



Illinois Premature Infant Health Network Second Meeting

October 30, 2007

Carolyn Grisko, President of Carolyn Grisko & Associates Inc., the firm that is helping facilitate the network, opened the meeting with welcome remarks and introductions.

COMMITTEE DISCUSSIONS

Each of the three committees – Continuity of Care, State Policy and Community Education and Outreach – briefly presented two or three ideas as initial steps the network could take in these three areas. Since the network operates on a general-consensus basis, they then opened discussion up to the group for feedback on these ideas. Notes on the discussions are bulleted.

The goal for this meeting was to cement two to three actionable ideas per committee, which each of the committees will further develop in conference calls later this month.

Continuity of Care

Dr. Rupa Nimmagadda, co-chair of the continuity of care committee, outlined a few ideas for consideration. Michelle Esquivel with the Illinois AAP is also co-chairing, but could not attend the meeting.

Dr. Nimmagada introduced the following ideas: 1) a survey of Level 3 NICU follow-up clinics around the state to determine the extent of the variety of services; 2) linking Early Intervention (EI) to families before they are discharged from the NICU, as well as strengthening ties between EI and primary care providers; and 3) developing, with funding, educational podcasts and teleconferences for primary care physicians so that they can better care for premature infants.

- Dr. Vasa said that the Illinois AAP's preemie provider education program will probably not be ready until the third quarter of 2008. In part, the AAP's Committee on Fetus and Newborns is modeling this program off another, similar program with a good track record for screening for peripartum depression.
- Pam Northrup of La Rabida is a member of the Illinois Neonatal Developmental Follow-Up Association. 10-15 active association members meet quarterly, and Pam agreed to help begin outreach to the group for inclusion in network initiatives and goals. The president of the association is Mike Nelson.

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- Participants supported the suggestion of a survey of Level 3 NICUs across the state.
- Dr. deRegnier mentioned that Illinois law requires that Level 3 NICUs have follow-up clinics or programs, but that it doesn't specify or mandate program contents. There was a general consensus that clear guidelines are needed and that this could be a future project for the network, once we have the survey results to glean from.

Policy

This committee is currently in the process of identifying co-chairs. In their absence, Margarite Wypychowski of Carolyn Grisko & Associates presented two main ideas, with Mark Mlynarczyk of MedImmune providing additional detail.

The first idea had first been introduced at the kick-off meeting in May, as network members identified a need for improved tracking and information gathering by the State on premature infant outcomes. Mr. Mlynarczyk presented a recent New York state senate bill as a possible model. The bill requires the state to gather data relevant to premature births, including the circumstances and types of birth, as well as maternal and neonate health factors and conditions.

The second idea centered around issues raised by Illinois Medicaid's new policy on access to care for premature infants.

- Participants were intrigued by New York S. 3493, the premature infant data tracking bill that also established a neonatology advisory council, as well as New York S. 5787 and its proposal to reduce neonatal intensive care admissions via early intervention and care for at-risk pregnant women.
- However, there was a consensus that any similar bills in Illinois need to allocate state funds, rather than just establishing additional unfunded mandates.
- The March of Dimes has a similar program called the NICU Family Support Program, which they have implemented at the University of Chicago's NICU, where one trained NICU professional works with families throughout their NICU stay. They prefer to implement the program at hospitals with limited resources, but these same hospitals often cannot finance the program. Program information and impact data to be emailed to the group.
- When it comes to the issue of the state's new policy, Dr. Vasa indicated that the Fetus and Newborn Committee of Illinois AAP will be sending a formal letter of protest regarding the new policy.
- Amy Zimmerman, representing Health and Disability Advocates, said that her organization is available to represent any families who are denied access to care because of the new policy.
- More information on the new policy was distributed to network members and concerned individuals were encouraged to contact the State Medicaid program.

Community Education and Outreach

Beth Wittbrodt of Pathways Awareness Foundation, Dr. Raye-Ann deRegnier of Northwestern and Children's Memorial Hospitals and Sarah Collins-Leak of the DSCC are spearheading this committee. Ms. Wittbrodt presented two ideas for group consideration: a website with a clearinghouse of information for families, caretakers and health providers of premature infants and a survey of public perception of premature infants.

- While participants liked the website idea, several pointed out that low-income families often have limited access to computers and the internet.
- Dr. Vasa proposed touch-screen information kiosks that could be developed and placed in NICU waiting rooms. Similar kiosks have been used for stroke and other medical problems.
- A few participants asked whether there was data that determined how well used such kiosks are.
- Dr. deRegnier suggested that a website might be more useful for another underserved population, rural families, especially downstate.
- Beth Wittbrodt of Pathways asked the group to consider what might be the most crucial content for a website, which we will discuss at the next meeting.
- A survey of public perception of preemies could be inexpensive and fruitful. Pathways Awareness Foundation and Children's Memorial conducted a survey from 2002-2004 of perceptions of infant and child development. They then expanded the survey nationally the next year, and found that of the parents and caretakers who noticed something developmentally wrong with their children, only 5% acted on that understanding.
- Carol Muhammad of La Rabida mentioned that DHS has an Early Intervention Clearinghouse – a lending library for parents and caretakers. Like the Illinois Neonatal Developmental Follow-Up Association, participants agreed that the network should reach out to the EI Clearinghouse.
- Another suggestion, by Sarah Collins-Leak of the DSCC, was that the network explore hospital and other provider programs that gear toward early gestation education of expectant mothers, especially low-income, first-time or teenage mothers. Little Company of Mary Hospital is building a new women's wing and planning to create such a program in the next few years.

