

Purpose for “the trip”

- ✦ Describe the role[s] of these medical teams in health care transition of youth with genetic and chromosomal conditions.
- ✦ Explore the health care transition practices used by these medical genetics teams.
- ✦ Articulate some of the complex issues experienced by genetics service providers and patients.

Qualitative Methods

- ✦ Underlying premise is that it’s critical to understand how people “define their situation” because the way people define their situation becomes “real” in its consequences.
- ✦ Most forms of qualitative research are designed to create a kind of “thick description” [Marcus, 1997] of a system, practice or situation...thick enough to then articulate sharper, more pointed quantitative questions that can be answered with less ambiguity and more focus.
- ✦ This quantitative data can, in turn, lead to to knew subject area where thick description is again useful.
- ✦ This “iterative” design is central to what has become known as Mixed Methods Research. [Tashakkori & Teddlie, 2010]

Qualitative Methodology

- ✦ One or two FULL days of semi-structured interviews with a very diverse set of 49 “key informants” from 5 clinics/states.
- ✦ Convenience Sample [responded to request]
- ✦ N = Five Clinics [of eight states]
 - ✦ What is the mission of the clinic?
 - ✦ What is your role in the clinic?
 - ✦ What are the challenges specific to *supporting transitions*
- ✦ Across-case [clinic] theme development of roles, practices and issues

The HEARTLAND CLINICS are places of...

- ✦ GREAT CONCERN AND STRESS BROUGHT BY PATIENTS AND FAMILIES
- ✦ GREAT KNOWLEDGE, COMPASSION & COMMITMENT
- ✦ GREAT HOPE!

Commonalities

- ✦ “Midwestern” is a unique socio-cultural reality that effects the practice of genetics services.
 - ✦ Serves Native-American and Hispanic populations
 - ✦ Patients typically travel great distances to the clinics
 - ✦ Outreach clinics are a part of practice
 - ✦ Limitations of rural and small town environments
 - ✦ Not a “transient population” [yet]. Thus, it is possible, even probable, that you will see many patients over an extended period of years. And their children.

THE “CONTEXT” FOR THE FIELD INCLUDES:

- ✦ The relevance of the field is EXPANDING RAPIDLY!
- ✦ Public recognition of that relevance is also accelerating!
- ✦ Technology specific to the field is developing RAPIDLY!
- ✦ These medical teams recognition of the complexity and the *interrelatedness* of the issues and needs required to address these issues is also emerging. However...

“Context” Continued...

- ✦ The process and the capacity to meet and to collaborate on these *interrelationships* are not yet developed.
- ✦ One key observation we made is that there is no consensus on the definition role of the geneticist or the genetics team relative to transition! Where does the geneticist fit in this process? Where they begin is understood. Where they end and with whom – and how - they connect is wide open...
- ✦ There is a continuum of definitions that range from “medical specific consultant” to life-long participation in the process.
- ✦ This seems to be one of the basic “tensions” inherent to the current practice[s] of transition.

Important “tensions” emerged...

- ✦ As expected, other “tensions” – some healthy and others, less so, exist within and among the systems serving folks with genetic-based issues.
 - ✦ Geneticists/teams recognize the complexity of issues and the need for ongoing [life-long] supports re: family, school, service agencies and other medical practioners. This leads to the need to “connect” those social institutions! But how? And for how long?
 - ✦ And, VERY IMPORTANTLY, who will PAY for that level of care?
 - ✦ This dilemma is growing in magnitude precisely because – as a result of the success in the genetics field - patients live longer and participate more fully in life.

Who Did We Talk To?

- ✦ 49 + Representative:
 - ✦ Geneticists
 - ✦ Genetics Counselors
 - ✦ Nurse Practitioners
 - ✦ Parent/Family Liaisons
 - ✦ Dieticians
 - ✦ Psychologists
 - ✦ Developmental Pediatricians
 - ✦ Others

What are Current Practices?

