (**Annexure**). After deliberations on the subject, IAP was asked to prepare a policy document on ToC which was submitted to DGHS in due course. The same was circulated online among experts and finalized based on the feedback received. IAP was then asked to develop standard operative procedures (SOPs) for its implementation which were finalized following deliberations and inputs from experts from the pediatric and adult care teams. After necessary approvals, the ToC policy and the SOPs were circulated by the DGHS nationwide in December 2023. Additional Chief Secretary, Principal Secretary and Secretary Health of all States and Union Territories, Director General (Medical Education) and Director General (Health) of all States and Union Territories, Director General (Employees State Insurance Corporation), Government of India, have been requested to disseminate the ToC policy along with SOPs to all the health care facilities ranging from District Hospitals to Tertiary Care Hospitals, autonomous institutes and major private hospitals in their jurisdiction. National Medical Commission has been requested to include the ToC in the Postgraduate (Pediatrics and Medicine) and Super specialty curriculum.

Definition

Transition of Care (ToC) is defined as “*purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centered to adult orientated healthcare systems* [1].” In practice, this translates to a shift from a child and family-centered environment of pediatrics to a patient-centered adult

medicine setting. ToC is often used interchangeably with Transfer of Care; however, the latter is the final outcome, a single event where care is handed over from a pediatric care provider to adult care provider, which ToC is a gradual process.

Goals of Transition of Care

The American Academy of Pediatrics states, “*The goal of transition in health care for YSHCN is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood* [2].” With continued good quality health care, the young adult is envisaged to attain full developmental potential and will be a productive member of the society.

Rationale for Transition of Care

According to the National Survey of Children’s Health, funded by the US Department of Health and Human Services, almost 31% of adolescents have one moderate to severe chronic illness, such as asthma or a mental health condition. Other common chronic illnesses include cancer, cardiac conditions, HIV infection, spastic quadriplegia, developmental disabilities and epilepsy. One in every 4 adolescents with a chronic illness has at least one unmet health need that may affect their physical growth and development, including attaining puberty, overall health status as well as future adult health [3]. Data on the prevalence of specific chronic diseases among adolescents highlights the magnitude of the problem in our country. Recently, data from India on 514 patients with transfusion dependent thalassemia (TDT) in North India revealed that 43% ($n = 222$) of them are aged above 18 years [4]. Likewise, a large thalassemia centre in Mumbai has 35% adult TDT patients (M Manglani, personal communication, June 15, 2023). Prevalence of epilepsy among 15

to 18-year-old boys and girls has been estimated to be 821 and 625 per 100,000 respectively [5]. According to 2022 estimates, over 8,50,000 children and adolescents are affected by juvenile diabetes; with an annual increase of 6.7% this figure is likely to be over 17,00,000 by the year 2040 [6]. The prevalence of asthma in children with mean age of 12 years is estimated to be 7.9 % [7]. According to estimates quoted by Indian Council of Medical research (ICMR), there are 80,000-1,00,000 children with severe hemophilia in India [8]. In some developed countries including USA, policy statements and guidelines on ToC of YSHCN are in place for over 3-4 decades [3,9], although the same is not true for most developing countries including India.

Need for ToC Guidelines

It is stated that ToC is *“to affirm that just as children receive optimal primary care in a medical practice experienced in the care of children, so too adults benefit from receiving care from physicians who are trained and experienced in adult medicine [2].”*

With increased survival of patients with chronic diseases, newer long-term complications and disabilities have emerged which require focused attention. Some examples include (a) Patients with transfusion dependent thalassemia (TDT) are now at greater risk of atherosclerotic cardiovascular disease and associated impaired glucose metabolism; (b) Cystic fibrosis (CF) associated diabetes mellitus which occurs only in 2% of pediatric patients with CF, but increases several fold in adolescence and adulthood; (c) Survivors of childhood cancer will develop health issues such as obesity, hypertension and hyperlipidemia [10-12].

