

**RESEARCH UTILIZATION SUPPORT AND HELP PROJECT**  
**INVESTIGATING COMMUNITIES OF PRACTICE**  
**RRTC ON POLICIES AFFECTING FAMILIES AND CHILDREN WITH**  
**DISABILITIES**

**Progress Report**  
**September 1, 2007 through December 31, 2007**

Because of the one-month delay in issuance of our awards statement (issue date, February 1, 2007), this report covers our activities through the first 10 months of operation of this project, “Investigating Communities of Practice.” The overall goals of the project include the following, all in relationship to the topic of enhancing family supports in early childhood programs:

- A. To synthesize and organize the best available research in order to increase the likelihood that evidence-based practices will be used by practitioners, families, and university teachers.
- B. To identify research gaps in order to influence future research agenda to focus on priority topics.
- C. To demonstrate the utilization of wisdom-based action through the compilation of success stories illustrating the use of evidence-based practices as a way to contextualize the research and increase the likelihood of its implementation.
- D. To create a web-supported environment characterized by user-friendliness, connectivity, state-of-art disability core concepts, and relevant information that will be meaningful for stakeholder groups—families, practitioners, researchers, and university faculty.

Following a discussion of further progress in launching the site, we will discuss progress on these goals in the context of our timeline for completion of Project Activities. For January 1, these include: (a) implementation activities; (b) collecting and uploading materials (research repository, success stories); (b) conducting panel discussions and town hall meetings on-line; (c) analyses of web traffic data and content analyses of discussion threads; (d) description of research agenda; and (e) conducting interviews with CoP members.

**Implementation Activities**

*Staff and Administrative Actions.* The staff and administration remain unchanged from our September Quarterly Report. Ms. Donna Beauchamp continues as the facilitator for the CoP, with her primary duties being facilitation of discussion and membership recruitment. As a parent of two sons with developmental disabilities, she brings insight, understanding, and encouragement to the members of the CoP. George Gotto serves as

the CoP Administrator. His primary duties include providing technical support to members, monitoring and analyzing web-traffic data, and managing the CoP research. Ann Turnbull and Jean Ann Summers continue to lead the overall efforts of the CoP. Mr. Jon Johnson (supported on our NIDRR Core grant) is responsible for maintaining a uniform and attractive graphic appearance of the site. Another NIDRR Core staff member, Dr. Nina Zuna, and one of our doctoral students, Kathleen Kyzar, are assisting in the tasks of collecting resources for members based on topics that emerge in the discussions.

*Site structure.* In response to comments from our leadership committee, members as a whole, and web-traffic data, we changed the structure of the CoP since our September Quarterly Report. We consolidated the Family Wisdom and Professional Wisdom topic areas, which now appear as “Gathering Wisdom.” The leadership committee and members at large were concerned that this prevented family members and service professionals from engaging one another in conversation. The feeling was that we had not created a site that brought families and service professionals together. Family members in particular were unsure whether they were welcome in the “Professional Wisdom” topic area. Furthermore, web-traffic data suggested that most people, families and professionals, were confining their comments to the “Family Wisdom” topic area.

We also added a new topic area called “Spreading the News,” which serves as a bulletin board where members can announce upcoming events such as local or national conferences, the release of a new book or other media, or personal information such as the birth of a new child or grandchild, a marriage, etc. We at the Beach Center use this area to announce upcoming panel discussions and town hall meetings in addition to any changes to the structure of the community. This area also contains links directly to two other new features discussed below: our video tutorials and CoP blog.

We completed four video tutorials in October 2007 and now have those posted in the CoP. They explain how to navigate the CoP web site, become a member, sign in and sign out, and how to start a discussion and reply to discussions. These tutorials are a great success. The web-traffic data indicate that they have now become one of the most frequently viewed areas of the CoP. We intend to complete additional video tutorials in the New Year that explain what to do if you forgot your password, how to add resources to the CoP, how to access the CoP Blog and wiki projects, and any other instructions requested by the CoP membership.

As we indicated above, the CoP now has a Blog. The purpose of the blog is to highlight issues that are discussed in the CoP as well as disability issues related to family supports that appear in national news outlets. Additionally, it provides another avenue for members and non-members of the CoP to get information and make comments of their own. Thus far the Blog has posts related to IDEA, inclusion, partnerships, tips and facts, and real stories. Matt Stowe, a researcher at the Beach Center, has taken the primary responsibility for managing the blog. However, other members of the Beach Center team have posted to the Blog and we are encouraging members of the CoP to make a blog post. A few members have expressed an interest but none have posted to the blog. To visit the

blog, please follow this link: <http://earlychildhoodcop.blogspot.com/> . Because the software that supports the main pages of the CoP does not have blog capabilities, the CoP blog was created using Google Blogger. As a result the blog pages have a different design and color scheme than the main pages of the CoP.

An exciting addition to the CoP, which has generated quite a bit of activity by a small group of members, is the ability to create wikis. Because the Tomoye Ecco software does not support wiki activities, we use Google Docs. This is not ideal because it requires that members have a username and password separate from those they use in the CoP. The new version of Tomoye Ecco, to be released in March 2008, will have wiki capability, which will make our wikis much more accessible. Despite the challenges to creating wikis, the CoP members have created wiki documents on strategies for improving intervention and reducing intrusion and a fact sheet that lists barriers to school-based interventions and how parents can address those barriers.

To see the CoP and link to our tutorials, wikis and blogs, go to our Beach Center website, [www.beachcenter.org](http://www.beachcenter.org), and click on “Communities of Practice.” Following is a brief description of each of the sections of the CoP:

*Spreading the News:* Building community results from getting connected. This is an area where members share with one another by letting others know how they can become involved with their organizations and posting announcements, flyers, invitations, etc.

*Gathering Wisdom:* To bring family members, practitioners, and researchers together to tell their own stories and discuss topics that affect early childhood family support. This is also the area where we are uploading real stories.

