MEMORANDUM FOR: **FICC Subcommitee on Integration and Continuity of Services**

RE: **Agenda for Subcommitee Meeting, July 28-29**

DATE: **July 11, 1994**

Enclosed you will find a preliminary agenda for the upcoming meeting of the FICC Subcommittee on Integration and Continuity of Services. Also included are the minutes from our last meeting on April 28-29 and the minutes from our Interim Meeting on June 16. As you will recall, the subcommitttee agreed to establish the interim meetings as a mechanism for federal subcommittee members to (1) learn more about communities and barriers to service integration, and to (2) identify potential strategies for coordination among federal programs.

At the meeting on July 28-29 we will continue to develop strategies for addressing our agreed upon focus: "reexamination of Federal, state, and local policies and procedures to assist families in negotiating the service system, in order to eliminate delays and unnecessary complexities in identification, assessment, and service delivery". In keeping with the strategy identified at our last meeting, we will focus on developing the criteria for the four community case studies to be solicited from states. The case examples will illustrate examples where service integration is not working, and will be used to provide ongoing guidance to the subcommittee. After we agree what needs to be included, we will work through SICC's to identify the four communites.

On Friday, I'd like to go back to a few issues which have been consistently represented in our discussions, but which have not been fully dealt with, nor put to rest. First is the issue of assessment, an already identified barrier, on which the FICC, through the Interagency Agreement, is supposed to be working. We need to decide how (or whether) we will address this (or any) specific issue. In preparation for this discussion, please review your agency's commitment to the Interagency Agreement to determine if it is still accurate.

Second is the issue of resources for subcommittee activities. We need to give some serious consideration to developing a strategy for generating/borrowing/piggy-backing on existing resources to carry-out/support subcommittee activities.

Finally, don't forget to bring/share information, materials, videos, etc. that may help us learn more about your program and its efforts toward service integration. We'll always leave time for this. See you on the 28th.

Merle McPherson, M.D.
Subcommittee Chair

PRELIMINARY AGENDA
FICC SUBCOMMITTEE ON INTEGRATION/CONTINUTY OF SERVICE

JULY 28-29, 1994

Thursday, July 28, 1994

10:00 - 10:15	* Overview of the Agenda Review and Approve Minutes from April 28-29 Meeting
10:15 - 10:30	* Summary of June 16th Interim Meeting.
10:30 - 12:00	* Develop Criteria/Guidelines for Four Case Examples to Be Solicited from States to Guide Subcommittee

Friday, July 29, 1994

10:00 - 11:00	* Dicussion of the Subcommittee's Role in Addressing the Issue of Assessment as a Barrier to Service Integration
11:00 - 11:30	* Identification of Potential Resources to Support Subcommittee Activities.
11:30 - 12:00	* Information and Materials Related to Service Integration
12:00	* Adjourn

FICC Subcommittee on Integration and Continuity of Services
Minutes

Thursday, April 28, 1994

DRAFT

Attending:
Carol Berman
Kim Boller
Pat Daniels
Duane French
Howard Foard
Ken McGill
William McLaughlin
Merle McPherson
Bonnie Strickland
Deb Ziegler

1. Dr. McPherson called the meeting to order at 10:00 AM. Members introduced themselves and the minutes from the November meeting were reviewed and approved (there was no subcommittee meeting in January due to inclement weather).

2. The proposed Framework for Subcommittee Activity paper was reviewed and approved for distribution to full FICC with the provision that the broader language from the statute would be used throughout the paper to define the population of children with special needs.

3. The results of the survey of subcommittee members was reviewed by Dr. McPherson (attached). The area of Coordination, as described in the Interagency Agreement, was identified by subcommittee members as most important. Discussion followed as to whether the subcommittee wanted to focus only in one area, or to address each of the five areas included in the Interagency Agreeement. Members agreed to have the area of Coordination as a priority with each member agency selecting activities in each of the other four areas areas related to the work of their own agency or entity. Subcommittee members will clarify with their agencies their relationship with the FICC and the Interagency Agreement.

