

Joint Meeting Sunday, February 29, 2004

Introduction and MCHB updates

Peter van Dyck, MD, MPH, Associate Administrator, MCHB

- Greetings and welcome to all LEND, LEAH, PPC and SPH programs. Hopefully this is the first of many such joint meetings, where we focus on collaboration across MCHB training programs.
- MCHB updates:
 - All Grantees Meeting, October 3, 2004 in Washington, DC. This meeting will provide an opportunity to look at how grantees can work together toward the common mission of MCHB as well as to learn from each other. Ideas and suggestions are welcomed for this unprecedented meeting for MCHB.
 - Bullying: A public awareness campaign will kick off March 1st to recognize, educate, and hopefully help address the problem. www.stopbullyingnow.hrsa.gov was developed by kids, for everyone.
 - Closing the Gap: The Disparities Initiative is an attempt to raise the issue of disparities around low birth weight infants, SIDS, and infant mortality. Additional grants are coming to three African-American communities in each of four states.
 - Hope this gathering is the first of many in the future and wishes for a successful and productive meeting.

The Performance Measures: "Grantgiver"

--A multi-program troupe providing levity and truth in song format!

Transition Discussion

An Overview of Transition

Bob Blum, MD, MPH, PhD. Outgoing Professor & Director, University of Minnesota, Center for Adolescent Health & Development; Professor & Chair, Department of Population & Family Health Sciences, Johns Hopkins Bloomberg School of Public Health

Case example: "Jimmy", a child with spina bifida who completes the same chores as his siblings, though it takes him a much longer time. In doing so, "Jimmy" fulfills the expectations of both himself and his parents.

- There are many things to remember when working with youth with disabilities:
 - There can be a different definition of severity between clinicians, parents, and youth
 - Clinical: disability patterns, the new epidemic of cerebral palsy, continuing autism concerns, etc.
 - Education and Social: low self-image, increased leisure time, arranged friendships, need for social feedback

- Sexual: misinformation, lack of education
- Financial: strain on families
- Wingspread Consensus Conference on Adolescent Transitions contained points from the American Academy of Pediatrics including core elements that need to occur for young people to improve transition outcomes:
 - Medical Home for continuity during transition
 - Developmental needs, especially for people with disabilities, must be a core part of training, curriculum, and licensure exams
 - Current medical summary (computer programs are available that condense summaries)
 - Create an established transition plan and follow it's guidelines
- Remember – this is not a linear process.

Healthy Ready-To-Work Program and Transition

Patti Hackett, MEd. Co-Director & Team Lead, HRTW National Center, Academy for Educational Development

- Health means everything!!!
- CYSHCN – children AND YOUTH with special health care needs
- Performance Measure 6 – Transition to Adulthood
- HRTW Program:
 - Six funded HRTW projects , in different phases of development and focus
 - Virtual center for HRTW – project officers live all over the country
 - Youth are talking, are we listening? What do *they* feel they need?
 - What to do in an emergency, how to get health insurance/SSI/vocational rehab, what could happen with a condition, learning to stay healthy
 - Lessons Learned by HRTW so far
 - Transition planning must start early, be collaborative, coordinated, and youth- and family-centered
 - Self-Determination skills are valuable for self-advocacy and self-esteem

LEND and Transition

Steve Contompasis, MD, Program Director, Vermont Interdisciplinary Leadership Education for Health Professionals

- 35 LEND Programs
- LENDs know and teach that medical homes and transition plans are keys to good transition.
- LEND programs train future practitioners around these and other key transition areas.
- Most LENDs have both didactic and clinical experiences around transition.
- Program highlights:

- UNC-Chapel Hill, UW-Madison HRTW, U-Oregon: partnering with high schools around IEP development, U-Vermont: developing curriculum for medical students on health, wellness, and disabilities through the generations.
- Need for additional training and collaboration around transitions.

LEAH and Transition

Al Hergenroeder, MD, Texas Children's Hospital & Baylor College of Medicine and LEAH

- Seven LEAH programs around the country
- Highlights:
 - Boston HRTW, Rochester: transition workshops, UAB: HIV, LEND & LEAH programs all have transition issues in their curriculum
 - Indiana: transition program for youth with diabetes has been in place for years
 - Baylor & Texas Children's Hospital: Through work with the executive steering committee, hospital administration now realizes the importance (fiscally) of good transition planning
- We're trying...but realize every day that we're just scratching the surface.
- Lessons learned and challenges:
 - Commitment is needed from the medical staff, financial commitment is necessary, it's good to take a long-range view, cultural competency is key, and there are already many good resources out there.

