

Family Support Summit Notes and Next Steps
January 9-10, 2006
Lawrence, KS

Purpose of Notes

These notes will serve as a review for attendees and as a vehicle to bring the people who could not attend up to speed on our discussion, issues, and next steps. The notes will include the following sections: Summary of the meeting, next steps, themes of the discussions, and two attachments - participant contact information and the 32 solutions we suggested..

Summary of Meeting

Origins

The meeting grew out of a concern of several of the participants and family support as a concept, policy, and practice was losing focus in the recent years. A small group of concerned colleagues met informally at the Alliance for Full Participation Summit in August 2005. At that meeting, John Agosta suggested we meet again soon to tackle some of the difficult issues around family support. The Arc, HSRI and the Beach Center decided to co-sponsor the meeting and that the Beach Center would host it. Most of the attendees to this meeting paid their travel expenses from agency or other funds. The Beach Center funded family representatives who did not have access to travel funds.

Sessions and Discussions

Monday afternoon

Welcome and introductions. Ann Turnbull asked people to introduce themselves and shared some of the past accomplishments related to families (National Goals Conference) and the Beach Center's current focus and relationships with family organizations. She then reviewed the purpose of the meeting which is to join together in a community of action to work together to move a family support agenda to the forefront, to generate action groups and action steps to move the agenda forward, and to observe and discover how an action group organizes and works toward its aim and the impact that a community of action can have on policy, practice, and family quality of life.

Sharing visions from policy and our past. Rud Turnbull and Sue Swenson facilitated the session. Rud introduced the overarching family goal and its five associated goals that were developed at the National Goals Conference (see handout in packet). There was some large group discussion on each of the goals that included suggestions for rewording should the opportunity arise for revision of these goals. The discussion centered around several themes that will be addressed below and include the issues of definitions of family support, a perception of a disconnect or tension between the ideal and reality (this has so many components to it – does this do it justice?), and the tension present that is a factor of the age of the person with a disability (child or adult).

Terminology and definitions. John Agosta and Kerri Melda lead a review and discussion of terminology. John reviewed some handouts (see packet) of family support definitions since 1983. The main idea from this presentation is that we (the field) doesn't really know what we mean by family support anymore. States and family support

programs are defining family support in many different ways. Major themes related to this session include: age of person with disability contributing to definitions of family support, where should this issue be “housed” or “owned” (e.g. is it a Medicaid issue, a MR/DD issue), what is a support and what is a service, data as useful as they could be because definitions aren’t clear.

Putting context into “whatever it takes” to support families. Cancelled to allow for more discussion.

Medicaid: Current status and future directions. Jean Tuller (see handout of slides and conflict of interest statement) and Bob Day each presented information on financing family support through Medicaid. Bob reviewed some of the basic differences between a medical policy such as Medicaid and a social service policy. A major themes of the discussion is who is in control of the care – family, individual, system, or providers?

State MR/DD funding: Current status and future directions. Cathy Ficker-Terrill and Chas Moseley both did presentations with handouts (see packets). The presentations reported family support data that the group is unsure about because of the various definitions of family support.

Dinner at the Turnbells. Fun for all.

Tuesday morning

Reflections from first day. Participants reflected on what they learned on Monday. Themes included feeling energized by revisiting past successes, murkiness of the situation caused by a lack of definitions, feeling the need to define the issues and context so that the group can focus on action, the changes in funding streams, amounts, and what it pays for, how self-directed funding and family support fit together.

Barriers. Cathy Ficker-Terrill briefly reviewed the barriers we have been talking about and all pretty much agree on (lack of funding, information, definitions, data, leadership, etc).

Large group discussion on solutions and next steps. Cathy Ficker-Terrill facilitated a session in which all the participants wrote down 3 potential solutions and actions. These were all written on poster paper. At the break, everyone voted for the four solutions (or 4 for the same solution) they felt that the group should work on. There were 32 suggested solutions. We voted and took the top five issues (combined into three) for action, but we don’t want to loose site of all the good ideas, so all solutions are listed in attachment B.

Work group session. We broke into three work groups (Consensus statement, data, DD Act and legislative work) to work on identifying specific next steps for each of the three major issues/solutions. Group membership was based on interest and some people moved between groups. The results and next steps of the work groups are laid out in the next section.

Work group reporting session. Each of the groups reported their recommendations. Cathy Ficker-Terrill facilitated the reporting and with some discussion we had work group facilitators and names assigned to significant immediate (next 6 month) steps.

Summary. To summarize who? Asked us to think about what we were going to tell people about this Summit and what we are going to take away from it. Participants

felt that we had regained momentum, there was excitement, and were pleased that we had next steps for action.