Another reason for ToC is to ensure ongoing treatment adherence. In the absence of proper ToC, adolescents are likely to have non-adherence to treatment. HIV-infected adolescents on anti-retroviral therapy (ART) remain largely asymptomatic and they may not feel the need for continuing ART; left unsupervised, they are at risk for poor adherence to treatment and treatment failure [13]. Similarly, poor glycemic control and higher emergency room visits among patients with type 1 diabetes mellitus, and transplant rejection among kidney transplant recipients due to loss to follow up are described when ToC is not well addressed [14-17]. Better satisfaction among YSHCN is described when ToC is well planned. This facilitates improved adherence and compliance to therapy [14,18]. Positive youth development programs associated with ToC have shown better self care and advocacy as well [18,19].

Barriers to ToC

Despite perceived need for proper ToC for YSHCN for their attaining full developmental potential, there are several barriers to ToC. These barriers exist at the level of pediatricians, family and patients, physicians and administrators.

Pediatricians may feel less comfortable referring their patients to an adult provider who is perceived to be less familiar with childhood-onset conditions. There is a fear of missing out/ losing contact with the patients for whom they have cared for years. There may be negative “research consequences” of reduction in patient numbers and a loss in long term follow-up. In private set up, there may be issue related to negative financial consequences.

If informed suddenly, patients and families are unable to cope with the transition to adult care and develop anxiety. Patients may feel anxious and distressed due to their emotional attachment to their pediatric health care providers and may fear going to an unfamiliar set up for further care. They may experience grief and loss when these trusting relationships end. Moving to adult services may be viewed by them as a step closer to disease complications. Adjustments are required for individual rather than family approach of adult physicians. Parents may suddenly feel excluded from all decision making.

Acceptance by the physicians and taking the YSCHN under their care is the most important aspect of ToC. However, physicians may have limited interest in pediatric diseases which they do not encounter in their day-to-day practice. It may appear to be an additional responsibility as they may have their own areas of interests. When the ToC services are still developing, physicians may feel inadequately equipped in care of childhood onset diseases. Administrators may also be unaware of the concept of ToC; in the absence of an existing hospital policy, they may be reluctant to provide support in terms of staff and logistics.

Overcoming the Barriers

This policy document describes interventions to overcome these barriers and ensure a smooth ToC in place [20-22].

1. Securing Support of Senior Leadership to Develop a ToC Policy (National, State, Regional, Hospital Level): Appropriate administrative heads at the state, district and hospital level (such as medical superintendent of the hospital) should be approached to solicit support. The administrators should be apprised of how investing in ToC will help to retain YSCHN in care and improve patient satisfaction and outcomes. The administrators may be provided with the data on the need for ToC, such as the number of youth who will need transition to adult services over

the next five years in the system/state/practice or the percentage of youth not receiving ToC services from health care providers in the state/ hospital. Leadership should be made aware of the evidence that population health outcomes are improved with a structured ToC approach.

2. **Defining the Age of Transition:** Opinion remains divided around the optimal age for transition. The USA 'Got Transition' recommends initiating transition discussion at 12-14 years of age and completion of all steps of transition by 18-23 years [20]. The cut-off ages of 12 years, 13 years and 18 years are suggested by others, based on hospital policy. Some have recommended a flexible approach, taking into account not only the chronological age but also the emotional and developmental maturity of the individual [23]. Yet others feel that this may be counterproductive as the adolescents may feel upset while comparing with peers. Across our country, the cut-offs for transition from pediatric to adult care for general patients are extremely variable across states and hospitals as well as differ in public versus private sector. Increasing the age of transition from pediatric to adult care from 12 years to 18 years, may have following implications: (1) It will increase the number of patients visiting the pediatric out-patient services as well as pediatric inpatient services; (2) Increased patient load may require additional staffing in Pediatrics. Given the economic implications, it may mean reducing the staff on the Medicine side. This staff rearrangement may have implications related to National Medical Commission regulations; (3) It will necessitate modifications in the ward arrangements, i.e., developing separate wards for adolescent boys and girls.

As adolescent care falls under pediatrics in India and in most parts of the world, YSHCN should be managed by pediatricians till these patients attain 18 years age. For the time being, in view of the above implications, the cut-off age for ToC of YSHCN may be allowed to remain the same as that for adolescents without special health care needs. However, in the long run, a uniform age cut off of 18 years for ToC of YSHCN should be mandated for the country.

