

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

**Progress Report**  
**May 1, 2007 through August 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 seven 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 evidence-based practice 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 September 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) initial analyses of web traffic data and content analyses of discussion threads; (d) develop research agenda; and (e) conducting qualitative interviews of Leaders and stakeholders.

**Implementation Activities**

*Staff and Administrative Actions.* Ms. Donna Beauchamp joined our staff in May, and brought a welcome boost of energy and creativity to our work. We have organized a Community of Practice (hereafter, “CoP”) Team led by Ann Turnbull and Jean Ann Summers, and coordinated by George Gotto. Donna Beauchamp is responsible for recruiting members and facilitating member participation. George is responsible for the

research portion of the site. Mr. Jon Johnson [supported on our National Institute on Disability and Rehabilitation Research (NIDRR) Core grant] is responsible for picking up where our consultants left off, to design and maintain 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 launch and structure.* As projected in our May Quarterly Report, we launched the site in early June, using the newly designed and customized site design developed for us by Mr. Johnson. The framework follows the organizational structure suggested by the Leadership Committee in our February 2007 meeting, with the addition of a few other topics which we thought would be helpful to the membership. To see the CoP, 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:

*Wisdom-based action:* To facilitate communication across stakeholders, we created one topical folder and placed the three aspects of evidence-based practice within that folder. Thus, the sub-folders are: *Family Wisdom*, *Professional Wisdom*, and *Best Available Research*.

*Conversations about policy:* To bring in policy-makers to the dialogue, we added a topic area on policy. On September 10, 2007 we will sponsor a panel discussion in this topic area.

*Celebrations:* The purpose of this folder is to provide a place for members to describe their successes and their joys. This is also the area where we are uploading success stories. The seven success stories were developed by graduate students at the Beach Center.

*Person of the month:* Here we will feature one person who can provide a range of information about family and early childhood issues, each month. Our first “person of the month” was Ann Turnbull, who presented a video and transcribed interview describing the purposes of our CoP. We have a new “person of the month” lined up for September.

*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.

*Member recruitment and site management.* For our site launch, we announced the CoP to a large distribution list consisting of people who participated in the face-to-face CoP meetings. These included federal agency staff, family leaders, service professionals, and researchers from across the country. We also partnered with Parent to Parent-USA (P2P-USA), who distributed our invitation letter to P2P groups across the country. Additionally, we sent invitations to 296 early intervention service professionals from 16 states. Promotional flyers were created and distributed at the Association for Persons in Supported Employment (APSE) Employment and Down Syndrome Congress conferences. Flyers were also distributed to smaller local groups such as the Center for Child Health & Development at Kansas University (KU) Medical Center, Autism Speaks, and the Autism Alliance of Greater Kansas City support group meetings. Flyers were also attached to “Words of the Week” emails (see Appendix A) to be forwarded to early childhood educators and service providers, parents, and families. We emailed special education directors across Kansas school districts with information and flyers as well as the Kansas Commissioner of Education. Finally, we asked all individuals from our initial mailings to share the invitations with anyone they thought may have an interest in the CoP. We continue to collect lists and plan to send out more invitations to join over the next several months. Our initial recruitment produced responses primarily from parents, which was to be expected since our first two months of operation has been in the summer, when many professionals (especially in education) are not involved. We will renew efforts to recruit professionals now that school is back in session, and expect to see more balance among our stakeholders in our next reporting period.

In addition to recruiting members, we decided that it is important to *maintain* member interest in the site. Therefore, we are producing a “Word of the Week” which is distributed via e-mail to our ever-increasing mailing list, including members and non-members. These are designed to be colorful and provocative e-mails which we hope will cause existing members to check back into the site as well as bring new members. The most recent “Word of the Week” notice is provided in Appendix A.

In addition, we are circulating a regular “Did you Know” e-mail to those who are CoP members, providing tips about the logistics and mechanics of navigating the CoP website. The most recent “Did you Know” notice is shown in Appendix B.

We are having ongoing discussions among ourselves and with our Leadership Committee to problem-solve issues that have arisen. One example is the question of whether participants can enter anonymous comments. Our initial policy has been to not allow anonymous comments because, as a “Community,” the idea of trust-building and the sense of knowing who is on the CoP is important. However, we have had some feedback from people (e.g., state and federal policy makers) who would like to join the discussions

with their personal opinions but do not want their comments to be construed as agency policies. We weighed the pros and cons of changing this policy and decided to allow people to register using only their initials, although we continue to ask for their full name and ask for a short biography from each member.

