

Steps for the Pediatric Team

There are seven major steps for preparing the Pediatric Team and guiding it through the actions it must take to make the transition process work.

1. Deciding to develop a partnership with an adult caregiver to provide a setting for adult patients.
2. Identifying a physician in the adult health care setting who has the skills and interest to become a partner.
3. Gaining support of pediatric academic and administrative authorities.
4. Examining attitudes toward transition with all pediatric caregivers and making a commitment to the process.
5. Developing a training plan for adult caregivers.
6. Developing a process for identifying and preparing patients appropriate for transition.

Deciding to Develop a Partnership

Before deciding to contact a potential partner in the area of adult health care, the pediatrician must go through a process of self-examination and define his/her commitment to the concept of transition and willingness to effectively transfer care for his/her adult patients. Hesitation may be generated as a result of fear of losing too many patients, economic erosion of the program, opposition by others in the pediatrician's institution, etc. Other concerns include whether the pediatrician is ready to let go of patients and support them and the receiving team in the process--not to selectively transfer patients, i.e., THE ONES HE DISLIKES, keeping the ones he likes. The pediatrician will have to put in some effort to overcome the feelings of: "I have come this far with these patients and I do not want to give them away"; or "I do not want to give away the transitionable patients who are probably the ones who are most mature, doing better medically and less of a problem. In addition, the pediatrician must face the issues of giving away information, a patient base for research, and income. Finally, the pediatrician must think about any possible resentment that might arise when having to teach other people in a relatively short time what may have taken a lifetime to learn. There can certainly be a feeling that "we are handing over these patients and all our knowledge and the adult team has done nothing to deserve it."

These negative feelings and concerns must be balanced by the realization that there are many benefits. Less time devoted to the patients lost may be more time to devote to other projects. Loss of the patient base for some types of research is balanced by

the ability to conduct collaborative research with experts in the adult care field. Finally, there may be a lessening of stress for the pediatric team as it shares the burden of caring for very sick and dying patients with another team of caregivers.

Of course the biggest incentive is providing one's patients with improved care that fosters their emotional and social growth. After having reviewed one's attitudes and feelings about the "issues of the heart" that relate to transition as well as the economic and practical issues, it is time to decide whether to forge ahead. These feelings will emerge over and over during the process of finding a partner and helping the adult program evolve. Dealing with them before starting the process gives you a better chance of avoiding sabotage of progress by unresolved feelings.

Identifying a Partner

The easiest place to look is in one's own backyard. Usually partnerships of this nature are developed along institutional affiliation lines (i.e., university, hospital, group practice, HMO, etc.). If there is a program already in place, it makes more sense to utilize this structure and improve upon it. The adult practitioner you seek should be interested in the disease/disability you treat as an area of knowledge and interested to at least explore the possibility of doing chronic care in the manner that is necessary for the special needs of the population in question. Most adult subspecialists do have experience in chronic care, but may not see the need for a team or may not have the insight into the issues of chronic congenital or genetic disease. The partner must be sensitive, willing to learn, and not have a "big ego" that would prevent him/her from taking at least some direction from pediatric caregivers. This last point is critical, in our experience. It is very difficult for a practitioner who may have many years of experience to step back into the learners role again--going on teaching rounds as the student, being supervised in one's work, etc. It will be important for you to convey the need for training in a non-threatening way, so you can encourage potential partners.

Adult caregivers may be very busy and not appear immediately interested in the prospect of putting in the training and care delivery time that taking on a new patient population demands. Do not become discouraged if the internists or other adult caregivers do not jump at this golden opportunity. The process may sound more enticing if research possibilities are discussed. Sometimes a younger person, still looking for his/her "niche" may find this new area appealing. The economics of the situation need to be presented in a positive light. It may be useful to highlight the possibilities of outside funding for this new endeavor. There does, indeed, seem to be reason for optimism. In our experience, the adult team has received a great deal of special recognition within their institution as well as nationwide. The involvement with the new patient population has also led to inclusion in exciting new research arenas. In addition, the economics have not been problem for the adult care institution.

It is probably better to choose an individual who is not a section chief or has not been overwhelmed by administrative responsibilities. A lab researcher who does not have

care of these patients must become an important part of the partner's professional identity. He must see it as a means to professional advancement, a source of new learning and professional interest, or a source of professional satisfaction, not a nuisance or a drain of time and energy.

Having found a potential partner, the pediatrician will need to continue to reach out to the adult caregivers. The new partner will need support, training and guidance for some time. The pediatrician will have to coordinate the process, in collaboration with the partner, until a structure is developed and the adult team is trained and functioning independently.

Gaining Support from Administrative and Academic Authorities

The pediatric team will need the time and permission to begin the process of helping develop and train the adult team. To accomplish this, the project must have the support of the authorities in the system who must approve and support new efforts. In an academic setting this includes both academic and administrative authorities. Individuals such as section chiefs and departmental chairmen must see this as a desirable, academically correct step to take and in the best interests of the patients. Fears of debasing patient programs or losing crucial revenue must be addressed with concrete information. Information about the exact economic impact, the decreased need for resources and the ability to devote more time to other pursuits should be presented.