*Translating Research:* One of the major goals of our CoP is to synthesize the best-available research for the benefit of families and practitioners. This is an area where researchers, families, and practitioners can “translate” research results so that they are meaningful to families and practitioners.

*Talking about policy:* The purpose of this section of the CoP is to more clearly identify policy barriers as well as solutions to those barriers.

*Town Hall Meeting:* Our Town Hall Meeting is a place where members can interact directly with our featured person of the month. Each month a different guest will be available to answer questions and facilitate discussion on a specific topic.

*Celebrating:* The purpose of this folder is to provide a place for members to describe their successes and their joys.

*Block Party:* This is a “fun” section, for people to add light-hearted comments and stories and to share bits of themselves.

*History of this CoP:* This section contains documents about the CoP generated prior to the launch of the site, as well as our Code of Conduct for members and other pertinent materials.

*Library:* Many key documents are or will be uploaded in their relevant topic areas (e.g., Best Available Research, Conversations about Policy), but they will be cross-referenced here. Therefore, members will be able to find and download resources without searching through the topics. Or vice versa, while engaging in topic discussions, they may find and download documents.

*Need help:* This section contains guidance and tips on how to navigate the CoP website. This is where the video tutorials are located.

*Member recruitment.* The recruitment activities described in the September Quarterly Report continued through this quarter. We identify and recruit 50 new individuals each week from both national and state organizations including Family Voices, Through the Looking Glass, PACER, and Parent to Parent-USA. As a result 101 people became members since September 1, 2007. The CoP now has a total of 265 members.

Members of our team (Ann Turnbull, George Gotto, and Donna Beauchamp) made presentations about the CoP at national and international meetings such as: Division for Early Childhood meetings in Niagara, Canada in from October 24 to October 27; The Office of Special Education Program (OSEP) national meeting from December 2 to December 5; and the annual meeting of the International Society for Quality-of-Life Studies December 6 through December 9. In addition to disseminating information about the CoP, we dedicated a portion of our presentations to describing how to become a member and inviting people to join. During the OSEP national meeting we had a resource display throughout the conference that provided information about the CoP and invited people to join. Donna Beauchamp stood at the display throughout much of the conference to provide additional information and invite people to the CoP site. This is an activity we will continue at future state and national conferences.

Another recruitment tool has been to write informational articles for magazines and newsletters. For example, articles about the CoP were recently published in *Exceptional Parent* (Vol. 37, Issue 8, Pg. 52); the current issue of *Friday's Child* (click [HERE](#) to see it), the newsletter of Family Voices, Inc.; *inSight* (Fall 2007, [Vol. 1, Issue 3](#), pg. 12) the official publication of The ARC of the United States; and Special Education Connection, the University of Kansas Department of Special Education Newsletter.

We are currently in the process of creating a listserv, which we will use to recruit new members and send updates to current members. At this time we send weekly e-mails to our members, which we call "Words of the Week" and "Did You Know?" Once the listserv is operational we will use it to distribute these two items. George Gotto and Donna Beauchamp are enrolled in a one-day course in January to learn how to manage the listserv.

Lastly, with the help of Jon Johnson, the Education Support Technologist at the Beach Center, we have created several fliers and are in contact with pediatricians' offices and Part C programs, where we hope to display this information. Additionally, this flier will be distributed at all conference presentations.

### Collect and Upload Research Repository

We began uploading research articles and highlights to the CoP Library during the last week of August. At this point we have 40 articles uploaded to the "Research Repository" in the CoP Library. These articles are related to the following topics: Family Quality of Life, Parent to Parent, Person-Centered Planning, Family and Professional Partnerships, Participant Direction of Funding, and Positive Perceptions. Staff from the Beach Center on Disability developed research highlights which provided an overview of each article for practitioners, families, and university teachers. Web-tracking data indicate that members download the articles and highlights. However, the articles are not leading to discussions. Therefore, we are exploring ways to generate conversation based on research. For example, for selected articles, we try to pull out the key point or question, frame a vignette around it or simply state why we think it is important and present it to the CoP. We have also attempted to creatively state the recommendations from the article in a discussion and ask people what they think. Donna Beauchamp, the CoP facilitator, is particularly good at presenting an idea in a way that resonates with members of the CoP.

### Collect and Upload Real Stories

Within the CoP, we changed the name from "Success Stories" to "Real Stories" because not all of the stories discussed successes. Additionally, we moved these from the "Celebrations" section of the CoP to the "Gathering Wisdom" area because we believed that more members would see them in "Gathering Wisdom" and they contribute to the cumulative wisdom of the community. Currently, there are 25 success stories in the CoP. These success stories come from a variety of places. First, eight were developed by a group of graduate students at the University of Kansas enrolled in a seminar taught by Ann Turnbull, the Co-Director of the Beach Center on Disability and a Professor in the Department of Special Education. The students conducted interviews with families and then wrote stories based on the interview transcripts, much as a journalist might do. These stories were then approved by the families before they were posted. All of the information provided in the stories was approved by the families. When requested, names and details were changed to protect the anonymity of the families. Second, Dr. Linda Mitchell, an associate professor in the Department of Curriculum and Instruction at Wichita State University, assigned a similar project for five students who participated in a graduate seminar with her during the Spring 2007 semester. These stories were added to the "Real Stories" repository. Third, the Beach Center worked closely with Dr. Barbara Barnett at the William Allen White School of Journalism & Mass Communications at The University of Kansas. Students in Dr. Barnett's class conducted interviews with 21 "pioneer" families across the United States who were innovative in their approach to finding supports and services for their children with disabilities. Thus far, nine of these

have been edited and uploaded to the CoP. Once the remaining 12 stories are edited, they too will be added to the repository. Fourth, one story highlights an article from the Kansas City Star, which told about a boy with autism who became an Eagle Scout. Finally, and perhaps most exciting for the CoP, two mothers of children with disabilities, posted their own stories chronicling the challenges they experienced and the steps they took to overcome those challenges.