GUEST SPEAKER PRESENTATION

Matt Powers, Health Management Associates

Summary

Mr. Powers concentrated on the financial significance and implications of Medicaid, both nationally and in Illinois. While he spoke mostly from his experience working for the Illinois governor's budget office and as Illinois Medicaid Administrator, he illuminated an interesting fact when he spoke of his current work at Health Management Associates: when one state makes a change in their Medicaid policy (e.g. expanding a waiver), any other state can do the same. Although Medicaid is the largest federal state program, it is not exclusively controlled from the top down.

Presentation

- To put government healthcare spending in perspective, the U.S. spent \$2.5 trillion on healthcare in 2004—that equals 17.2% of the entire economy.
- Illinois spent \$100 billion on healthcare in 2004.
- Defined by members, Medicaid is the largest U.S. health insurance program. In 2007, Medicaid will have 62 million unique recipients, including non-citizens. The only population segment that has historically not been eligible for Medicaid are single, childless adults without disabilities.
- Medicaid is jointly funded by the states and federal government and managed by the states. Illinois' Medicaid funding is 50% state, 50% federal.
- Medicaid accounts for 44% of all federal funds to the states, the largest single component of those funds to states. This results in a strong relationship between a state's finance and Medicaid offices.
- State tax revenue and Medicaid spending can vary widely, depending on the year. For example, in Illinois in 2002, Medicaid spending growth was up 12.4% while state tax revenue growth was -7.8%.
- Fiscal pressures like the above in Illinois in 2002 forced aggressive Medicaid cost containment from 2003-2007.
- The new disease management programs are targeted to the 4% of Medicaid enrollees who equal 48% of the expenditures. Often these are people with multiple chronic, severe conditions, many of whom are now the focus of disease management programs.
- Although in most states mothers and children are in managed care programs, in Illinois less than 10% are under managed care. Most Illinois mothers and children are under fee for service.
- All Kids, which will allow more births to be covered by Medicaid, and Illinois Health Connect, which makes significant changes to the existing Medicaid program by implementing a primary care case management program, were identified as major Medicaid issues for the network.

Members then asked Mr. Powers what they should be doing as advocates for premature infants. Mr. Powers highlighted the importance of arming yourself with as many facts as possible to support your request and to begin developing relationships with policymakers early on in a legislative session. Far too many groups, he said, come to Springfield and hold a lobby day two days before the budget is finalized and expect to be heard. Instead, organizations should start by inviting legislators and policymakers to briefings or events when the legislature is out of session as a first step in cementing relationships for the long haul.

Next Steps

Participants agreed that we would convene meetings or conference calls with each of the three committees before the end of the year to begin moving on the initial committee actions described in this meeting summary.

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Attendance List

October 30, 2007

Dr. Swarupa Nimmagada

Lenny Gibeault Stroger Hospital Perinatal Center

Sharla Luken Division of Specialized Care for Children (DSCC)

Sarah Collins-Leak DSCC

Pam Northrup La Rabida Children's Hospital

Lisa Weber La Rabida Children's Hospital/Consortium for Children with Medically Complex Needs

Carol Muhammad La Rabida Children's Hospital

Dr. Rohitkumar Vasa Mercy Hospital/IL AAP

Dr. Raye-Ann deRegnier Children's Memorial/Northwestern Memorial Hospitals

Beth Wittbrodt Pathways Awareness Foundation

Amy Zimmerman Health and Disability Advocates

Stephanie Erickson Christopher House

Karie O'Connor March of Dimes

Mark Mlynarczyk MedImmune

Mike Osborne MedImmune

Kristen Sabetta MedImmune

Carolyn Grisko Carolyn Grisko and Associates

Margarite Wypychowski Carolyn Grisko and Associates

Diane Eikenberry Carolyn Grisko and Associates

IPIHN COMMITTEES AS OF OCTOBER 30, 2007

Continuity of Care

Co-Chairs

Michelle Esquivel, Illinois AAP
Dr. Rupa Nimmagada

Members

Carol Muhammad, La Rabida
Pam Northrup, La Rabida
Omar LaBlanc, Stroger Hospital
Dr. Rohitkumar Vasa, Illinois AAP, Mercy Hospital
Sarah Collins-Leak, DSCC
Dr. Barbara Johnston

State Policy

Co-Chairs TBD

Members

Amy Zimmerman, Health and Disability Advocates
Mark Mlynarczyk, MedImmune
Sharla Luken, DSCC
Lisa Dye, March of Dimes
Dr. Rupa Nimmagada
Pam Northrup, La Rabida

Community Education and Outreach

Co-Chairs

Beth Wittbrodt, Pathways Awareness Foundation
Sarah Collins-Leak, DSCC
Dr. Raye-Ann deRegnier, Northwestern and Children's Memorial Hospitals

Members

Karie O'Connor, March of Dimes