Next Steps and Work Groups

Develop process and virtual place for interaction and collaboration. Beach Center staff is looking into ways that technology (internet, websites, list servs, conference calls) can facilitate the work we want to do. Summit participants outside the Beach Center will be asked to collaborate on this very important facet of our work so that whatever system we develop for communicating and collaborating is helpful for the group and our work ahead. The primary point of contact on this issue is Denise Poston. Specific next steps include:

- Set up an immediate system for communicating. All group members receive the list of names and contact information. Please let Denise (denisep@ku.edu) if the contact information is not accurate. If new people are invited in, please forward their contact information to Denise.
- Develop draft web-based “intranet” site that includes the ability to send email to individuals and the group, post documents, and have discussions. Target date 10 February, 2006.
- Have a conference call from 5-8 participants from a variety of perspectives to get their reaction and suggestions for draft site. Target date - 17 Feb 2006.
- Refine site based on suggestions. Target date - 28 Feb 2006.
- “Subscribe” all participants to virtual collaboration system. Target date – 1 March 2006.
- Some members of our groups may need some support to enable them to contribute and communicate to the extent that they prefer. Beach Center staff will talk to several members who expressed this concern and help brain storm and problem solve to address this issue. Target date – 15 February, 2006.

Meet again in six months. Jane Rhys from the KS DD Council will explore forums, potential funding from ADD, and dates so that we can meet again in Kansas in about 6 months.

Work group 1 – Consensus statement. Group members - Rud Turnbull, John Agosta, Nina Zuna, Jean Ann Summers, Kathryn Weit, Pam Epley, Susana Ramirez, Barbara Levitz, Holly Riddle, Margaret Zillinger. Rud Turnbull will facilitate this group. The group will develop a statement of consensus that will be the foundation document for our work as a group. It will help address the issues of definitions, some of the barriers to family support, and provide a basis for some of the work the other work groups are conducting. Rud will do first draft and email it to the Consensus group for comments/feedback.

The statement will start with the following structure:

1. Begin with recitals of fact: 4 categories-these will be our “where as clauses”
 - Economic data
 - Demographic data

- Legislative history
 - Legislative future
2. Use the National Goals to guide us—to tell us the outcomes; these will be our “now therefore clauses”
 - A call to action at the federal/state level and not for profits (RWJ)
 - A call to action for legislative policy to promote the use of the national goals
 3. Statement of explanatory notes - These are used to justify our definitions and other points
 4. Actions to take
 - Focus on DD, but make it available for others to sign on
 - Need to connect with other family groups
 - Need to take a harder stand on the issues
 - Need a strong statement that talks about control
 - Need to put it out and have the guts to stand behind it

Work group 2 – Data group. Group members – Chas Moseley, Cathy Ficker-Terrill, Pam Shipman, Jean Tuller, Frank Stahl, Tamar Heller, Kerri Melda, George Gotto, Connie Zienkewicz **Help on group membership.** Jean Tuller and Chas Moseley will co-facilitate this group. This group addressed the issue of data collection and using available data in a way that is helpful to multiple stakeholders in decision-making. The group identified several specific next steps including:

- Help states use data appropriately by clarifying existing data points and definitions, identifying what data should be collected for what purposes, and drafting a set of suggestions. This would then be presented at the November 2006 meeting of NASDDDS (Jean Tuller, Chas Moseley)
- Contact Mary Catherine Rizzolo and Charlie Lakin about their data collection efforts to get some clarification and present some of the issues that were raised about the data at this meeting.

Work group 3 – DD Act reauthorization and legislative activity. **(Ann, how do you want to identify John Agosta as facilitator? Did you have a chance to call him?)**

Group members – Dee Spinkston, Agnes Johnson, Jane Rhys, Sue Swenson, Patty McGill Smith, Ann Turnbull, Nancy Ward, Denise Poston, Who else was there? This group addressed the issues of participating in the DD Act reauthorization and working with Congress to get appropriations allocated for family support. The group felt it was important to use the consensus statement for a foundation for communicating our message to legislators. The group members agreed that members who were not at the meeting and some participating in other work groups needed to be part of this effort. Specific action steps include:

- Begin a dialog with ADD – John Agosta, Patty McGill Smith, Rud Turnbull, Dee Spinkston, Nancy Ward, Madeline Will, and a few others could serve as the groups “ambassadors” to other agencies and the HELP Committee of the Senate.

- Bring/keep family support to the front at the Governmental Affairs committee meeting in February – Joe Meadours.
- Work on getting appropriations into next budget -Sue Swenson
- Coordinate/liason with SABE on family support issues – Nancy Ward.
- Get family voices heard so that they can be used as material for advocacy – Agnes Johnson and Beach Center

Major Recurring Themes/Issues

Over the course of the sessions and work groups, several cross-cutting themes emerged that will probably continue to guide our work and the context within which we operate. These issues are in no particular order.