### Panel Discussions and Town Hall Meetings

Initially, we planned to sponsor a total of seven panel discussions on a bi-monthly basis. However, we discovered that it is much more difficult to recruit members to participate in panel discussions than we thought it would be. We found that people are both very busy and reticent to participate in online panel discussions. The reticence seems to be primarily due to the technology. People who normally have no inhibitions about presenting to groups of people need a lot of support and encouragement in order to participate in an online discussion.

Despite this challenge, we sponsored two panel discussions over the last four months. The first panel discussion began on September 10 and lasted until September 14. This panel was comprised of three members of the policy research team at the Beach Center: Rud Turnbull, Co-Founder and Co-Director of the Beach Center and Distinguished Professor in the Department of Special Education at The University of Kansas; Matt Stowe, Research Associate at the Beach Center; and Samara Klein, Research Associate at the Beach Center. The title for this panel discussion was “When Parents and Schools Disagree—What Next?” This panel discussion generated five separate conversations and included eight members of the CoP who were not a part of the expert panel.

The second Panel Discussion began on December 10 and ran through December 14. The title of this panel discussion was “Supports that Improve Family Quality of Life.” The panelists were Carol Kennedy, a mother of children with disabilities, a former teacher, and early intervention provider; George Singer, a researcher interested in effective family supports and a professor who trains teachers of students with severe disabilities; Brandy Ethridge, a researcher interested in the efficacy of family supports for families of children with disabilities; and Susan Yuan, a mother of a child with a disability and a researcher who in recent years has been involved with promoting support for parents with disabilities to raise their children successfully at home. Interest in this topic arose out of a meta-analysis written by two of the panelists (George Singer and Brandy Ethridge) and published in *Mental Retardation and Developmental Disabilities Research Reviews* (2007, vol. 13, pg. 357-369) under the title “Primary and Secondary Effects of Parenting and Stress Management Interventions for Parents of Children with Developmental disabilities: A meta-analysis.” In this article they reported that negative impacts experienced by parents of children with developmental disabilities are neither as common or as severe as once thought. They explain that family resilience, rather than family catastrophe, best characterizes families of children with disabilities. The result of this panel discussion were two, fairly extensive discussions that included a total of 10 CoP members and 22 responses.

The Town Hall Meetings were initially planned to alternate with the Panel Discussions on a bi-monthly basis starting in May 2007. We began the first Town Hall Meeting in June and structured it around the “Person of the Month.” The Person of the Month is an “expert” from one of the four stakeholder groups (family member, professional, researcher, policy leader) who introduces a topic for discussion related to his or her area of expertise. The Person of the Month is available for one month to facilitate discussions on the selected topic. The first Person of the Month was Ann Turnbull, Co-Director of the Beach Center. Dr. Turnbull introduced our best thinking on Wisdom-Based Action in a video presentation. She then facilitated the following discussions: “Burning questions about family wisdom,” “Fostering wisdom-based action,” “Reaction to family wisdom,” “Burning questions around professional wisdom,” and “Reaction to professional wisdom.” In all, these discussion topics led to a total of 21 individual posts made by 19 different members of the CoP.

The second Town Hall Meeting was facilitated by Judy Swett, the Early Childhood Coordinator at PACER Center in Minnesota where she provides individual assistance to parents of young children with disabilities and, when appropriate, attends IFSP/IEP meetings, conciliations, mediations, or other school meetings with parents. Judy is also the mother of two daughters, one of whom was a ten-week premie and has PDD/NOS, ADD and other physical disabilities. Judy facilitated discussions for the month of September focused on six topics that were introduced in an audio presentation. These topics were: her own experiences with early intervention services; the most pressing issues in early childhood today; OSEP’s family outcomes for all early intervention programs; resources needed by EI programs to do the best possible job in supporting families to achieve OSEP’s outcomes; resources are available to families from sources other than EI programs; her grand vision of how the Early Childhood Family Support CoP can be a helpful resource for practitioners and families. This Town Hall Meeting was not as successful as the first and generated very little discussion. We discussed this with three key members of the CoP as well as three members of the Core Leadership Committee (Mary Jane Brotherson, Linda Mitchell, and Carol Kennedy). Each of these people said that they listened to the interview with Judy Swett, but did not realize or see a need to ask any further questions.

As a result of this feedback, we structured our next Town Hall Meeting with Sookyung Shin differently. Sookyung is a mother of two children, her youngest having significant developmental disabilities. She participated in an interview in which she discussed her recent vacation to Southern California with her children. She answered questions about preparations, the flight, accommodations, challenges, and sibling issues. The interview was conducted live, in the Town Hall Meeting area, by George Gotto and Donna Beauchamp. They typed questions and submitted them. Sookyung, who was online at the same time, answered the questions as soon as they appeared to her. The purpose of conducting the interview in this way was to experiment with new ways to generate conversation. This was more successful than the previous Town Hall Meeting in that it generated 29 responses. However, only eight members of the CoP participated in the meeting.

Our next Town Hall Meeting is scheduled for the month of January 2008 and will feature Janice Fialka, the mother of a young man with a developmental disability, the author of several books and articles, and is currently the Special Projects Trainer for Michigan's [Early On ® Training and Technical Assistance](#) (Part C of IDEA). We will conduct the interview with Ms. Fialka just as we did during the previous Town Hall Meeting. However, we will invite people to submit questions to her at a specific date and time. Furthermore, we will give personal invitations to CoP members who we know have interests in the areas of Janice Fialka's expertise.