Finally, we project the development of an animated tutorial to provide visitors to the site with a guided tour of the CoP along with information about how to join and participate. The script for this tutorial is nearly complete. We will then begin recording the videos that guide members through the community.

*Core Leadership Committee Changes:* In our May Quarterly report, we listed members of our Core Leadership Committee. Following the launch of the CoP, we are now re-thinking that Leadership Committee make-up. These individuals continue to be active with us in our face-to-face CoP, and are (for example) actively participating with us in planning our NIDRR State-of-the-Science Conference next spring. However, as busy national leaders, some of them have been unable to be actively involved in the on-site CoP. We therefore are changing the membership of the Leadership Committee to include members who have been active and regular participants. So far, as we noted above, these have primarily been parents. We will plan to add more practitioners, researchers, and policy specialists as we gain participants from these stakeholder groups. Currently, our new Core Leadership Committee consists of:

Nora Behrens, Cerebral Palsy (CP) Parent Network, Nevada (parent)  
Carol Kennedy, Island Parent Association, Martha's Vineyard, Massachusetts (parent)  
Tricia Luker, Respect ABILITY Law Center, Michigan (parent)  
Judy Swett, PACER Center, Minnesota (parent)  
Samara Klein, Beach Center Policy Division, Kansas (policy specialist)  
Nancy DiVinere, National Parent-to-Parent Organization, Vermont (parent)  
Mary Jane Brotherson, Iowa State University (researcher)  
Linda Mitchell, Wichita State University, Kansas (researcher)

#### 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 identified a total of 32 articles related to the following topics: Family Quality of Life (9), Parent to Parent (6), Person-Centered Planning (10), Family and Professional Partnerships (4), Participant Direction of Funding (1), and Positive Perceptions (2). Staff from the Beach Center on Disability developed research highlights which proved an overview of each article for practitioners, families, and university teachers. We intend to finish uploading these 32 articles and highlights by September 15. Thereafter we will continue to collect and upload additional materials.

#### Collect and Upload Success Stories

Currently, there are seven success stories in the “Celebrations” section of the CoP. These success stories 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. 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 are being edited and will then be added to the “Success Stories” repository. Finally, 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. Once these stories have been edited, they will be added to the “Success Stories” repository.

Panel Discussions and Town Hall Meetings

Initially, we planned to sponsor a total of seven panel discussions on a bi-monthly basis starting in April 2007. However, due to the delays discussed in our first quarterly report, and to the time required to customize the Tomoye software and create an attractive web environment, we did not begin work on the panel discussions until August. The updated plan is to sponsor seven week-long panel discussions each month starting in September 2007 and ending in March 2008. (This will result in the same number of panels that we committed to do in our proposal.) The first panel discussion will begin on September 10 and will last until September 14. This panel is 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 is “When Parents and Schools Disagree—What Next?” In this panel discussion, our disability policy experts will answer questions and respond to comments about due process and resolving disputes under the Individuals with Disabilities Education Act (IDEA) and Section 504. Each month we will rotate panel discussions between policy issues, family wisdom, professional wisdom, and research. Thus, the schedule for the panel discussions is as follows:

September 2007	Policy
October 2007	Family Wisdom
November 2007	Professional Wisdom
December 2007	Research
January 2008	Policy
February 2008	Family Wisdom

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 will be 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 Individualized Family Service Plan/Individualized Education Plan (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 preemie and has Pervasive Developmental Disorder/Not Otherwise Specified (PDD/NOS), Attention Deficit Disorder (ADD) and other physical disabilities. Judy will facilitate discussions for the month of September focused on six topics that are introduced in an audio presentation. These topics are: her own experiences with early intervention services; the most pressing issues in early childhood today; the Office of Special Education Programs’ (OSEP’s) family outcomes for all early intervention programs; resources needed by Early Intervention (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.

#### Develop Research Agenda from Content Summaries

Thus far the majority of substantive comments are being made in the “Family Wisdom” topic area (please see Table 5 below). Furthermore, most of the comments being made in other topic areas are coming from parents or siblings. The content analyses we have begun on the discussion threads (see our description of the content analyses, below) are beginning to point the way toward a research agenda based on family needs and interests. In addition, family members have commented in response to our question, “What do you think when you hear the word ‘research’”? Two sample comments from this discussion thread illustrate family preferences about research:

As a parent, I am usually looking for what works “right here – right now” and have little time to spare finding, reading and trying to understand research. I also

don't have a lot of funds to use to pay for journal subscriptions and often didn't know how to find what I was looking for. . . . It also isn't appealing to use my limited respite time to go the library and look for and read research when my husband and I desperately needed a fun night out. (Parent A)

I usually come across pertinent research by inadvertently stumbling over some secondary source. As much as I know I need to be on top of it to feed information (or at least the right questions) to Jack's neurologists, educators, therapists, etc., I really can't even begin to keep up. I don't have the time, access, (or, frankly, the attention span – lol [laugh out loud]) to pour over primary sources. (Parent B)

This theme about research illustrates the critical need for researchers to engage in more effective knowledge translation to produce research information that is usable to parents. We will explore further what this issue means for both the format and content of research that families want to have available.