Administrative authorities must also be contacted. The same types of issues will arise. Administrators are particularly interested in the loss of revenue from decreased number of hospital admissions, decreased utilization of lab and other services, etc. Again, one needs to present the positive aspects of the shifts that can take place when these patients are transferred. Administrators may already be disposed to the concept since these patients may have poorer insurance or are outlayers in the DRG system. If you are located in a children's hospital, the administration may also be glad to rid themselves of the headache of caring for patients who are technically "too old" to be admitted under hospital by-laws. If there will be a substantial loss in revenues, it will be helpful to have ideas about developing other projects to replace the care of adult patients.

Before going to present the project, gather the information you may need to "make your case. It may be helpful to use the worksheet **Identifying Patient Demographics for Planning the New Adult Health Care Program** (page 13) to organize the fiscal information. (Save this information, because your partner will need the exact same information to gain support in his/her care setting.) In addition make a list of potential academic advantages (new types of research possible with skills of adult caregivers; studying the process of transition; new training opportunities for students and house staff, etc.) and new revenue sources. You can use the worksheet, **Contact Check List for the Pediatrician**, to make sure you have covered all the bases (page 14).

**Identifying Patient Demographics for Planning
the New Adult Health Care Program**

This data should be obtained from the pediatric unit for planning the new adult program. This format can also be used to continue to maintain information about the progress of the new adult unit once it is established.

IN-PATIENT

Total Patients Registered (over 18) _____

Total Patients Admitted (from _____ to _____) _____

Total Number of Admissions (from _____ to _____) _____

Average Length of Stay _____

Median Length of Stay _____

Average Number of Patients In-House _____

Services Utilized

OUT-PATIENTS

Number of Visits (from _____ to _____) _____

Number of Patients (from _____ to _____) _____

Number of New Patients (from _____ to _____) _____

Services Utilized

Contact Checklist For the Pediatrician

The following is a convenient checklist to assure contact with individuals important in the process of establishing a new program.

- _____ Section Chief
- _____ Department Chairman
- _____ Hospital Administrator
- _____ Individual Disciplinary Departments
 - _____ Nursing
 - _____ Social Work
 - _____ Dietary
 - _____ Physical Therapy
 - _____ Respiratory Care
 - _____ Psychology
 - _____ Other
- _____ Fiscal or billing office for Financial Information

Examining Attitudes Toward Transition with the Pediatric Team

Once you have worked your way through the first steps and are onto the next ones, it is important to begin discussing the possibility of a transition program with your own care team. Be sure to show enthusiasm and commitment. Remember all the feelings and attitudes you struggled with before coming to the conclusion to move ahead with transition. Your team members will have to go through the same process. Be supportive, but also do not allow the process to be diverted by their concerns. They will need to discuss how to deal with shortcomings of the other team, how to have patience and give of oneself in the pursuit of the ultimate goal. This will mean accepting mistakes, trying to control derisive remarks, and not expressing negative feelings in front of patients. If a particular team member has extremely strong negative feelings, these must be addressed in a private meeting. The team should set aside times to meet alone and with the adult team as it develops to discuss concerns and feelings, so they do not fester and undermine the process.

The concept must also be introduced to professionals outside the team, but within the same care setting. Nurses on the pediatric in-patient unit to which our Cystic Fibrosis patients had been admitted felt that they needed to understand and feel comfortable with the transition process and the new care setting so they could help inpatients begin to accept the new setting. **Visits to the new care setting, a complete understanding of how a patient's care will be transferred, and personal meetings with the new caregivers are part of that process. All personnel must understand your concept of transition.** Feedback about why particular patients are or are not transitioned helps the other staff members understand the concept. In our experience, one concept that needed repeating was that transition did not occur automatically at a "magic age". This idea was frequently mentioned by floor nurses, often in hopes that a particularly difficult patient would be sent on to the adult setting. Inpatient staff also need help in understanding "failures" of transition-sometimes the feelings of a patient who has elected to return to the pediatric setting can quickly color staff opinions of the adult program if the pediatric team does not provide accurate feedback. Please be sure to let all caregivers in the pediatric setting know about the successes! It helps them to be positive, enthusiastic advocates for transition with younger patients and their families.

You can use the Consolidation of Commitment Checklist (page 16) to help you touch all the bases in this process.

Consolidation of Commitment Checklist

- Present idea to team.
- Facilitate team discussion of feelings.
- Facilitate ongoing inter-team meetings to deal with feelings and concerns.
- Present idea to non-team staff.
- Allow inpatient staff to know and visit new program.
- Explain rationale of transition and selection process to non-team staff.
- Insure feedback about transferred patients for non-team staff.
- Educate non-team staff about reasons for failures to prevent "rumors".