### Develop Research Agenda from Content Summaries

This is perhaps the most exciting part of the CoP at this time. As we mentioned above, we began incorporating wikis into the CoP. A wiki is software that allows multiple users to create, edit, and link documents easily and simultaneously. They are a part of a larger movement in web-based environments which make use of Web 2.0 technologies. These include social network software, wikis, file sharing, blogs, and vlogs among others. Each of these are platforms that encourage open networks and lend themselves to applications that enable collaboration and communication, and, as O'Reilly, the person who coined the term Web 2.0, explains, they are platforms that "harness collective intelligence."

In our effort to "harness collective *wisdom*" of families, practitioners, researchers, and policy leaders, and include them in the research and dissemination efforts of the CoP, we developed wikis and invited the community to participate in analyzing the content of discussions and using it to create strategy sheets. Once they are complete, we will format these sheets and make them available through the Beach Center web site as well as the CoP.

Our first wiki project was based on a discussion in the CoP titled, "Intervention or Intrusion?" This discussion included 26 comments from nine CoP members. The conversation began with a story in which a mother described her first encounter with early intervention services. The social worker came to her home and the mother spent hours cleaning her house and making sure her children were dressed in their nicest clothes. She wrote, "The professionals may have thought of this as an intervention, but it felt like an intrusion to me. Have you ever felt this way about in-home services for your child?" Other parents, professionals, and researchers went on to address this issue primarily through their own stories or by highlighting specific research related to the topic. Once the conversation ended, George Gotto and Donna Beauchamp converted it into a tip sheet and posted it as a wiki. We then invited the whole community to the wiki to edit and add to the tip sheet. Appendix A contains the wiki document created by the community. It includes four tips or statements, each of which is followed by specific strategies for parents to use. The four tips are:

1. You can be an empowered decision-maker. You can question intervention approaches that you believe are not appropriate or are stressful for your child.

2. You are the ultimate decision-maker about where you prefer to have Early Intervention services delivered – in your home or elsewhere. The possibilities for where services can be delivered are not limited, but they must be a part of *your* reality.
3. Utilizing every day activities as opportunities for therapy can help your child make greater progress and help you not to feel like a “therapist”.
4. The Individual Family Support Plan, IFSP, meeting is a good place to start building a partnership with professionals.

The CoP is currently developing additional wikis related to: 1) comments parents hear from schools and how to reply; 2) questions families want to be asked by educators and other professionals; 3) a fact sheet about services for occupational and physical therapy; 4) how to know and act on your rights as a parent. To view these wiki documents, please follow this [LINK](#) and use the following information to log in:

Email: [ecfscop@gmail.com](mailto:ecfscop@gmail.com)

Password: ECFSCoP!

As we mentioned above, the software (Tomoye ECCO) that supports our CoP does not currently have wiki capability. A new version of Tomoye ECCO, which will be released in March 2008, will have wiki capabilities. In the mean time, we use Google Docs to create the CoP wikis. This is inconvenient in that members have to remember an additional user name and password in order to participate in the wiki projects. Yet, we are encouraged by the fact that two of our current wikis were started by CoP members who are not affiliated with the Beach Center on Disability.

Lastly, we believe that the use of wikis helps us fulfill the mission of giving families and practitioners a voice in the development and dissemination of research. It also helps researchers to learn how to present research in a format that is accessible and useful to families and practitioners.

#### Collect Web Traffic Data

Various parameters concerning the ways in which members access, use, and benefit from the community’s content are automatically measured by the software that supports the CoP. The following information reflects the measurements through December 28. Table 1 displays the basic web traffic data from our quarterly report in September as well as current data. The table demonstrates that the activity on the site has been much more vigorous during the past four months than it was initially. Our membership has grown to 265 members who have posted 765 comments.

Table 1

Totals from June 1, 2007 to December 28, 2007

	<b>August 30</b>	<b>December 28</b>
Number of Page Views	145,809	642,513
Number of Topics	15	19
Number of Discussions Created	61	148
Number of Individual Posts	251	765
Number of Memberships	162	265

Table 2 demonstrates that the CoP has an influence far beyond our membership. We know from other web traffic data that each person who visits the CoP site views an average of 14 pages before leaving the site. Therefore, we can conclude that the information on the site is interesting to our visitors. However, our challenge in the coming months continues to be finding ways to entice more non-member visitors to become members.

Table 2

Page Visits by Members and Non-Members, Last 90 Days

	<b>Page Visits by Members</b>	<b>Page Visits by Non-Members</b>
December 1-28	2,878	107,966
November 2007	3,001	127,143
October 2007	1,892	105,367
September 2007	3,597	124,733
August 2007	3,719	78,887
July 2007	4,267	38,867
June 2007	3,830	28,055
<b>Total</b>	<b>23,184</b>	<b>611,018</b>

Interestingly, while Table 3 demonstrates that the “History of this Community of Practice” and “Block Party” topic areas are visited more often than any other topic areas. Yet, these two areas generate almost no discussion. The area that generates the most discussion, “Gathering Wisdom,” is the fifth most viewed topic area. One area of concern for us is that the “Town Hall Meeting” topic area is the tenth most viewed area. This is where we host the person of the month, which as we noted above is not generating as much conversation as we hoped it would. One simple remedy, which we hope will result in more activity is to move this topic area closer to the top of the front page so that more people see it and visit it. We may also consider changing the title of this topic area to something that creates more interest. We are encouraged to see that people are visiting the “Spreading the News” area where we post information about events and activities relevant to the CoP.