### 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 August 30. Table 1 demonstrates that there have been a total of 145,809 page views by members and non-members. It also shows that 162 members posted a total of 251 comments.

Table 1  
Totals from June 1, 2007 to August 31, 2007

	<b>Totals</b>
Number of Page Views	145,809
Number of Topics	15
Number of Discussions Created	61
Number of Individual Posts	251
Number of Memberships	162

Table 2 demonstrates that since May 2007 memberships have increased each month. This is largely due to recruitment but may also reflect that members are inviting friends and colleagues to visit the site.

Table 2  
Memberships by Month

<b>Month</b>	<b>Memberships Created</b>
August	99
July	32
June	18
May	13

<b>TOTAL</b>	<b>162</b>
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Table 3 demonstrates that there have been significantly more non-member page visits than member page visits. Our challenge in the coming month is to find ways to entice more non-member visitors to become members.

Table 3  
Page Visits by Members and Non-Members, Last 90 Days

	<b>Page Visits by Members</b>	<b>Page Visits by Non-Members</b>
Aug. 1 to Aug. 31	3,719	78,887
July 1 to July 31	4,267	38,867
June 1 to June 30	3,830	28,055
<b>TOTAL</b>	<b>11,816</b>	<b>145,809</b>

Interestingly, while Table 4 demonstrates that the “History of this Community of Practice” topic is visited more often than any other topic area, we know that most of the conversations are taking place in the “Family Wisdom” and “Block Party” topic areas.

Table 4  
Most Viewed Topic Areas, Last 90 Days

<b>Rank</b>	<b>Topic Area</b>
1	History of this Community of Practice
2	Best Available Research
3	Professional Wisdom
4	Family Wisdom
5	Conversations about Policy
6	Block Party
7	Library
8	Celebrity Encounters
9	Celebrations
10	Need Help?

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

Table 5 shows which topic areas have generated the most discussion thus far. Clearly, family wisdom is the topic that is generating the most interest. The most encouraging information is that half of the 18 discussion threads on family wisdom were initiated by CoP members who are not affiliated with the Beach Center. If we remove the four discussion threads Beach Center staff originally posted to seed the CoP when it was launched, the majority of the remaining 14 discussion threads were started 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. The discussion 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 EI stands for early intervention or early intrusion which leads to family members discussing how they prefer to receive EI services. More specific themes and issues to emerge from our preliminary content analysis include:

- (1) The ways parents prefer to receive early intervention services and how these preferences reflect their values.
- (2) How parents communicate their child’s strengths and needs to professionals.
- (3) Parental awareness of their legal rights and those of their children with disabilities. For example, one discussion thread discusses legal issues associated with admittance into daycare and preschool.
- (4) Strategies for dealing with/accepting their situation and their child’s disability. For example, some parents have mentioned prayer, inspirational literature or videos, hearing about other parents’ challenges and success.

Table 5  
Number of Discussion Threads by Topic Area

<b>Topic Area</b>	<b>Number of Discussions</b>
Family Wisdom	18
Professional Wisdom	9
Best Available Research	6
Conversations about Policy	5
Celebrations	2
Block Party	12
History of this Community of Practice	1
Library	4
Need Help?	4
<b>TOTAL</b>	<b>61</b>

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.

The “Professional Wisdom” topic area contains more substantive conversations but they are mostly generated by Beach Center Staff at this point. However, the longest discussion in this topic area was started by a parent who asked, “is anyone aware of a good resource for families on how to communicate their child's strengths and needs with professionals?”

Professionals, researchers, and other parents responded to this question with relevant information and experiences.

Based on the trends we see in these topic areas, our next steps will focus on recruiting professionals, researchers, and policy leaders to start and participate in discussions. Experience shows that they will be better able to identify discussion topics that will appeal to their peers.

### Conduct and Analyze Structured Surveys

We are scheduled to begin structured surveys in September. The survey questions have been written and you can find an example in Appendix C. We will now begin designing the survey using a software package called SNAP. This is a web-based survey program that automatically downloads information into a database after a person completes a survey. Our sample will include all members of the community of practice.