3. **Self-management/Self-care:** Self-care or self-management is the practice of activities that an individual initiates and performs on his or her own behalf to maintain life, health, and well-being. Self-management is a patient-driven operational process with the ultimate goal of empowering the patient in his/her own care.

Education program of self-management for chronic

diseases has shifted from the traditional approach to the empowerment model. Empowerment is defined as helping people to discover their innate ability to control their diseases and situation. Due to increased number of patients with chronic diseases, it is necessary to pay attention to patient empowerment. However, physical, psychological and emotional maturity of the patient should be taken into account while embarking on coaching on self-management. In cases where the patient him/ herself is deemed unfit; a caregiver should be identified who should receive coaching in self-care. Empowerment on self-care entails the understanding of the disease, the treatment rationale, the source of symptoms, recognizing deterioration-clinical- versus laboratory-based, and taking appropriate action including seeking help from health professionals and operating within the medical system [24]. Psychological empowerment of patients is important for their active participation in self-care. To achieve this, preparation must begin well before the anticipated transfer time, preferably in early adolescence, when a series of educational interventions should discuss about ToC. Various methods suggested for coaching in self care include lecture session, question and answer, presentation of PowerPoint, photo presentation, educational pamphlets, and peer training to which several digital forms of training methods may be added. In addition to the disease-related information, the content of sessions should consist of daily activities, fitness and health, nourishment, stress relief, job and home environment, time management and expression and creativity.

4. **Transition Initiation and Assessment of Readiness:** The patients and their families should be informed well in advance about ToC. Got Transition (USA) suggests initiating the process at 12-14 years, which is 6-8 years before the actual transition takes place. However, the process of ToC should be initiated at least one year before the actual transition [25]. It is important to periodically assess whether the YSCHN are adequately equipped in self-care, health care utilization skills, decision making skills and self-advocacy. This assessment allows the care providers and patients and their families to know the gaps and to act upon the required areas. Studies on the assessment of transition readiness using specific questionnaires addressing different domains have highlighted a correlation between transition readiness and outcome. Assessment of transition readiness is also important to understand the needs of the patients and their families so that resources around health care, education, and psychosocial needs can be individualized. There are validated tools available for such screening, such as the Transition Readiness Assessment Questionnaire

(TRAQ) - a tool that is not disease-specific, and easy to administer [2,26].

5. **Communication With the Receiving Team of Physicians:** In developed countries, it is easy to decide about transfer of YSHCN as there are well developed systems in place. In our country, as the system is being initiated now, it is important as a first step to identify a physician who will be entrusted with the task of caring for patients with specific diseases. Currently, there are institutional differences regarding the availability of speciality/ sub-speciality care. In institutions with specialty services, one or two adult care physicians/ specialists may be identified to take care of young adults of the concerned specialty. In situations where the YSHCN have to be transferred to the adult Medicine department, a physician(s) who will be interested in looking after the patients with specific diseases needs to be identified. This may be done with the help of the administration. Communication regarding the need for ToC should be developed with the identified physician(s). They need to be apprised about specific needs of the adolescents and young adults with specific diseases. An ongoing communication needs to be built between the receiving adult-care team and the pediatric team as and when needed. The adult physicians may be provided with relevant resource material. Collaborative partnership with the physician team is important for the process of transition, including organizing joint clinics, transition completion and transition registry. Patients who need ToC usually have a long and often complex medical history. A detailed ToC document should be prepared by the treating pediatric team and provided to the receiving physician for future reference. This is especially needed if the medical records are not automatically transferred with the patient's transition.
6. **Process of Transition:** A hospital policy describing in detail the actual process of ToC needs to be available with duties on both ends clearly delineated. Casual agreement is easy to make, but it is less likely to succeed in the long run. See. At a minimum, a hospital ToC policy should state (i) the age of transition, (ii) transition initiation and assessing readiness, (iii) nominated care providers - both pediatrician(s) and the receiving physician(s), (iv) joint care clinics, (v) care coordinator/ counsellor/ nurse(s). It is important to educate all staff about ToC. For information of patients and families, a patient information sheet for ToC should be developed which should be validated.