Table 3  
Most Viewed Topic Areas, Last 90 Days

<b>Rank</b>	<b>Topic Area</b>
1	History of this Community of Practice
2	Block Party
3	Spreading the News
4	Talking about Policy
5	Gathering Wisdom
6	Celebrating
7	Translating Research
8	Need Help?
9	Library
10	Town Hall Meeting

#### Conduct Audit/Content Analysis of Discussion Threads

Table 4 shows which topic areas have generated the most discussion thus far. Clearly, gathering wisdom is the topic that is generating the most interest. The most encouraging information is that 19 of the discussion threads in gathering wisdom were initiated by CoP members who are not affiliated with the Beach Center. This indicates that family members are beginning to take charge of the CoP content. This is especially evident when we consider that members are also initiating the wiki projects discussed above. The discussions started by these members related to issues that affected their daily lives. For example, discussions revolved around the accessibility issues, legal rights, defining moments versus refining moments, and messages of hope. The most successful discussion thread thus far asks whether parents know and understand their rights. As we mentioned above, family members and service professionals are not only participating in the discussions but are beginning to participate in the content analysis of these discussions. Their analysis is being transferred to wikis and blogs, where it has the potential to be viewed and used by many more people than would be possible if information were only published in academic journals.

Table 4  
Number of Discussion Threads by Topic Area

<b>Topic Area</b>	<b>Number of Discussions</b>
Gathering Wisdom	52
Library	42
Talking about Policy	15
Block Party	14
Translating Research	7
Town Hall Meeting	7
Spreading the News	7
Celebrating...	3
History of the CoP	1
<b>TOTAL</b>	<b>150</b>

The numbers related to the discussions in the “Library” topic area are deceiving. They don’t reflect actual conversations but rather the number of research articles and highlights that have been posted. As was discussed above, these are not generating much conversation.

As we mentioned in the September Quarterly report, the discussions threads in the “Block Party” topic area are important in that they provide a place for members to get to know each other and interact in an informal, fun way. However, the conversations are not substantive. They deal with topics such as celebrity encounters and fun facts.

Based on the trends we see in these topic areas, we continue to focus on recruiting more professionals, researchers, and policy leaders to start and participate in discussions. One thing we have done is to invite members from these groups to participate in panel discussions. The result has been more professionals, researchers, and policy leaders signing up for memberships and a slight increase in their participation. However, family members continue to be our most active members.

Conduct and Analyze Structured Surveys

We created a structured survey using SNAP Surveys, survey development software used for web-based surveys. The survey consisted of 20 questions asking members to rate the community of practice. There was one additional question, which asked members if they were willing to participate in an in-depth telephone interview. To view the online version of the survey, please follow this [LINK](#). The individual questions are listed in Appendix B.

The survey was sent to 250 people. A total of 28 (11.2%) responded. The majority of the respondents were either family members (11 [39%]) or service professionals (16 [57%]), with the remaining respondents being either researchers (8 [29%]) or policy leaders (1 [3.5%]). These numbers total more than 28 because several of the respondents selected more than one role. Half (14) of the respondents had been members of the CoP for five months or more. Only two of the respondents had been members for one month or less. Table 5 demonstrates how often the respondents visited the CoP, how often they participated in discussions, and how often they downloaded information or materials. As with the web traffic data, these data indicate that people visit the site more often than they participate in discussions.

Table 5  
Visits, Discussions, and Downloads

	More than once a week	Weekly	Bi-weekly	Monthly	Bi-monthly	Less than bi-monthly
	% (#)	% (#)	% (#)	% (#)	% (#)	% (#)
CoP Visits	25 (7)	7 (2)	25 (7)	32 (9)	1	7 (2)
Discussions	18 (5)	1	3	7 (2)		61 (17)
Downloads			4	18 (5)	1	61 (17)

Respondents to the survey answered 15 questions about the quality of the CoP based on a five-point likert scale where one (1) was the most positive response, three (3) was neutral, and five (5) was the most negative response. The response stems varied depending on the questions.

Table 6 displays the percent and number of responses to the four questions related to the ease of navigating the CoP. These questions asked about locating content, starting discussions, responding to discussions, and finding answers to technical questions. The positive news is that the vast majority of the respondents did not find it difficult to navigate the CoP. At the same time, a sizeable number of respondents were neutral about the ease of navigation. In terms of both starting a discussion and getting answers to technical questions, slightly over fifty percent were neutral.

Table 6  
Ease of Navigation

	Locate Content	Start Discussion	Respond/Contribute	Technical Questions
	% (#)	% (#)	% (#)	% (#)
Very Easy	7 (2)	25 (7)	25 (7)	18 (5)
Easy	64 (18)	18 (5)	21 (6)	21 (6)
Neutral	21 (6)	54 (15)	46 (13)	54 (15)
Difficult	7 (2)	4 (1)	7 (2)	
Very Difficult	--	--	--	

It is very important to us that the CoP is useful to its members. In particular, we were interested to know if it helped members to make contacts, make friends, and locate information. We also wanted members to let us know whether the facilitators of the site (George Gotto and Donna Beauchamp) were able to provide the assistance members required. The overall data from these four questions are quite positive. For example, over fifty percent of the survey respondents believed the CoP was useful or very useful when

Table 7  
Utility of the CoP

	Making Contacts	Making Friends	CoP Facilitators	CoP Information
	% (#)	% (#)	% (#)	% (#)
Very Useful	11 (3)	7 (2)	18 (5)	36(10)
Useful	43 (12)	18 (5)	36 (10)	32 (9)
Neutral	39 (11)	68 (19)	36 (10)	25 (7)
Slightly Useful	4 (1)	4 (1)	--	7 (2)
Not at all Useful	4 (1)	4 (1)	4 (1)	--
No Reply	--	--	7 (2)	--

it came to making contacts, getting information, and facilitation. Perhaps the best news is that 68 percent of the respondents found the information from the site to be useful or very useful. As with the ease of navigation questions, we are concerned with the number of “neutral” responses to these four questions.

We also wanted to know what CoP members thought about the overall quality of the CoP. We asked them to rate the quality of discussions, contributions (i.e., articles, videos, research highlights, etc.), and organization. We also asked one question about the overall relevance of the content. We were very pleased with the responses to these four questions. In each case, well over fifty percent of the respondents found the quality of the CoP to be good or very good. In fact, over 80 percent of the respondents rated discussion content, contribution content, and organization as good or very good. In terms of relevance, 78 percent rated the CoP content to be relevant or very relevant.

