

Appendix 1. Summary of transition barriers from needs assessment for University of California, San Francisco Cystic Fibrosis Center Transition Program and subsequent interventions with process comments through an ecologic framework of addressing barriers at patient/provider (intra- and interpersonal) and system level.

Barrier/Need	Intervention	Comments ¹
Patient/Family Level		
Parental concern and anxiety about transition process and child's ability to execute self-care	Transition guide	Pediatric providers directly address parental transfer concerns in clinic. Providers track patient's progress in disease knowledge and management skills.
Patient's lack knowledge and skills to manage own CF care	Age appropriate checklists introduced at 8 years of age; benchmarks for demonstrating knowledge, self-management, and self-advocacy are introduced.	1 on 1 work with provider during clinic encounter engages patients in process of learning about CF and how to manage treatments and illness. Providers advance patients through curriculum; remediate and review as indicated.
Lack of familiarity with adult CF care and Adult CF team	Brochure introduces Adult CF Team and clinic. Adult consultation during Pediatric hospitalization to introduce patient and family to adult team. Adult CF Team participates in parent night.	Pediatric providers endorse knowledge, skill and availability of Adult Team. Conversations with teens about adult CF care start before High School. Stylistic differences between pediatrics and adult medicine discussed.
Distance to adult program with concern for missed classes and work	Adult CF Nurse practitioner sent to suburban, outreach clinic site.	Pediatric Team agrees to host Adult NP at suburban clinic in alternate months. Fiscally sustainable compared to physician staffing.
Provider Level		
Pediatric and adult CF care teams not working together with infrequent opportunities to discuss care delivery problems	CFF Quality Grant funding and QI meetings initiated bi-monthly, now quarterly QI meetings attended by pediatric and adult CF team members.	Participation in QI meetings and projects supported by travel and work-release re-imbursement. Provider survey indicates continued enthusiasm for QI meetings and professional fulfillment from projects. Joint meetings considered valuable and now part of clinical culture of the center.
Adult CF physician providers not able to maintain suburban outreach clinic	CFF Quality Grant partly supported a nurse practitioner as adult CF Clinic Coordinator and permitted training as adult CF Provider.	NP trained in adult CF care sets criteria for safe participation in outreach clinic. Electronic medical record (EMR) supports remote access to data and decisions.
Pediatric providers lacked information regarding status of former patients. Adult providers lacked	Transition readiness assessments at QI meetings inform adult center of coming patients; review of patients	EMR allows all providers to review current patient health status and serves as a repository for transition assessments.

information about incoming patients.	update pediatric program on status of patients who transferred.	
No systematic approach to transition patients and families	Transition guide and notebook	Providers from all disciplines active in Transition program. Patient and family experience does not hinge on a single meeting or provider.
Differences between delivered CF care between sites	PDSA cycle developed at QI meetings	Nutritional standards first subject to undergo standardization between the two centers. Dieticians took key roles to initiate and change plan of care within both adult and pediatric centers.
Clinic/Hospital Level		
Pediatric patient information difficult to access by the Adult CF Team	System-wide EMR	Psychosocial and developmental issues known to pediatric providers were now available to adult team through EMR.
Transfer of care to adult team during acute hospital admission without prior knowledge of family* *Specific indications for hospitalization under adult care include but are not limited to marriage, pregnancy, incarceration and age greater than 25 years.	Inpatient CF nurse toured pediatric patients and families to the adult floor. Adult consultation during pediatric hospitalization of transition aged adolescents. Shared care model developed to help ease transfer for some families.	Patients had the opportunity to return to pediatric team for de-briefing on their experience and support in progress through transition process.
<p>1. Comments are drawn from provider surveys and group meetings describing group and individual activities on behalf of the transition program</p> <p>CF: Cystic Fibrosis EMR: Electronic Medical Record PDSA: Plan-Do-Study-Act QI: Quality Improvement</p>		