Joint Clinics: Joint Clinics are the clinics which are attended by both the pediatric and adult care teams. These

joint care clinics aim at familiarizing the patients with the staff and environment they are moving to. These should also be attended by the care coordinators and the nurses. It is important to transfer the records and relevant data regarding the patients' illness at the time of actual transfer or before that. Special needs of the patients should be discussed by both the teams and management plan be drawn in advance. The place where the joint clinic is organized should be closer to the adult care department. A visit to the department should be organized. Frequency of such meetings can vary depending upon the number of YSHCN requiring transition.

Transition Completion, Transition Registry and Follow-up

A summary of patient's record should be prepared carrying information about the specific health issues if any, requiring attention. The summary should be handed over to adult care team at the time of transfer of the patient. A nurse or a counsellor (transition navigator) needs to be identified for any assistance required during the transfer. The navigator may be disease-specific, if the numbers of YSHCN are large enough. In settings with a small number of cases requiring transition, only one navigator can be entrusted with the task. To minimize the chances of loss of follow up, a transition registry needs to be maintained [27]. The registry should be maintained by the transition navigator under the supervision of the pediatric team. Administration should make arrangements for secretarial help required. A follow-up visit 3-6 months after the transition is recommended to ascertain if YSHCN is attending the adult care services.

Standard Operating Procedures (SOPs) for Implementation of ToC

We suggest the following instructions to be in place to ensure uniformity in ToC across the country.

At the National / State Level

The ToC policy should be circulated from the MoHFW or DGHS to the following:

- Health Secretary of the State / Union Territory (UT)
- Directorate of Health Services / Medical Education of the States and UTs
- Director General, Employee State Insurance Corporation (ESIC), Ministry of Labour and Employment
- The MoHFW / DGHS should also share the policy with the National Medical Commission (NMC) for including ToC in the postgraduate (Pediatrics, Internal Medicine) and super-specialty curriculum.

- State Health Secretariat/ DHS of the state / DG- ESIC should share the document with all medical colleges/ PG institutions/autonomous institutions such as AIIMS/ District Hospitals/ Missionary Hospitals/ Children Hospitals in public and private sector
- The Medical Superintendent/ Principal/ Dean / Director of the Institution/ Hospital should discuss the ToC with the Head of Department (HOD) of Internal Medicine/ concerned specialty and Pediatrics and take necessary steps for implementation (see below)

At the Hospital Level (Medical colleges, Autonomous institutions, District hospitals)

Step 1: Define the age of ToC taking into account prevailing age cut-off for Pediatrics / adult care in the particular hospital.

Step 2: Identify the pediatrician/ specialist pediatrician from whom the YSHCN needs to be transitioned, the physician/ specialist who will be receiving the YSHCN and the transition coordinator/ navigator (medical social worker/ Counselor/ nursing officer).

Step 3: Responsibilities of the pediatrics team must be defined. The formalities for transition for YSHCN should begin at least one year before the actual ToC.

- A written document can be prepared for patients and caregivers explaining the need of ToC and its timing.
- A program of self-care and patient empowerment for self-management of the particular disease should be developed. This includes developing written material/ leaflets/ lectures and group discussion for the patients, caregivers and treating team.
- Assess the readiness for transition
- Joint clinics for patients to be transitioned should be established with collaboration of the pediatric and adult care teams
- Patient management plans should be discussed with adult care team
- The complete records / copy of records to be transferred (physical/ digitized) should be finalized
- The pediatric team should be accessible to both the adult care team and the transitioned patients (need-based)

Step 4: Responsibilities of the adult care team include:

- Participation in the joint Clinics
- Providing uninterrupted care to YSHCNs

Step 5: Maintaining disease-specific transition registry at

the hospital level (transition coordinator/ navigator should be doing this task)

Step 6: Follow up of transition 3- 6 months after actual transfer of the patients for transition completion and picking up loss of follow up (transition coordinator / navigator should do this task)

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ANNEXURE

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