Developing Training Program

Training the adult caregivers is an ongoing process. Much of this training will come within the context of shared care and rounds. It is important to have a total structured program, however, in order to assure the quality of adult care. A training program should be planned considering the following components:

1. A bibliography compiled by each team member for the members of the Adult Team.
2. Meetings between same discipline members of each team.
3. Teaching rounds in both the outpatient and inpatient pediatric care setting for all Adult Team members. (This experience is to expose them to both the details of care and the relationships among team members.)
4. Supervision of cases relating to disease specific information. Styles of caregiving should be addressed carefully. Remember the reason you are doing this is to expose patients to a different mode of care delivery. Some hints are O.K., but be careful!
5. System of telephone consultations with pediatric team.
6. Inpatient pediatric nurses should help the adult team nursing coordinator plan and execute training of adult inpatient nurses.
7. Concensus of care conferences.
8. Compile specific treatment protocols to assist in condition of care.

Developing a Process of Identifying and Preparing Patients

Preparing patients and families for the move to the adult health care setting is part of a total process of helping the patients grow up. We found that having a separation point helped focus our efforts toward assuring patients' understanding and independence needed in adulthood. The process starts many years before the patient and family ever meet the adult care team. The following timetable was developed for our setting:

- Patients are helped to take responsibility for medications and treatment at as early an age as possible (by ten at latest.) The adult team is mentioned as a long-term, future goal to pre-adolescents--for when they are "ready".
- At age thirteen, patients are seen by themselves during routine outpatient visits. Parents are invited to join the session later. The patients are expected to be able to respond to questions about their symptoms, treatments, etc. Parental involvement is encouraged to become more supervisory and less active.

- A planned re-education program for each adolescent is carried out. Understanding of disease, rationale of therapies, source of symptoms, recognizing signs of worsening and what to do about it, how to seek help from health professionals, how to best work the medical system and, for older adolescents, insurance issues are included. At age fifteen-and-a-half to sixteen, a detailed explanation of the Adult Program is given to the patient and family, suggesting that most people are ready to start seeing the adult team at age 16.
- Between the ages of 16-18, after discussion of readiness by the Pediatric Team, the adolescent has a first official visit with the adult team in the pediatric clinic. Following that visit, patients and families are encouraged to voice their feelings both positive and negative to adult team members and the pediatric nurse. At this time similarities between teams are emphasized and concerns addressed.
- Subsequent office visits are held with the pediatric and adult teams until the patient is deemed "ready." The patient and family are invited to tour the adult facility and to address questions and concerns to the adult team. A brochure is provided about the adult program's facilities. It includes a map with directions from key access routes along with contact team members' phone numbers. A fact sheet of key departments at the adult facility is also provided.

The decision that a patient is "ready" for transition must be made by the entire team, with input from the patient and family. This assessment can occur in a number of ways, but should be organized and standardized for your team. In this project, the pediatric Clinical Nurse Specialist gathered information from the patient, family and team and then addressed the following set of issues:

1. Does the patient take responsibility for his/her own care most of the time?
2. Does the history the patient gives of his/her disease/life correlate with the team's knowledge of the history?
3. Do the parents no longer persist in saying "I can't make him/her take his/her medications?"
4. Has the patient been in the pediatric Inpatient unit less than 2-3 times in the past year?
5. Can the patient describe the symptoms of an exacerbation in illness?
6. Does the patient ask to speak directly with the health care team?

8. Is the patient developing clear vocational and future oriented goals?
9. Can the patient make the change without experiencing a particularly acute loss of the relationship with a particular pediatric team member?

If the answer to all the questions is "yes", then the patient is deemed ready for transition. If the answer to any question is no, then a plan is made for services such as counseling with the pediatric team social worker, education about medical issues with the pediatric team nurse or other personnel, special support from a team member to whom the patient has been very attached to move on, etc. (If the patient has been frequently hospitalized in the past year, transition proceeds only if the patient and family express a desire to move to the adult setting.) A checklist, **What Patients Need to Know About Their Disease** (page 20), was developed to help both teams assess knowledge. The patient is then reassessed to determine readiness. This assessment process provides only a guideline to the team. Some patients may be able to transition to the adult team, with the recommendation for further services in problem areas from the adult caregivers.

What Patients Need to Know About Their Disease Checklist

----- What is Cystic Fibrosis?

----- Genetics of Cystic Fibrosis (handout).

----- Treatment regimen:

- 1. Antibiotics
- 2. Aerosol
- 3. Chest PT
- 4. Inhalers
- 5. Nutrition
 - a. Enzymes
 - b. Vitamins
- 6. Exercise

----- Complications (if applicable):

- 1. Hemoptysis
- 2. Pneumothorax
- 3. Diabetes mellitus
- 4. Arthritis

----- Help in coping:

- 1. Employment
- 2. Peers/communication
- 3. Lifestyle/image changes
- 4. Insurance
- 5. Family planning
 - a. Birth control
 - b. Adoption
 - c. Artificial insemination
- 6. Life expectancy

----- Other:

- 1. Usage of O₂
- 2. Heart/Lung transplant