Pediatric Pulmonary Centers and Transition

Mary Marcus, MS, RD, PPC Co-Director, University of Wisconsin

- Pediatric Pulmonary Centers
- 7 PPC programs around the country
- Most of PPC work around transition is with youth with asthma and youth with Cystic Fibrosis
- Different programs take different approaches to transition, i.e. some start planning in pediatrics and some in adolescence, some as a cohort
- CF Family Education Project is available across the country (a pharmaceutical company helped with distribution)
- Moving On handout & the transition survey at Wisconsin
 - Survey results: hospital policies are a big barrier to transition; non-CF and CF non-pulmonary transition aren't as smooth as established CF transition programs; a good transition is a truly collaborative effort.

Schools of Public Health and Transition

Myrtis Sullivan, MD, MPH, Asst. Professor, Community Health Sciences, University of Illinois at Chicago

- U-Illinois-Chicago Transition Program (may be similar to other SPHs)
- Hauser and Dorn Transition Study – 18 Sickle-Cell patients and providers – none had a formalized transition process
- Across SPHs, we all agree something needs to be done, but nothing is formally coordinated yet
- MCHB CATCH grant MeHTA: Medical Homes for Transitioning Adolescents with Asthma:
 - Uses focus groups, advisory board, academic and community collaboration
 - Themes: emotions and the impact on asthma management; the effect of asthma on daily living; info, support and asthma management
 - Results: patients have issues with medical management, comfort with treatment options, and roles in care. Who's responsible for a successful transition? It would be helpful to have some way to practice the transition process.

Questions & Suggestions

- A central repository for all transition resources and information would be helpful to programs and patients/families.
- Disciplines should go to their accrediting bodies to push getting transition content into curriculum.
- Insurance and employment discrimination is always a problem, especially for people with invisible disabilities.
- Current challenge is to have sufficient federal support for transition research, so we can get evidence-based practice or tell what models work best. Without this, the necessity of transition is a tough sell to third-party payers and to others.

Next Steps:

- Keep talking!
- AUCD will send out requests to the network for input on ideas.
- The possibility exists for a training website for all present groups to share information, ideas, and resources, and establish linkages. (Proposed date: June, 2004).
- Planning for the meeting started a great group process; need to keep the group working together.
- If you have ideas on something that can be done across training programs or want to participate in the group, contact your group member
 - LEND: Steve Sulkes (Strong Center, Rochester, NY)
 - LEND: Rita Hohlstein (Waisman Center, Madison, WI)
 - LEAH: Rich Kreipe (Strong Center, Rochester, NY)
 - LEAH: Al Hergenroeder (Baylor University & Texas Children's Hospital)
 - PPC: Mary Marcus (University of Wisconsin)

- SPH: Kris Gupta (University of Illinois at Chicago)
- AUCD: George Jesien, Crystal Clement
- MCHB: Denise Sofka , and a representative from the Division of CSHCN

MCHB Strategic Plan

Laura Kavanagh, MPP, MCHB Training Branch Chief, HRSA

- The Strategic Plan includes goals related to:
 - Ensuring a knowledgeable and skilled workforce
 - Supporting a diverse, culturally competent, family centered workforce
 - Improving practice through interdisciplinary training
 - Developing effective MCH leaders
 - Enhancing training, policy and health outcomes
 - Supporting MCH training
- Creating connections between research and practice is a priority for MCHB. Transition would be an excellent interdisciplinary research topic around which programs can apply for grants.
- If you have comments on the Strategic Plan, please send them to Laura by the end of March.

Measuring Leadership

Virginia Reed, PhD, AUCD Project Consultant, Dartmouth Medical School

- The Leadership Project examines the development, assessment, and measurement of leadership. Knowing specifically what leadership is and the training elements that produce effective leaders will be helpful to all leadership training programs.
- Programs have told us what leadership looks like five years after completion of a training program; what does the potential for leadership look like before a training program? How can future leaders be recognized?
- A draft report was handed out analyzing Training Directors' narrative leadership profiles. Highlights include:
 - There were more identifiers of academic and clinical leadership, fewer suggestions of advocacy or public policy leadership. This seems to be more difficult to measure and programs generally focus on clinical training and research.
 - Most descriptions of leadership match the performance measures.
 - There were many references to collaboration as a leadership activity. We're still determining what that means and what to do with it.
- Next steps:
 - Focus groups have been conducted with LEND, LEAH and PPC faculty, staff and trainees. These results will be analyzed and written up in early April.

- Leadership Meeting in Seattle – there's still room available to register!

Wrap Up and Next Steps

- Hopefully this is the first of many joint meetings. Let's keep the collaboration going!
- Meeting planning workgroup will continue to meet. If you have ideas or suggestions or would like to join in, please contact your program's representative (see Transition: Next Steps above).
- You will be contacted in the coming weeks for ideas on transition projects in which multiple MCHB training programs can participate.
- AUCD will be adding a Meeting section to the current webpage (www.aucd.org) where meeting notes, resources, presentations, photo albums, and more will be posted.
- Discussions will be held with MCHB regarding content for the training programs website that will encourage collaboration.