### Conduct and Analyze Qualitative Interviews of Core Leadership and Stakeholder Leaders

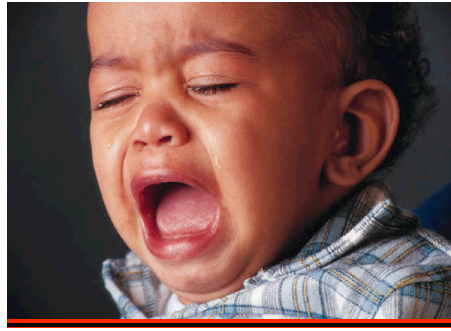
We began contacting Core Leadership Committee members on August 20, 2007 to conduct qualitative interviews about their perceptions of the implementation of the community of practice. As of the August 30, we completed interviews with the following three members: Judy Swett, Mary Jane Brotherson, and Samara Klein. Generally, their comments were very positive.

Judy Swett mentioned that she felt the CoP provided a place for service professionals and families to interact in ways that were not possible prior to the launching of the CoP. Judy also felt that the site was very family friendly and she appreciated the “richness of the conversations and respect for comments being made” on the site. She also indicated that she appreciated ease of using the site, in particular she liked that she could subscribe to specific discussions and automatically receive an e-mail when a new post was submitted. Judy’s main concern was that we need to continue to recruit and get the word out to families and practitioners so that the depth and richness of the conversations will continue.

Mary Jane Brotherson felt that overall the CoP has been a very good for parents, which is exciting for her as a researcher because she envisions that the CoP will be a great incubator for future research topics. As professor who is extremely busy, Mary Jane appreciated the subscribe function because it allowed her to see new comments in her e-mail without having to visit the site and search for new comments. She was very happy that we now allowed people to join but be anonymous if they chose. She thinks this is good and will help researchers and policy leaders who may want to post but don’t want their comments seen as representative of the positions supported by the agencies and organizations that employ them. Mary Jane wished that the site had spell check capabilities for posting comments and encouraged us to find a way to incorporate that.

Samara Klein was excited about the CoP but was concerned about the paucity of discussion threads in the policy section, which is where her interests lie. In order to encourage more participation in this area she sent invitations to her friends and colleagues. Samara encouraged the administrative team to allow anonymous posts so that policy leaders in particular would feel comfortable making comments that stray from the official stance of the organizations they work with. Samara found that navigation in the community was not always as easy as she would like. For example, she pointed out that it was not clear how one could save a comment and return to it later. She suggested making this the topic for a “Did You Know” mailing. She also wished for clearer instructions about how to post comments, files, and photos.

## Appendix A: Words of the Week



### Words of the Week: Does Policy Promote or Prevent Support at Home?

Please enter our Early Childhood Family Support **Community of Practice (CoP)** to read the stories, share your own, or offer information. This week's topic, shown above, comes from a question recently asked by one of our Community members. You can learn about this member's personal experience by reading the story in our CoP. You can also read previous discussions and respond to any by completing our **free** membership profile and selecting *Early Childhood Family Support* as **your** Community

We have customized areas for participation that include Families, Practitioners, Researchers, & Policy leaders. Enter into your area of interest or expertise. Move from one area to another. It's a **Community**.

If you are already a member, Welcome Back! You can continue to comment in any previous topic area, or start your own conversation.

If you are new to our site, we're glad to have you. As a visitor, you can **read** any of the ongoing discussions. However, participating in the conversations is a member privilege. Please join us now!

[www.beachcenter.org](http://www.beachcenter.org)

Click on Communities of Practice

See you there!

## **Appendix B: Did You Know?**

Dear CoP Members:

This week's "Did You Know" installment concerns member profiles, which help strengthen our community because they allow us to get to know one another. In particular, there are three aspects of the member profiles that help us to learn about each other: Roles, About Me, and Picture.

"Role(s)" refers to your role outside of our CoP. You may choose one or more of the following roles: Family Member, Practitioner/Service Professional, Researcher, and Policy Leader.

"About Me" is a place where you can tell other community members something about yourself.

"Picture" refers to a photo or picture of yourself, your children, or an animal or object that reflects something about you. Regardless of what picture you post, anything is better than the default image that displays when you don't post your own.

So, did you know that to modify your profile you do the following?

