MAKING IT WORK

Any process that spawns a manual to guide the uninitiated through its phases is undoubtedly one that promises to be fraught with problems and impediments to success. The process of developing a model of health care delivery that assures the smooth transition of adolescent/young adult patients to appropriate adult health care settings is truly such a process. There are a variety of obstacles, on at least two levels, that must be considered. On the first level, attitudes and beliefs of health caregivers are the primary impediment to progress. Simply accepting the idea of transition and of the need to specially prepare the adult health care system to provide appropriate care acceptable to these patients and their families is difficult for some. These attitudes and beliefs must be understood, respected and dealt with before any success can be expected. Once these initial obstacles are overcome, the second level of the more practical impediments to transition must be addressed -who will do it? how will they learn to care for these patients? how will the process be financially supported? Sounds overwhelming!! Take heart -- with commitment, ingenuity and guidance from this manual, it can be done!

Dealing with Feelings and Attitudes

A major impediment to starting the process of transition is the Pediatrician's feeling against transition and transfer of care. Several assumptions and beliefs may underlie that reluctance:

1. Pediatric caregivers can manage all patients regardless of age -- it is more important to be a specialist in the type of disease treated than in the treatment of a particular age group.

2. Adult patients can be comfortably and appropriately cared for in pediatric or adolescent wards with no detriment to their well-being. Patients like the familiar surroundings.

3. Pediatric nurses and house officers enjoy or do not mind caring for adult patients, particularly those they have known for years.

4. There is a historical paucity of caregivers in adult settings with adequate training in the specifics of care of the "pediatric disorders" -- they do not know how to care for these patients and have not bothered to learn. There is no reason for the pediatrician to take the initiative to get them interested.

5. It is painful to break long-established emotional bonds with patients and families and probably not worth it.

6. There will be negative economic consequences for the patients and the caregivers--adult hospitals are "greedier" and the overall pediatric program may suffer if revenues from adult patients are lost.

Many pediatricians feel that to transfer patients after a certain age is to "dump" them. This view leads to feelings of guilt. In some situations, there are economic, professional and emotional disincentives for pediatricians to accept and actively seek transition for their patients. For many it may just be an inability or unwillingness to accept change. Most may wonder if the work and pain of initiating this process will be worth it. It, therefore, requires a high level of commitment from the pediatric caregivers to pursue the goal of developing appropriate health care in adult settings for the long-term survivors of pediatric disorders.

At the same time, feelings and beliefs of adult health care providers have also stalled the process of transition:

1. Adult caregivers are unfamiliar with "pediatric diseases" -- for established caregivers it may be uncomfortable to become "trainees" again. Being supervised on cases is for residents, not attendings.

2. These patients and their families are too demanding, too time-consuming and the patients are very immature.

3. Patients with chronic pediatric conditions are poorly insured and with DRG's will be an economic drain that is not desirable.

4. This type of patient may force the system to change its care patterns--what is done now is comfortable and works fine. Why should our system have to change to accommodate these patients who have been "spoiled" by the pediatric health care system.

5. The type of care these patients demand (team care, etc.) is not available in the adult care system and is costly to establish--administrators and caregivers will never accept the idea.

Many adult caregivers are unaware of the existence of the growing population of survivors of chronic pediatric conditions. If they are aware, they assume that such patients will not be particularly satisfying to care for or may be a drain on already strained resources. These caregivers, who are specialists in their own areas, may feel resentful or offended when pediatric professionals come to "show them the right way to care for patients". In addition, adult caregivers often feel that their pediatric counterparts assume that the teaching process is all one way--the pediatrician will show the internal medicine specialist the "right way" to provide care. Unfortunately,

this kind of approach negates the important contributions of adult specialists to develop better models of care for adult patients.

Despite the feelings and beliefs on both sides of the fence, the need for developing appropriate models of health care for survivors of chronic pediatric conditions is critical. Feelings can be acknowledged and overcome. Beliefs can change with information and experience. In the process of completing our project these issues had to be addressed and addressed again all along the way. The effort was, happily, worth it. Our beliefs about the positive benefits of transition for patients were confirmed. So......take the plunge!

Charting Your Course

Thinking about obstacles can be discouraging, so for the remainder of the manual, we will turn the tables. Obstacles become challenges that lead to a series of goals and steps needed to meet those challenges. Achieve each of these goals and transition becomes a viable, workable process. Within each goal, there are specific steps or activities for pediatric caregivers, for adult caregivers and for the two groups together to attain.These goals and objectives were developed as a result of our specific experiences, but can be applied to the process no matter what the disease entity you may be treating or what configuration of health care settings are to be involved.

There are eight objectives that are basic to the development of a care model that will support a smooth, successful transfer of patients from pediatric to adult care:

- EXPLORE ONE'S COMMITMENT TO TRANSITION
- IDENTIFY INITIAL PARTNERS
- SECURE INSTITUTIONAL SUPPORT
- ASSURE ECONOMIC FEASIBILITY
- DEVELOP A STRUCTURE
- DEVELOP A SUCCESSFUL PARTNERSHIP
- ACHIEVE A SUCCESSFUL TRANSFER OF PATIENTS

Making the process work requires:

1. Assessing which goals you have achieved.
2. Planning the necessary actions to be taken to achieve those, as yet, unmet goals.