4. The issue of how to bring all subcommittee members to a common understanding of our vision was discussed and options for accomplishing this in an expeditious manner were suggested:
    a. agencies might share what they are doing relative to service integration. This may include bringing in community constituents to provide direction for the subcommittee.

b. the subcommittee might conduct an interagency consensus conference with families and communities to determine what's working and what isn't working relative to the services, etc. addressed in the Interagency Agreement.

Discussion followed on how to move forward relative to these suggestions. Dr. McLaughlin shared a possible mechanism for conducting such a conference through a NIDRR National Center or through an interagency transfer of funds to support such a conference.

Deb Ziegler suggested that the subcommittee already has access to a substantial amount of information from consumers, including the responses from the questionnaire sent out after the Combined Meeting. The Executive Committee needs to review those responses as a step toward identifying the specific issues that the subcommittee needs to address.

The subcommittee agreed that specific examples provided at the family, community, and state level would be helpful in determining how the subcommittee can be helpful. Carol Berman reviewed a study with six communities which has been conducted during the last six years to determine lessons learned, and suggested that perhaps the subcommittee might want to use a similar approach.

5. Howard Foard suggested that we approach our work from a more generic approach, where each agency can find a common ground in the issues facing children, families, and communities. There are some mechanisms already in place by several agencies which could be built upon to address our purpose.

6. Duane French suggested that we as a group (the FICC) should support a combined national policy agenda. He pointed out that while sharing our various initiatives would be a great help in educating ourselves, such an activity will not likely help families and children. We many be creating little pockets of succes but may not be impacting the "system", which is really what we should be doing. We need to avoid "bureaucratizing" this activity to the extent that it makes no difference. We must identify a mechanism by which we can actually accomplish something, perhaps through an entity outside of the federal government that can operationalize real issues and make recommendations for change at the federal level to effect national policy. We need to utilize the resources that we already support such as national centers, UAP's, etc.

7. Ken McGill noted that the Interagency Agreement already has identified things that need to be done that are not already being done. He suggested focusing on these already existing agreeements after some ratification from the participating agencies and customers that these are still legitimate

concerns. Perhaps we could develop policy recommendations based on what is and is not being done in relation to the Interagency Agreement action steps as they are already identified.

8. A general discussion of the Interagency agreement followed in terms of how it was developed, its intent, and whether it was really operational at this point in time. Duane French suggested that since the Agreement focuses on assessment, we should begin to operationalize on that issue. The committee agreed to expand the Interagency Agreement to go beyond child find and assessment to include service delivery.

9. The subcommittee agreed to act on the issues as stated in the Interagency Agreement. Dr. McPherson summarized as follows:

   a. need to identify ways to stay connected to the real world, perhaps by bringing together a group of families, communities.

   b. look at federal statutes to see how they overlap, and/or contradict one another, and use communities and families to help us make recommendations that can effect change.

   c. take the document that is now written and go through each area to select an activity. For the meeting on Friday, each subcommittee member will go through the list of agreed upon actions and prioritize the top 2-3 activities ~~for~~ the subcommittee to address.

The meeting was adjourned at 12:00 noon.

Friday, April 29, 1994

Attending
Carol Berman
Kim Boller
Bobbie Stetner-Eaton
Ken McGill
Bill McLaughlin
Merle McPherson, Chairperson
Bonnie Strickland
Deb Ziegler

Visitors
Wes Brown
Mark Hull
Deb Sosa
Audrey Witzman
Frank Zolla

1. Dr. McPherson called the meeting to order at 10:00 AM. Beatriz Mitchell reviewed the results of the questionnaire which was distributed at the Combined Meeting in January regarding the role of the FICC, and suggested that more community-based responses might provide additional information. Dr. McPherson suggested that, if additional responses were solicited, respondents should be expanded to include health and others. Deb Ziegler indicated a need to refine the questions included on the questionnaire.

2. As planned, subcommittee members reviewed the summary of the Joint Actions outlined in the Interagency agreement to determine the specific focus of subcommitee activity. Discussion focused primarily on the following items from the summary:

   a. provide Federal leadership in the re-examination of policies and procedures which may delay identification and service delivery (A-1 on summary).

   b. Assist families in negotiating the application process (B-2)

   c. Issue policy directives to foster collaboration (A-4a)

   d. Focus special attention on to hard to reach families (A-4b)

   e. Support exemplary models (D-1)

The subcommittee agreed to combine aspects of each of these items with the following focus:

Re-examination of Federal, state, and local policies and procedures to assist families in negotiating the service systems, in order to eliminate delays and unnecessary complexities in identification, assessment and service delivery.