Table 8  
Overall Quality of the CoP

	Discussions	Contributions	Organization of Content	Relevance of Content*
	% (#)	% (#)	% (#)	% (#)
Very Good	39 (11)	32 (9)	21 (6)	32 (9)
Good	46 (13)	50 (14)	64 (18)	46 (13)
Neutral	14 (4)	18 (5)	11 (3)	7 (2)
Bad	--	--	4 (1)	7 (2)
Very Bad	--	--	--	4 (1)
No Reply	--	--	--	4 (1)

\* Response stem for this question was: Very relevant, Relevant, Neutral, Slightly relevant, Not relevant.

In addition to rating various aspects of CoP, we invited respondents to write comments about the site. Twelve of the respondents chose to write a comment. Three of these individuals identified themselves as family members, four self-identified as practitioners, two as both family members and practitioners, one as a researcher, one as a family member and researcher, and one as a family member, researcher, and policy leader. Appendix C contains the complete transcripts of their written comments.

With only two exceptions, each of the respondents made positive comments about the CoP such as:

*“I really love this and I have encouraged other members of my group to join.”*

*“This is a great resource and help.”*

*“I think the CoP is very important and can only grow in importance. Keep up the good work!”*

*“I think the CoP is off to a tremendous start!”*

*“The CoP is great! I like the variety of info and 'places'....great conversations..you can jump in whenever it feels right and you want to share or get info.”*

*“I am thoroughly impressed with the cite and each time I visit...”*

While there were many positive comments such as those listed above, there were also suggestions and comments that will help us to improve the site. For example, members mentioned that they receive too many announcements. One person wrote, “For me, as a professional, the announcements come too frequently for me to keep up.” This is a complaint that we have heard before and to a certain extent is easily remedied. One reason members receive announcements is that they have a “subscription” to specific topic areas or discussions. When a member has a subscription to a topic or discussion she receives an e-mail each time a new post is made. We do not have control over member’s subscriptions but we can find a better and clearer ways to let members know how to manage their subscriptions. For example, we will create a video tutorial about how to manage subscriptions. Additionally, we will make an announcement in the “Spreading the News” topic area about managing subscriptions and will provide a link to the video tutorial.

Another complaint, primarily from family members, is that the CoP is too academic or scholarly. For example, three of the comments were:

*“I can read some materials and discussion threads, however, and much seem to be by scholarly people and few by ordinary parents like myself. It is a bit intimidating.”*

*“The website is too professional for the everyday person to access. In discussions all opinions need to be heard and not corrected as if a child.”*

*“It seems that most of the participation is from Beach Center staff and I feel nervous about participating. The topics don't seem very relevant to my everyday life.”*

We take these complaints very seriously because we want the site to be useful and relevant to family members. One strategy we developed and just started to implement is to put all discussions about research in the context of a real story or situation. In this way, we hope to make research findings more accessible to family members. Donna Beauchamp, the CoP facilitator, who is a parent and not a researcher, is instrumental to this effort.

Lastly, some members expressed concerns related to navigational issues such as logging in, starting or responding to discussions, and finding information. We constantly look for ways to improve the navigation of the site. Our most recent efforts in this area are discussed above in the section labeled “Implementation Activities.”

## Meeting of Core Leadership Committee and Stakeholder Leaders

We hosted a full-day, CoP meeting on October 24, 2007 during the Division for Early Childhood meeting in Niagara, Canada. This meeting included members of our core leadership committee (Judy Swett, Nancy DiVenere, Mary Jane Brotherson, Linda Mitchell, and Pam Winton) and CoP members from each of the stakeholder groups. This meeting gave us the opportunity to update the members on the CoP activities and solicit suggestions about how to improve the site. Another purpose of the meeting was to brainstorm about the upcoming State-of-Science meeting (March 2008) sponsored by the Beach Center and how the CoP could help set the agenda for that meeting.

George Gotto presented the web-traffic data to the group and gave a general tour of the CoP site, discussing the success and concerns for each area. A number of the meeting participants commented that it was helpful to have George go through the site and explain how it is being used. They also indicated that it did not work to have separate sections on family wisdom and professional wisdom. Based on these comments and those we received in emails and phone calls with members who did not attend this meeting, we combined those topic areas into a new section called "Gathering Wisdom."

During the meeting we also talked about a number of ways that university faculty can incorporate instructional activities related to the CoP in their classes. These activities can be directed toward providing students opportunities to interact with families, practitioners, and researchers; additionally, activities can be developed to help build the CoP with new content. We highlighted Linda Mitchell's class project of having her students use a 3-tiered process of interviewing families and writing stories for the CoP. These have been posted to the site. We are now working together to prepare a description of Linda's assignment to the students, grading rubrics, and final products. We talked about the possibility of having a section on the CoP related to conversations about family input into undergraduate and graduate programs related to the preparation of early intervention personnel. An additional advantage to bringing students to the CoP sites is that they will hopefully continue as members once they leave school and become practitioners in the field.

As was described in the September Quarterly Report, the CoP mission changed to incorporate wisdom-based action as an outcome. To help our efforts in this area, we talked about the possibility of submitting one or more proposals to the University of Chicago for their project on Defining Wisdom that would particularly target the health area. A small group got together later on Thursday evening to talk about how we might best craft a proposal for that competition ([www.wisdomresearch.org](http://www.wisdomresearch.org)). We decided that someone from the Beach Center would contact the Project Officer at the University of Chicago to inquire more into what they are looking for in terms of a focus, whether it would be judicious to have a co-PI from the Parent to Parent network, and their thinking behind the requirement that the PI must be not more than 10 years past their terminal degree. After we did more study of the website description of this project, we decided that a call to the Project Officer is not necessary. The description is explicit in that they are looking for projects that will define wisdom, carry out scholarly research, and be lead

by people with terminal degrees are in the early stages of their career so that the benefit of the project can influence their future work across decades. We believe that it will be very appropriate to have a broad advisory team for the project comprised of parent to parent leaders (Nancy and Kathy), as well as other family leaders and researchers, and George Gotto will serve as the PI.