- Lack of clarity about what our fundamental issue is, what is our scope, what is reasonable to take on as a field and work group. “Who owns this issue, and what are we trying to own” sums it up. The answers to this question range from “family support is whatever it takes to support families to have a quality of life” to “Medicaid funds being spent on people living in family homes”. The issue of data and definitions contribute to these issues. Do we want to be inclusive and expansive or should we focus so that we could perhaps have a greater impact?
- Tension around the issue of family support for families of children and families of adults – self determination or family determination? There may be some common elements to family support, but there are differences depending on whether the focus is on families of children, families of adults living at home, families of adults living outside the home, and parents who have disabilities. The consensus statement will most certainly clarify this somewhat.
- Current data and data collection is not really useful or meaningful because states are reporting many different things as family support. Group members alternately quote data and advise caution about reading too much into current data. This problem is exacerbated by the lack of an accepted definition of what family support it, and the differences between supports and services. By evolving to “whatever it takes” we sort of lost focus about what family support is and how to hold states and agencies accountable for outcomes.
- There seems to be a disconnect between potentially competing groups in the county around family support. This tension could be characterized as a gap ideas and reality, haves and have nots (in terms of power, money, services), families and practitioners, policy and practice, money spent for services and money spent on families, families of majority culture and families of diverse cultures, individuals and families, MR/DD and other disability groups.
- The family support issue, like many other issues relates to having control of one’s destiny and life, including the services and supports needed to effect that life.
- The issue of accessing quality services included sub issues such as effectiveness, knowing about services, and having integrated services.
- Culturally competent supports and services was mentioned explicitly just a few times, although it could be that this was a theme that ran through every issue. This includes issue of having families define what is family support for them within their cultural context, providing information in languages and formats that are accessible and helpful, and bringing diverse family voices to the forefront.

Appendix A – Participant Contact Information
Appendix B – List of 32 Solutions

32 Potential Issues or Solutions

1. Craft a statement of consensus 23 X's
Clarify authority of families and adults who are self-directing
Goals whereas statements support call for family control
Roadmap Federal and States
2. "Just do it"—semi-annual meeting to keep on target 8 X's
3. Identify data points for collection/grants collect survey data 9 X's
 - Go to ADD → clean up data
 - Segmentation
4. NASDDDA → Annual meeting on family support 13 X's
 - Help state directors to restructure
5. Talk to families—get input for statement of consensus 1 X
 - Find nontraditional ways to reach families
6. Create message of hope for families
7. Regular meetings for families across the nation 12 step Alanon model 3 X's
8. Use state teams from Alliance for full participation
9. Target→ process Reauthorization DD Act
 - Attaché consensus statement 16X's
10. Alliance with Aging issues and strategies
 - National Caregiver Alliance
11. Find a way to provide information to younger families using simple language 4X's
 - Better access for families→family networks
12. Clarify family expectations
 - define what a family can "realistically" expect from the government
13. Educate policy makers: Empowered families→empowered children 1 X
 - Priority of family support
14. Focus on next generation advocacy leaders to focus on family support 2 X's
15. State grass roots advocacy 2 X's
16. Strategies to convene families to receive various input from grass roots 7 X's
 - Ask local experts→families
 - Build support→share new strategies
17. Sell (educate) the current providers on the concept
18. Dialogue with E.I. Community
19. Focus on Title XIX, DD Act, Aging, E.I., Special Ed \$, State General Funds, Community and Faith-based funding, child welfare family #'s to change public policy 5X's
20. Redesign waivers (and special education \$'s) to family control of resources and direction
21. Families understand justice rules on day care and after school care
22. Paradox shift—families getting so little--\$3000.
 - Allow families to direct needed supports
 - matching outcomes with funding
23. Define family support in context of children and adults. 8 X's
 - Recognize cultural diversity

- Craft solutions for resources
 - Blend public and private \$'s and resources within political context and cultural context
24. Find better strategies to disseminate accessible information
 25. Researches—collect family voices so they are heard by policymakers and other families
 26. Create avenue to disseminate information on success on Family Support 4 X's
 27. Bring information back to families to include them in discussions 6 X's
 28. Information for families to access supports and have knowledge for informed choices. 2 X's
 29. Broaden mission: Control Destiny across the lifespan (age 18 and up; family and child)
 - Take 2-3 doable things and come back in six months
 30. Delegation → A.D.D. Pat. M.
 - Funding for policy strategies
 - Support Family Support Movement
 - Family Support 360> Rewrite the act
 31. Senate Health Committee → Rewrite DD Act Reauthorization 1 X
 32. Keep focus on Family Support only