3. Strategies for implementation were considered and agreement reached that subcommittee activity should occur at three levels:

   a. Letter from Judy Heumann to additional agencies and entitities providing services to young children and their families to engage their participation on the subcommittee.

   b. Obtain from states, four case examples from communities where service integration is not working and use these examples to inform and guide the subcommittee.

c. Bi-monthly interim meetings of the subcommittee, with an expanded membership to include representation from a broader and more representative service sector including private providers. The bi-monthly meetings would address such issues as examination and potential coordination of FY 96 priorities; developing common guidances; and identifying joint funding initiatives. Discussion also included the need (through staffing or contract) to identify a mechanism for conducting sophisticated analyses of the regulatory, policy, and legislative changes which would be needed to impact on already identified barriers such as eligibility and funding issues.

4. The subcommittee agreed upon an interim meeting date of June 16, 1994 from 9:00 AM - 12:00 noon. Bobbie Stetner-Eaton will arrange a meeting place. At this meeting the group will (a) examine current Federal efforts that are attempting to address the issue of service integration, and (b) hear an indepth discussion from one or more Federal initiatives. It is expected that each interim meeting of the subcommittee will hear from at least one community-based and/or state initiative.

5. Products and examples of information on service integration were shared by Dr. McPherson with an invitation to all members to share relevant information.

The meeting was adjourned at 12:00 noon.

INTERIM MEETING OF THE FICC SUBCOMMITTEE ON INTEGRATION AND CONTINUITY OF SERVICES

Thursday June 16, 1994

DRAFT

Attending:
Merle McPherson, Chair
Carol Berman
Pat Daniels
Patty Kassold
Ken McGill
Roseanne Rafferty
Bobbie Stettner-Eaton
Bonnie Strickland
Rusty Toler
Barbara Wagner

Presenters:
Suzanne Bronheim
Virginia View

Dr. McPherson reviewed the agenda and shared a new systems document entitled Integrating Education, Health, and Human Services for Children, Youth, and Families: Systems that are Community-Based and School Linked. This document is significant in that it represents the consensus of a multitude of major stakeholders on the principles of systems integration. We will attempt to obtain copies for all subcommittee members.

Dr. McPherson reported on the FICC Reauthorization Hearing which was held on June 15, and shared the testimony given by a local parent, exemplifying the continuing barriers to services for children with special needs and their families.

Agency Activities
Members shared information on a number of linkage activities from their own agencies/entities:

Ken McGill (SSA) briefed the subcommittee on a regional SSI meeting which was co- sponsored by MCH, Medicaid, Part H, and Vocational Rehabilitation. Rusty Toller (SSA) described the Georgia Common Access Application which assists families by consolidating the application requirements of AFDC, WIC, and HUD.

Barbara Wagner (CMHS) reported on a recently formed HHS committee which appears to have a similar purpose as our subcommittee, and suggested that to the extent appropriate, that we communicate with that

Bobbie Stetner-Eaton (OSEP) reviewed the Service Integration Project which is a collaborative effort between the Assistant Secretary for Planning and Evaluation (ASPE) and the Office of Special Education Programs (OSEP). Bobbie will invite this project to present at our next interim meeting on September 1.

Patty Kassold (DOD) shared a 3-site project in which DOD and state Title V programs are collaborating to assure coordinated services for for military families and their children with special health care needs.

Rosanne Rafferty (NIDRR) identified several established interagency initiatives as well as new ones and suggested that we continue to build upon these to create new opportunities for collaboration at the community level.

We agreed that, to the extent possible, this subcommittee should also try to learn about, and coordinate with, service integration efforts of agencies not represented on the FICC.

Community Initiatives

As the subcommittee had previously agreed, the majority of the meeting focused on learning about existing community-based initiatives from which to inform the activities of the subcommittee. The Maternal and Child Health Bureau sponsored the first in a series of these presentations.