Charting your progress toward attaining each of the goals will help you plan your future actions. Each situation is unique and there will be different levels of progress toward each goal, depending on the current configuration of your health care setting, the history of relationships between pediatric and adult subspecialists and specific aspects of your locality, such as: reimbursement sources, geography and the demographics of the patient population.

Following your self-assessment, refer to the appropriate sections in the remainder of the manual for guidance on how to meet your goals and what step to take next. There are separate sections to guide the pediatric team and the adult health care team, as well as one which explores the tasks common to both teams.

STOP
GO TO SELF-ASSESSMENT ON NEXT PAGES

SELF-ASSESSMENT

Put a check next to each step you have already taken. Then decide on your next steps.

GOAL 1. Explore one's commitment to transition.

Pediatric Team Steps:

_____ Examine willingness of all caregivers to give up care to others

_____ Examine willingness of all caregivers to put in extra effort to reach out to and train adult team.

Adult Team Steps:

_____ Examine willingness to put in extra effort to gain support in adult system, to learn a new area and to modify methods of delivery of care.

_____ Examine willingness to be a "learner."

_____ Examine current commitments in relation to time needed to start a new project.

GOAL 2. Identify initial partners.

Pediatric Team Steps:

_____ Identify potential partners -- adult subspecialists.

_____ Make contact and secure initial agreement to plan together.

Adult Team Steps:

_____ Identify interested M.D.s in key subspecialty.

_____ Determine level of departmental/partner interest in providing back-up to the interested M.D.

GOAL 3. Secure institutional support for idea.

Pediatric Team Steps:

_____ Gather general information about financial, service system, and academic impact of transition.

_____ Make presentation to administration and academic key players about impact/benefits of transition.

_____ Secure assurances that the program and the extra time needed to get it started have institutional support.

Adult Team Steps:

_____ Gather information about financial, service system and academic impact of taking on the new group of patients.

_____ Make presentation of material to administration and academic key players.

_____ Secure commitment to working on financial, staffing and moral support for this project.

Self-Assessment Continued

Joint Steps:

_____ Share information about demographics, costs, funding sources, academic benefits, etc.

GOAL 4. Assure Economic Feasibility.

Pediatric Team Steps:

_____ Gather specific information about patient payer mix.
_____ Assemble information about reimbursement sources' number of patients, long term needs for services, etc.
_____ Estimate financial impact of losing patients.
_____ Assemble information about length-of-stay.

Adult Team Steps:

_____ Obtain information about payer mix, reimbursement sources from Pediatric Team.
_____ Compare information about payer mix, etc. with own system costs.
_____ Consider effect of DRG's on costs/income.
_____ Obtain institutional commitment to financial support.

Joint Steps:

_____ Explore outside funding sources.

GOAL 5. Develop a structure.

Pedlatric Team Steps:

_____ Develop mechanism for identifying "ready-for transition" patients.

Adult Team Steps:

_____ Develop team structure and meeting strategy.
_____ Develop structure of adult outpatient and inpatient care.
_____ Develop on-call and "coverage~ structure.

Joint Steps:

_____ Decide on an organizational structure and chart it.
_____ Establish a Transition Committee with members from each Team.
_____ Establish plan for observation of Pediatric Team by Adult Team.
_____ Develop plan for regular inter-team meetings.
_____ Develop a plan for the transfer of written records.

GOAL 6. Develop a Successful Partnership

Pediatric Team Steps:

_____ Examine attitudes and feelings of all pediatric caregivers.

Self-Assessment Continued

_____ Secure commitment of pediatric caregivers to transition (including inpatient caregivers.)
_____ Develop awareness of what Adult Team can teach as well as learn.
_____ Develop a training program for Adult Team.

Adult Team Steps:

_____ Examine attitudes and feelings of all adult caregivers.
_____ Secure commitment of Adult Team members to being "gracious" learners in pediatric setting.
_____ Participate in training program with Pediatric Team.

Joint Steps:

_____ Set formal way to know each other's area of expertise.
_____ Set specific meetings to deal with inter-team concerns.
_____ Have key member on each team as inter-team "trouble-shooter."
_____ Utilize consultant or training materials for "team-building" activities.

GOAL 7. Achieve a successful transfer of patients.

Pediatric Team Steps:

_____ Develop a timetable for preparing patients and families.
_____ Develop a program for preparing patients and families for transition.
_____ Secure acceptance of transfer by patients and families.
_____ Provide complete and timely information to Adult Team when patients are transferred.

Adult Team Steps:

_____ Develop a timetable for meeting patients and families.
_____ Develop a system for meeting and assessing transition patients.
_____ Secure acceptance by patients and families.
_____ Provide feedback to pediatric caregivers about transferred patients.
_____ Train inpatient staff and consultation services on special aspects of care of transitioned patients.

Joint Steps:

_____ Share information about successful and unsuccessful patient transfer to improve system.
_____ Develop plans for patients who cannot tolerate transfer.