Welcome and Introductions


Absent: Molly Kitchell, Kimberly Minniear

No longer members: Phyllis Kikendall, Senator Connie Lawson

Acting Chair Susie Lightle called the meeting to order at 10:15 am.

Our newest member, James Elicker, was welcomed.

Approval of January 18, 2012 Minutes

The ICC approved and adopted the January 18, 2012 minutes with no changes.

Council Subcommittees Meeting & Reports

There were no formal reports from the three subcommittees. The council decided not to hold subcommittee meetings today in lieu of a working meeting scheduled for the next ICC meeting.

New Business for the ICC

• Discussion of ICC Member Roles and Responsibilities

Dawn opened a discussion concerning what the membership sees as their roles on the ICC and how active they want to be. Currently, the ICC carries out what is federally required of all state interagency coordinating councils (to advise and assist the lead agency). Dawn wanted to determine if the ICC was interested in maintaining that role or if there was interest in taking roles that are more active, and to determine if members felt that their experience serving on the ICC was worthwhile—that members are spending time wisely and feel that they are making contributions to First Steps. Dawn also wanted to note that there is support available to assist with committee meetings outside of the ICC meeting times. Michael Conn-Powers and resources through First Steps’ contract with Indiana University are available to support meetings.

Dawn identified two priorities that may serve to guide the efforts of the ICC:

1. continue to address the financial needs of the program, and
2. Insure high quality services within current fiscal constraints.

Ideas/questions generated by the ICC included:
• Changes in the quality of services with the recent move to organizing individual providers under agencies (increased consistency and accountability were noted, but data concerning quality of services is missing);
• Problems that the SPOEs are experiencing, and collecting accurate/reliable data concerning these problems;
• Working with Early Head Start, Children with Special Health Care Needs, and other programs with similar mandates and possible funding sources;
• Partnering with child care programs to offer community screening opportunities through Child Find (it was noted that the local child care resource and referral agencies did provide training on “Ages and Stages” and could provide some level of support concerning screening within child care programs); and
• Opportunity to provide guidance concerning the data collected through the state’s integrated case management system under development.

Member discussion noted the need for a concrete work plan that could provide greater direction and specificity to the membership.

In summary, Dawn noted that there appears to be a common desire to do more than “advise and assist” through additional staff support. She also noted that there is a need for a more concrete work plan with detailed steps. She proposed that the ICC use the next scheduled ICC meeting as a working meeting to develop such an action plan. Once the ICC has developed this action plan, the ICC can invite additional partners to assist in carrying out the action plan.

• Discussion concerning ICC member shortages

Presently the ICC is missing members representing the following state entities: Mental Health, Department of Education, and the state legislature.

• Draft Family Participation Agreement

Dawn shared a draft “family agreement” concerning family participation/cost participation that was being developed by one of the SPOEs. She asked the ICC to share their thoughts and comments concerning the proposed agreement. Council members noted that some provider agencies and SPOEs have similar documents outlining expectations they have for families (e.g., children are dressed, fed, and ready for therapy prior to the arrival of the First Steps provider).

There was a question concerning family involvement/expectations for children who are enrolled full time in child care. While acknowledging that this is a challenging situation, Dawn pointed out that monthly contact/communication is still required.

Dawn stated that First Steps would send an email to all SPOEs and service agencies concerning the draft family participation agreement.

• Discussion of the role of child care providers during First Steps services
During the discussion concerning family expectations, council members noted that child care providers should be present when First Steps therapists are providing services; and child care programs should receive copies of the IFSP/treatment plan to insure everyone is on the same page. It was stated that there is no clear communication to child care providers concerning their roles and the expectation other than to hope that they are present and involved. If child care providers do not see participation with First Steps as part of their job, then a discussion with the family in terms of finding a suitable child care provider may be warranted. Melanie noted that there might be a need for an online module for child care providers that explains how they can work with First Steps providers. Melanie noted that if there was such a module, she could make it a part of their required training and Paths to Quality effort. Jamie noted that there is a presentation at the upcoming ITSI conference concerning how to work with First Steps. The ITSI conference might be good because of the high turnout of First Steps providers. Ann Ruhmkorf noted that she is also involved with developing online trainings and could work with Melanie/Bureau of Child Care to look at joint work on an online training module.

Part C Coordinator’s Report

Dawn reported that Financials are a still the top priority of First Steps—to balance the budget. A year ago, First Steps started the year with a $17 million deficit. Current, First Steps has $5 million deficit. Tackling the deficit has been challenging given the large percentage of families who are eligible for free services and accessing both Medicaid and health insurance. An additional challenge has been insuring that all families are enrolled in Medicaid and accessing health insurance benefits. First Steps service coordinators may need to step up their efforts and assist families with completing the necessary paperwork to access these resources. Dawn also mentioned that working with Children with Special Health Care Needs as a “payer of last resort” could help as an interim solution. She also reported that there is a continued need to work with insurance companies to pay First Steps (the state) in a timely fashion. Dawn shared her plans for shrinking the $5 million deficit. She hoped the deficit would be closer to $2 million by June, and that First Steps is given another year to shrink that amount.

FSSA is developing the Integrated Case Management web-based data management system to serve as an umbrella case management system. Dawn and staff are working to integrate FS data elements into the new system. They are also looking at all of their reporting needs, noting that this is a good time for ICC members to identify needed reports and include them in the request. This is a very large project- initial implementation may begin in July 2013.