1. Suzanne Bronheim shared the Communities Can Initiative which has identified and provided technical assistance to fourteen diverse communities, building upon the strengths of these communities to create responsive systems of community service. Suzanne emphasized that in order to help we must (1) provide specific assistance, such as giving permission for states and communities to create consolidated programs to eliminate barriers that funding streams create, (2) provide support for communities in building generic system of care rather than categorical ones, and (3) help communities build upon what's already there, such as helping to leverage private support within the community. Communities Can is now being expanded to include additional communities. Information was shared on how communities affiliated with FICC constituences could participate.

2. Virginia View shared Promoting Success in Service Integration: A Study of Six Communities, a recently completed six-community initiative to address issues of service integration for children with special health care needs and their families. Among lessons learned, Virginia emphasized that (1) attempts to replicate successful programs by simply replicating the same mix in different setting won't work. Issues and potential solutions are

different in every community and must be addressed differently (2) federal and state programs must establish (with input and vision from communities themselves) a common set of values and outcome expectations for integrated systems, (3) more attention must be focused on the developmental nature of collaboration (4) Federal and state programs need to provide leadership and support for service integration by providing good examples, and (5) data must be generated to support and further characterize well-integrated community systems of care. A final report on this initiative will be available soon.

Joint Initiatives

The subcommitee discussed potential joint initiatives and strategies for collaboration. It was noted that Reauthorization could create an opportunity to mandate greater collaboration at the federal and state level through laying the groundwork for establishing (a) common reporting requirements (b) a single reporting mechanism (c) coordinated assessment procedures, and (d) coordinated eligibility criteria among programs serving young children. This would require that agencies work together to make recommendations for reauthorization of Part H.

Leadership development was suggested as another possible area of joint interest and collaboration. We need to produce leaders who can cross boundaries to facilitate the development of, and sustain integrated community systems. Suzanne described a possible initiative for providing leadership grants for parents.

It was suggested that we look at permanent structures and mechanisms already being supported by Federal programs and expand the scope of these efforts to address issues of common concern.

There was general agreement that input must be solicited from families who are not part of the organized network of services. This representation is critical to determine what doesn't work for families who have difficulty navigating the system.

Three levels of collaboration were suggested as a framework for considering Federal coordination of priorities.

* development of common initiatives which are commonly developed, presented, sponsored, funded, and monitored (ie. some interagency agreements).

* development of collaboratively planned initiatives, in which agencies plan together the broad agenda of needed priorities, but each agency assumes responsibility for different identified priorities based on agency function.

* Sharing priorities and initiatives as they are being developed even if

there is no collaboration. Often agencies are unaware of what others are funding, supporting, or requiring.

Two strategies for systematically obtaining input from communities on federal funding priorities might be (1) asking already identified communities affiliated with our agencies what they would like to see from the FICC, or (2) sponsoring a meeting of families serving on SICC's to make reccomendations on funding priorities for service integration. The feasibility of creating a separate FICC priority drawn from funds voluntarily contributed by member agencies was discussed with agreement to pursue this option.

Rusty Toller (SSA) briefly discussed the Disability Reengineering Report which will have significant impact on how SSA addresses, defines, and assesses disability issues. We will ask that this report be shared at a future meeting of the FICC.

The next interim meeting of the FICC will be on September 1 from 9:00AM - 12:00 noon at the Switzer Building, Room 3065. Don't forget the next regularly scheduled meeting of the FICC on July 28-29.

8-11-94

w/ Toby Smith
Parents networks

Connie Garner: Fed Inter. Coordinating Council (1991 -- IDEA Reauth.)
Kathi Way:
Jeremy Buchman

coordination of early ed.
SSI.
1) Neonatal practitioner
2) spec. ed
3) parent w/ child disabled

5 depts Ag WIC DoD -ministers ED HHS (20 agencies)
age 0-8
7 points
coordination of funding streams
state ICC 5 states - HHS 2/3 1/3 Ed
Part H - IDEA -- reimbursement Medicaid
3rd party payer

discrepancy
Portability a problem (Mass.
demonstrable delay: eligibility I 5 domains or II informed clinical opinion
3 doors of entry
25%/50% disability
"condition w/ high probability of delay"
multiplicity of delay
discretion: III "at risk" of delay CA.
all states track -- (not being used for homeless kids
Coordination of services, funding, eligibility criteria
not objecting
Fed $ as subsidy
• MI, MA, HA environmental risks;