Based on our meeting we also came up with strategies for improving our face-to-face CoP meetings. First, we will commit to having advanced interaction on the CoP website prior to the meeting with documents posted and with threaded discussions. This will allow more time at our face-to-face meetings for participants to (a) describe their ongoing family support work and (b) critique and improve decisions and next steps. Second, we will consider feasibility of having a meeting separate from DEC so that CoP members will not be pulled off into other activities and unable to participate. Additionally, we hope this will allow CoP members who are not able to come to DEC to participate in other face-to-face meetings. Third, we will ensure that there are times during our meeting for small groups to work on their shared agenda. This is also something we want to begin doing in the on-line CoP so that more members will be involved. Finally, we will encourage people outside of the Beach Center to be facilitators of the “Words of the Week” discussion on the CoP.

## Appendix A:

### **Example of a CoP Wiki Project**

This is an online document that can be edited by anyone. Feel free to do with it as you wish.

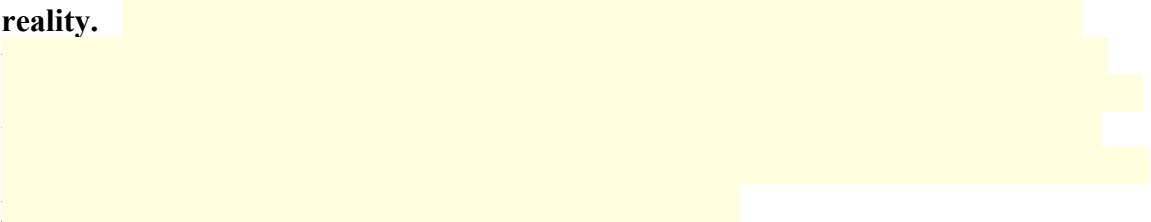
**Strategies from the Early Childhood Family Support CoP**  
**(<http://beachcop.beachcenter.org/CommunityBrowser.aspx?id=393&lang=en-US>)**

### **Intervention or Intrusion?**

**1) You can be an empowered decision-maker. You can question intervention approaches that you believe are not appropriate or are stressful for your child.**

- Early Intervention, EI, services should be focused on engagement, independence, and social interaction with intended outcomes directed by what *you* want for your child.
- Take time to reflect on what and when you believe services are appropriate for your child and your family. One mom shared that she wanted to spend more “precious time” with her young son before introducing “more stress into his little life” through appointments, services and therapies.
- If you receive mixed messages about how EI can benefit your child, for example, if your child’s doctor and the EI director have different ideas, share with both what information is conflicting. Hopefully, they can reach a consensus about what your child needs and a trusting partnership may form from these discussions.
- If your child resists some of the EI activities, crying or becoming frustrated, talk with the therapist about why the activity is important. Ask if there are other options that might prevent your child’s distress and possibly even provide enjoyment while reaching the same goal.

**2) You are the ultimate decision-maker about where you prefer to have Early Intervention services delivered – in your home or elsewhere. The possibilities for where services can be delivered are not limited, but they must be a part of *your* reality.**



- When deciding where to have EI services delivered, it is helpful to “begin with the end in mind”. What is your vision for how your child will live life – included in typical settings or supported in specialized settings?
- Many families want help in knowing how to involve their child with other family members and with the community.
- EI visits can be held anywhere – daycare centers, grocery stores, playgrounds, Dairy Queen, the beach, etc. They can also be held anytime. Consider what is convenient for you, your child and family. You could meet when older siblings are home.
- Natural environments are places where you would find typically developing infants and toddlers spending their time. This could be at home, a childcare center, a park, or a schooled-based EI program. The location where services are delivered depends on where you are comfortable.
- Natural environments can change as children get older and their world expands. Think of places other than home where your child spends time. For example, if you have a paved driveway, but “Aunt Sue” has a gravel driveway, then both spots might be good places for EI visits.
- Ask questions of your team to make sure that you learn all sides of issues – the pros and cons of where services are provided.
- It is perfectly okay to NOT want therapy in your home and for you to tell professionals how important it is for your home to be more of a “sanctuary”. Some parents want their home to be a “safe haven” and to not be associated with therapy. Others welcome therapy being done in the home and believe this leads to greater progress.
- Many families want to get out of the house with their child and to not have therapy at home.
- Being actively involved in community life helps you and your child to be known, have an identity, in the community and not feel isolated.

**3) Utilizing every day activities as opportunities for therapy can help your child make greater progress and help you not to feel like a “therapist”.**

- A routines-based interview with your Early Childhood coordinator can provide good information about bedtime, bathtime, mealtime, etc. This will help in planning interventions.

- Share what pastimes you, your child, and your family enjoy. Include your child's favorite toys, television characters, and activities.

**4) The Individual Family Support Plan, IFSP, meeting is a good place to start building a partnership with professionals.**

- The IFSP meeting is where you can take the lead in letting professionals know what you want for your child - your concerns and priorities.
- Seek to develop trust through positive communication with professionals.
- The more those professionals know your own values and your own ways of communicating, the easier it is for them to match their style to yours so you can understand each other better.
- Feel free to share if there are terms or initials that you do not understand or want to use. For example, if a professional suggests that you “work with” your child and you feel that you don’t want to “work with” but would rather “play with” your child, let them know.

## **Appendix B: CoP Evaluation**

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14. How useful have the CoP facilitators been to you in terms of finding information?

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20. Please share any comments or suggestions you have for the Early Childhood Family Support CoP.

## Appendix C:

### **Written Comments from the CoP Evaluation**

**Family Member:** I really love this and I have encouraged other members of my group to join. I have a list serve for families in Kansas City that are affected by autism and I have encouraged them to join as well.