- 1) Click on this link: [Early Childhood Family Support](#)
- 2) Click "View my Home Page" in the Participate menu on the left side of the screen.
- 3) Click "Modify my Profile" in the Participate menu.
- 4) A profile box will appear and you click "Modify this Account."
- 5) Now you may change, add, or delete anything in your member profile. To add a photo or another image you should:
- 6) In the Picture field, click on Browse.
- 7) Navigate to the appropriate file and select the photo.
- 8) If the image does not require cropping, choose "Do Not Crop."
- 9) If the image does require cropping, choose "Crop"
- 10) In the image cropper, the left image displays the original and the right image displays a preview of the final version. The crop tool is the moveable, colored square that can be enlarged or reduced with the + and - symbols. Click on the crop tool and move it around until the preview version is satisfactory.

11) Click Crop.

12) Finally, click "Submit" and all the changes you made will be saved to your member profile.

If you have any questions about this or suggestions for future installments of "Did You Know" please contact me.

Best wishes,

George Gotto, CoP Administrator

## Appendix C:

### **Investigating Communities of Practice**

Thank you for agreeing to complete this survey. We want to know your opinion about the Early Childhood Family Support Community of Practice (CoP). We will be asking your opinion about ease of access, helpfulness of technical support and also about the value of the content. We also want to know what you have learned from your participation and whether the ideas gained on the CoP have resulted in any changes for you. Please complete the following questions by clicking on the appropriate reply.

**Completion of this survey indicates your willingness to participate in this project and that you are at least age 18.**

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[Note: All structured surveys will be composed in our survey software, and will be developed using a Likert scale report format for respondents. The following is a draft of the items, without inclusion of the response formats. Final copies of the protocols will be available to the Human Subjects Committee-Lawrence (HSCL) upon request.]

#### **Implementation Questions**

1. The purpose of the Early Childhood Family Support CoP is clearly stated.
2. I am able to identify and access the components of the website:
  - a) research repository
  - b) success stories
  - c) town hall meetings
  - d) panel discussions
3. Technical support from the facilitator is:
  - a) responsive
  - b) easy to understand
  - c) prompt
4. Security precautions to protect information on the site:
  - a) are adequate to protect confidential information shared by the members
  - b) allow me to feel comfortable sharing information and participating in discussions
5. I have been connected with answers to queries within 24 hours
6. The CoP facilitator is helpful, relevant, and knowledgeable about connections for resources.
7. The membership joining process is clear and easy to do.
8. When I joined the CoP, I received a welcome e-mail.
9. When I joined the CoP, I used the tutorial to learn how to access the site
10. (if yes) the tutorial was helpful.
11. The search capability of the CoP is useful and helps me to find the information I want.
12. The facilitator was able to link me to information and/or other members in a timely, relevant, and useful way.

## Knowledge Questions

1. I have participated in the postings, applications, and activities associated with:
  - a) research repositories
  - b) success stories
  - c) town hall meetings
  - d) panel discussions

[When respondent clicks “yes” he/she will be taken to a web page with the following questions for each of the 4 types of activities. Following is a prototype of these questions for the success stories.]

- a) The success stories contained information that was new to me.
  - b) The success stories gave me some ideas or strategies I can use.
  - c) The success stories made me feel “connected” to the other members because of similar experiences.
  
2. Following are some terms taken from the knowledge or information shared in the CoP. Please check the statement that best reflects your understanding of the meaning of that term:
  - a) Family support consensus framework
  - b) Evidence-based practice
  - c) Etc. (based on contributions and topics)

**Behavior Changes** – Different versions of this instrument will be developed for family members, professionals, and educators/researchers. Following are examples of questions for family members:

1. Emotional Support: Please indicate the degree to which the following statements describe your experiences in interactions with the CoP:
  - a) I have felt a sense of connection to others with similar situations to mine.
  - b) My participation on the CoP has helped me to cope with stressful situations in my family or job.
  - c) I have learned some strategies to bring us closer as a family.
  
2. Informational Support: Please indicate the degree to which the following statements describe the impact of the information you learned on the CoP:
  - a) I have gained information that has helped me to be more effective with my child.
  - b) I have gained information that has helped me to be more effective in communicating with my child’s service providers.
  - c) I have gained information that has helped me to find more services for my child or family.
  - d) I have gained information that has helped me to understand my rights as a parent.

3. Material Support: Please indicate the degree to which the following statements describe the impact of information you learned on the CoP:
- a) We have been able to get additional or more useful health care services as a result of our participation on the CoP.
  - b) We have received help to complete forms or other applications to get additional supports we are eligible for.
  - c) We have found resources or help to get housing, transportation, or other material needs met.
  - d) We have found resources that helped me or other family members get additional education or job training.

Thank you for your assistance. We will be choosing some of the people who respond to this survey to follow up with more in-depth telephone interviews. Would you be willing to be called?

yes  
 no