Service Package

4 deliverables at no out-of-pocket
: evaluation + assessment
Q: def of plan
: case management : important if doesn't
(garnering all
services and if there
med necessity
: development of plan
: procedural safeguards

indemnity approach: KW Q payor of last resort
v. Champus
: not private 3rd party payees
can't impact cost to family: can bill family if no placement
↑; life-time limit

all 57 ~~Reps~~ States / + territories

"Garnering resources" Part H --
Medicaid
"Tit V - health services
SSI
Even start
Head S
Early start
child care block grant
no redundancy / efficiency
Beckett waiver
(appropriate resources)
Those eligible for 8 programs
not "enabled" people who
know ~~at~~ how to set things

1/3 4.5 million (6-21)
(moderate & severe)
2 Bil on health therapies
out of State & local — PT
(transportation but OT)
KWi " low ball $2 bil
doesnt include assistive tech.
where you go for PT/ST/OT?
schools? clinics? hmos? public health?

hard jobs of paraprofessionals;
cross-purposes

Kids / Medicaid reimbursement -- discrimination
40% eligible nationally

[long plan] NO → gaps / conflicts of services
eg. reimbursement from Champus
eg. preauthorization
• early -- brain reorganization reorganizat basis
(efficacy of 1st 36 months)

ID -- Child Find -- majority 2/3
but eligible from birth to 21
• Pediatricians not aggressive

SSI -- || • 133% of poverty / 300% Medicaid / higher than SSI 100%
disability Zebley criteria to better moderate to severe (than IDEA)

(will people be responsible)

SSI -- cash benefits

Ed { perceptions out of control
SSI { not just a check; but targeted; what is outcome test?

middle ground

- architectural modifications -
- respite care
- assistive technology - Medicaid waiver pay / community based
- personal assistant

Case management

explanations

money
- reporting endo
- illustrative
- unintended how money spent

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The Arc

Government Report

Published semi-monthly by The Arc, a national organization on mental retardation
National Governmental Affairs Office • (202)785-3388, FAX (202)467-4179, TDD (202)785-3411

Vol. 24 No. 13 July 14, 1994

IN BRIEF.....

- Health care reform remains the central focus in Congress. Major House and Senate committee action is now complete. Leadership in both are now working to develop bills to take to the floor within the next several weeks. The Arc and the CCD continue to work closely with Congress to ensure that the bills that go to the floor include provisions to meet the needs of people with disabilities (p.2).

- The House passed its FY 1995 appropriations bill for the Departments of Labor-Health and Human Services and Education on June 29. The House numbers for many programs, including those that serve people with mental retardation, are below the president's budget request (p.9).

- Housing authorization legislation is moving in Congress. The House Banking, Finance and Urban Affairs Committee reported out its authorization proposal, H.R. 3838, on June 16. The Senate Banking, Housing and Urban Affairs Committee Subcommittee on Housing and Urban Affair reported out its bill, S.2049, on June 21. Both bills contain provisions which will have an impact on people with mental retardation (p.12).

- The Bipartisan Commission on Entitlement and Tax Reform met for the first time on June 13. Chaired by Sen. Bob Kerrey (D-Neb.), the commission's goal is to recommend long-term budget savings for statutory entitlement programs and alternative tax proposals. The commission wants to submit an interim report to President Clinton by Aug. 6 listing what it considers to be viable solutions to hold down federal spending from entitlement programs. The final report is due Dec. 16 (p.13).

- On June 20, the American Association of Retired Persons released the results of a survey indicating that Americans want comprehensive health care reform. The current poll surveyed 1,203 adults age 18 and over, and its results support similar findings in an earlier AARP poll (p.14).

- July 26 marks the fourth anniversary of the Americans with Disabilities Act. On that date, the final provision of ADA becomes enforceable. It covers employment discrimination for businesses which employ between 15 and 25 employees (p.15).