Currently FS is down in their child count and Dawn is checking to see if there is a problem or if the system is missing children. She noted that the average family income level was also dropping and is evaluating why. The state monitors the reasons children exit from FS and Dawn noted that it might be time for training SPOEs on completing the exit codes correctly due to some inconsistencies.

Legislation was passed to establish a separate outreach center for the Deaf and Hard of Hearing. Currently the School for the Deaf has some of these functions, but this will change once they identify center. This Center will have major responsibilities, including tracking children from birth to 21 who are deaf/hard of hearing, track progress, track services. The initial legislation is aimed at identifying where this center will be housed and what will be its budget. Future legislation will act on these recommendations. Dawn will be meeting with the
legislated planning group to discuss best practices in First Steps. For First Steps, this is a low incidence disability (less than <1%).

There is a position opening at First Steps and Dawn hopes to have it filled by next meeting

Open Discussion

• Jaimie provided a brief update on the Purdue University Collaborative Research project shared at the last meeting. The project did not get the funding. There was discussion concerning future possibilities and the possibility of an invitation to see what could be done on a smaller scale (e.g., conduct a small scale pilot study). The study included a survey of families concerning what was important to them concerning the treatment approaches carried out. Jaimie will talk with them to see if there is future interest.

• Danny shared a summary of a proposal he has developed to implement a social media approach for engaging families to talk with one another. Social media is a low cost tool we can use to raise awareness about First Steps. It can create social connections between parents, caregivers, and industry professionals. Most importantly, it can facilitate peer-to-peer relationships with parents of children with special needs. Parents whose children have even the most challenging diagnoses should be able to find a parent somewhere that can empathize, give advice, and provide moral support.

Just about 2 weeks ago, Mashable, a social media website with 20 million unique monthly visitors, ran a story about how a social media network helps families with autism issues. My Autism.com started in June of last year and now has 22,000 individual registrants across the USA. Social media works. Parents helping parents works.

Since our last meeting, I continued my research and spoke to a social media expert from IPFW FW. He is the father of two children with autism, a bestselling author, and a home schooler. Based on my research and our conversation, I recommend that First Steps do the following:

• Consult with as many social media experts as is feasible;
• Tally what monetary, technology, and human resources are available for the project; and
• Create a social media strategy based on that data.
This might include two possible strategies depending on the amount of resources dedicated to this effort.

• A low resource strategy might involve:
  o Updating the First Steps web page to be more user friendly
  o Creating a low-maintenance Facebook page and giving control to someone in each cluster.
  o Creating a few low cost videos to post on the web page, FB page, and YouTube.
  o Create a minimal amount of important content for the FB page and updating it regularly.
  o Connecting the web and FB page to existing FB pages of star bloggers, key websites, etc.
• A medium resource strategy might involve everything above, and include putting a single person in charge who "owns" the role of social media pro. That person would be responsible for:
  o Responding to all FB comments, including removing unwanted comments and/or forwarding them on;
  o Adding posts through Twitter, Pin It, and Google+ accounts to net more people.
  o Updating content regularly for all clusters; and
  o Adding videos that would be more professionally done.
This position would be from 8-20 hours per week, assuming videos are produced elsewhere.

Once these things are in place, use the videos and social media to teach parents to engage with their child as much as possible; engage with other parents and seek support, advice, and assistance; and mentor each other. Where social media is not readily available, we can count on word of mouth from people that *do* have it to reach out to them through existing rural support groups and bring technology to them.

Concerning the use of videos, videos are the entry point and can reach virtually all users. They should be shot *well* if not *professionally.* They should feature parents where possible to create peer-to-peer acceptance from users. They should be short, and should invite parents to open up, share, connect, learn, and seek support. They should be targeted to specific groups as well as the general audience. They should all point to the web page and social media.

Becky noted that her survey of LPCC members found that the most requested approach for promoting family participation was the use of social media (Facebook). Danny noted that the proposals look at the use of a website, Facebook, Twitter, and hosting short videos of families sharing information of use to other families.

• Dawn shared that there were two new FSSA staff at DDARS:
  o Shane Spotts is now DDARS Director
  o Greg Jinks is Acting Deputy Director of DDARS

• There was a discussion concerning the biggest challenges that FS faces, other than fiscal. Dawn noted that it was quality of services, including the availability of services. Are new children getting what they need in a timely fashion? For example, children may get services (e.g., developmental therapy), but it may not be the right service (e.g., speech therapy). There may be a need to examine current service delivery models/patterns, particularly in areas where large numbers of children receive several services. Are we working in a more interdisciplinary nature since providers are working under a single agency? What about shortages of services in rural areas- the advent of provider agencies has helped but there is still a large gap. Finally, it was noted that for some provider agencies, many providers worked as independent contractors and were not communication or working collaboratively with other providers. There may be a need for service coordinators to have the tools they need for carrying out their monitoring functions rather than or in addition to their managing paperwork.
• A final discussion topic concerned how do you evaluate the quality of services. First Steps currently measures child and family outcomes, but the feeling is that the measures may not be reliably accurate. Currently, there is very little done that evaluates the quality of services. Better measurement of child and family outcomes could be used as a measure of quality. This could include movement to use the Department of Education’s ISTAR-KR as an ongoing progress monitoring tool.

Next meeting of the ICC was changed from August 8 to August 9.

Please note that the next meeting of the ICC will occur on Thursday, August 9, from 10:00 am to 3:00 pm, at Easter Seals Crossroads. Future meetings of the ICC will be scheduled at the August meeting.

Public Comment

There was no public comment.

Adjourn

Meeting was adjourned at 1:45 pm.