- ✦ Everyone is doing something
- ✦ Services are comprehensive and multidisciplinary
- ✦ Emphasis on resources, referral, and coordination
- ✦ Variation across sites
- ✦ Influenced by the providers, school, family, or condition
- ✦ Guided by the knowledge, resources, & capacity of clinic

So What is the Problem?

- ✦ Most have an end point; often it is 21



- ✦ Many clinics compensate by providing services beyond 21 and/or offer adult clinics

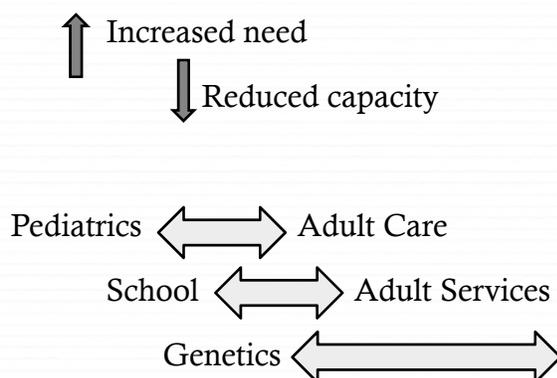
What are the Very Real Challenges?

- ✦ No one person with designated responsibility
- ✦ Billing and reimbursement
- ✦ Constant is not always a constant
- ✦ Lack of adult providers to transition to
- ✦ Complexities of disability service systems
- ✦ Transition is locally driven

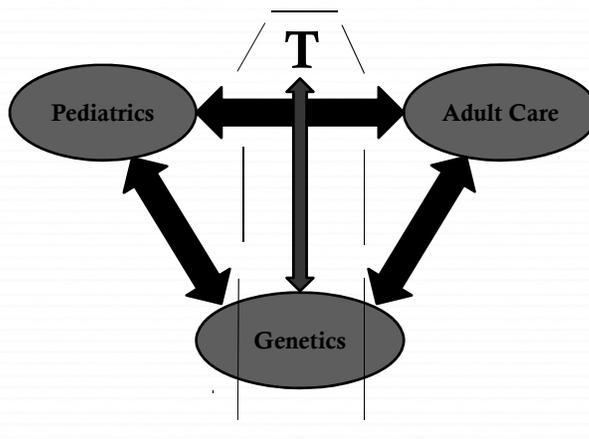
How are They Being Addressed?

- ✦ Team approach
- ✦ Assigning someone to coordinate
- ✦ Sharing information and resources
- ✦ Communicating with primary care providers
- ✦ Providing input to schools
- ✦ Planting seeds
- ✦ Encouraging family expectations and advocacy
- ✦ Promoting independence and self-advocacy

What are Transition Realities?



What is the Role of Genetics?



What are Questions to Consider...

- ✦ What are the specific responsibilities of Genetics?
- ✦ What happens when the quality of pediatric to primary care transition services are less than adequate?
- ✦ What happens when others with primary responsibility for transition fall short in providing services?
- ✦ What should/can Genetics do?
 - ✦ When youth still need transition services
 - ✦ And may not get them anywhere else

What are Some Ideas & Suggestions?

- ✦ Establish clearly defined roles & responsibilities (consultant)
- ✦ Start during diagnostics, take the lead, drive future services
- ✦ Include some time at every meeting for future issues & transition
- ✦ Develop a transition flow chart and protocols
- ✦ Shift pre 21/post 21 practices to pre 14/post 14 or earlier
- ✦ Ask the right questions of families, develop vision early
- ✦ Designate responsibilities for transition (Social Worker)

Ideas & Suggestions (Cont.)

- ✦ Conduct a cost benefit study (quantify value of Genetics)
- ✦ Promote change in billing policies
- ✦ Create a virtual team
- ✦ Design strategies that put youth in the drivers seat
- ✦ Disseminate resources on best practices
- ✦ Determine procedures for expanding clinic reports/communication to include information/recommendations related to transition
- ✦ Continue work groups on topical areas