**Family Member:** It isn't easy to join or to log in to participate. It seems that most of the participation is from Beach Center staff and I feel nervous about participating. The topics don't seem very relevant to my everyday life.

**Family Member:** I have difficulty accessing discussions etc. because I must log in and can't recall my log in info....Wish it would just recognize me (my computer) and let me join in immediately. I can read some materials and discussion threads, however, and much seem to be by scholarly people and few by ordinary parents like myself. It is a bit intimidating. But I do like seeing that if I can get into a discussion my thoughts will be viewed by a variety of professionals. Anyway, the main block to me participating and using the site more lies in logging in and not remembering my log in information.

**Practitioner:** This is a great resource and help. My main comment is that more members would make the CoP that more helpful to everyone. However, I know that efforts are being made to do this, it takes time. Also people are so busy, they are reluctant to join or participate very much. My experience is that the staff is trying to improve the site and make it more helpful to participants. I really appreciate the help and support that I have received here.

**Practitioner:** Just a comment: As a practitioner, receiving multiple e-mails on a daily basis whenever new comments are added is too much. My Inbox has been needing more "weeding" as I just don't have time to stop and read every comment. I'm still interested in staying tuned in to the gist of the discussions but have considered ending my membership because I'm feeling inundated. For those who are conversing, I'm sure the format is very useful; I'm just observing more than commenting. Are there variations in the frequency of how we can receive information? I have passed along pertinent postings when I think they make a point especially well. For example, after a recent discussion with a special education director about her belief that the school is required to tell parents their child is mentally retarded (she very much believes in labeling), I passed along one of the postings about using the "r" word. I think the CoP is very important and can only grow in importance. Keep up the good work!

**Practitioner:** I have not accessed the CoP website often, and when I did, it was to get an idea of the scope and content, rather than to interact. I am interested in how well this is working for family members, for whom it's intended. It seems relevant to family lives and very user friendly. For me, as a professional, the announcements come too frequently for me to keep up. I am interested in topics, but just don't have the time to follow up and participate in the discussions. I am not a blogger, nor do I participate in

other online discussion groups, so it may be that this just isn't my preferred method of communication. Overall, my impression is very positive of the CoP as a resource for families of children with disabilities. I don't know how valuable it is for professionals, except maybe those who have not worked much with families and would like to get to know family interests, needs, and perspectives better. Thanks for the opportunity to provide feedback.

**Practitioner:** I think the CoP is off to a tremendous start! The facilitation is excellent and essential. The front page is helpful to know what kinds of forums are available. The graphics and pictures add interest and are inviting. I did have problems signing on but received very timely help from George to correct the problem. It did keep me from immediate participation however. I notice when I sign on that there are 6 different combinations of my first and last name to choose from, and if I hit the wrong one, I can't sign on. It would help to eliminate the extras. I wanted to participate in the related services discussion but could not find the document posted to respond to (my book is about school-based collaboration with therapists, families and teachers, so I have lots to say!). I emailed Chuck last night though and will follow his directions. I have been able to download other documents, and have found them very helpful. One question- where are the blogs and wikis referred to in the survey? My biggest issue with participating in the CoP is setting aside time due to my schedule and out of town travel. I belong to list serves and receive numerous emails everyday, plus have just finished a book, and often do not have time to sign on and see what's posted. The email alerts are very helpful. I have authored an online tutorial for Maryland's Infant/Toddler Program, and have observed that users go on site to find specific information rather than "take" the tutorial, and that a fast and easy method of finding topics is important to users. One of the issues we struggled with is defining our audience so we could target content. I notice there are some discussions on the CoP that are not robust, and wonder if there are too many threads/topics for the broad array of users you have. It takes time to participate and people may have to select a discussion and focus participation on that one.

**Family Member / Practitioner:** The CoP is great! I like the variety of info and 'places'....great conversations..you can jump in whenever it feels right and you want to share or get info. It's great to have the Block Party, etc areas....as well. Navigating the CoP is a bit tricky for me...I guess I keep looking for an index or table of contents. But I know that eventually I'll have the swing of it. I wish that when we got the emailed posts, we could just respond right there...then we could still go to site, and post, but I'd be able to participate more often, if I could just fire off an email response. I find the exchanges really great, and would very much like to fashion something similar, for parents here. We are already talking about how we might do it. Living on an island, we don't have access to the various speakers and events that you might have, living on the mainland. So we are thinking of how we might do something similar...and host 'speakers' every few weeks, that would be available to address various areas of interests to families. Today's world is so 'fast' and people do so many things at the same time. The CoP is very helpful, as a way of seeing how best to reach out to folks. Once upon a time, meetings and such were great. But many folks just don't have the time to go to meetings. They are interested in doing 'specific projects', and something like this is just what they are looking for!

**Family Member / Practitioner:** The website is too professional for the everyday person to access. In discussions all opinions need to be heard and not corrected as if a child. I do not go onsite too much for this reasoning. I work in a professional environment, I want to hear the real life struggles and solutions not what is in theory or what is politically correct. academia thinks differently than most others who just want a conversation. Overall the site is an excellent idea but needs to think what the mission is. Keep academic discussions in the section they belong to.

**Researcher:** It is particularly useful if you have a concrete dilemma or problem. The CoP is a wonderful way to tap into the wisdom and experiences of many people as well as to research that they may know about.

**Family Member / Researcher:** When I joined, our state was in the final stages of a Families First Conference (held in Las Vegas). I am the Chair for the 2009 conference, but plan to utilize the CoP more often.

**Practitioner / Researcher / Policy Leader:** I regret not being able to log into the site more to contribute to discussion due to my hectic schedule it's not as possible as I'd like to be right now. I am thoroughly impressed with the site and each time I visit, I'm able to utilize current research and see the "family" of family members' contributions, which are helpful to read and understand what is happening in the field!