

**EMPOWERING PARENTS OF CHILDREN WITH SPECIAL HEALTH CARE
NEEDS: HARNESSING THE POWER OF THE INTERNET**

Project: 2003 – 2004 Access to Electronic Health Information
University of Washington Subcontract # 669861

Institution:

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Submitted by:

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NARRATIVE DESCRIPTION

1. Summary/Introduction

Empowering Parents of Children with Special Health Care Needs: Harnessing the Power of the Internet is an 18-month project conducted by the Center for Children with Special Needs (Center), a program of Children's Hospital & Regional Medical Center. The Center worked closely with two key partners, the Washington State Fathers Network (WSFN) and the Washington State Parent to Parent Support Program (WSP2P). The purpose of the project was to link key parent leaders with public librarians to train parents of children with special health care needs to advance their skills and abilities in using the Internet to seek health information and resources.

The project utilized a train-the-trainer model to deliver three workshops in specific geographic areas in Washington State identified as being of greatest need. A parent coordinator – public librarian pair attended each workshop. At the conclusion of each workshop, each pair attending the workshop returned to their home community to deliver 2 – 3 realistic activities or events over the next six months. Every pair participating in the project delivered at least one activity in the months following their training.

Project outcomes were shared via the journal: *Health Education & Behavior*. A poster session is planned for the Joint Conference on Health in Wenatchee, WA October 4 – 6, 2004. Training materials developed for the project are posted on the Center's web site – <http://www.cshcn.org>.

2. Geographic region/Number of counties

The project targeted three areas of special need in Washington State. Three train-the-trainer workshops were delivered, impacting the following counties:

- Workshop 1 – Kitsap, Grays Harbor, Mason, Thurston, and Pacific counties
- Workshop 2 – Spokane, Lincoln, Whitman, Garfield, and Asotin counties
- Workshop 3 – Chelan, King, Kittitas, Yakima, Walla Walla, and Columbia counties

3. Collaborations/Partnerships

The Center for Children with Special Needs worked closely with two parent organizations, the Washington State Fathers Network (WSFN) and the Washington State Parent to Parent Support Program (WSP2P). Representatives of these two organizations participated on the project's Advisory Committee. In addition, they reviewed all project materials, shared information about the project with their staff and members, shared information about the project in organization newsletters, and contributed helpful ideas and feedback throughout the project. The Center will continue to work closely with both WSFN and WSP2P.

The Washington State Department of Health (DOH), Children with Special Health Care Needs Program was also a partner with the Center. Included in the handouts for project participants was a bibliography from DOH, *Library Resources for Families with Children with Special Health Care Needs in Washington State*. The handout was of particular interest to the librarians participating in the project. DOH staff members were included on an email distribution list of key stakeholders, receiving each project quarterly report and other feedback and information. The Center maintains a long-standing relationship with DOH, particularly the Children with Special Health Care Needs Program.

The Whitman County Library and the Yakima Valley Regional Library both became strong partners with the project. Contacts were made with library staff encouraging support of the project. The two library systems provided a variety of “in kind” support services including: extra staff time, computer equipment, meeting room space, meeting arrangements, and onsite coordination of the workshop. These relationships continue, and the project has resulted in positive outcomes for each library system. The libraries have gained members (parents of children with special needs) for their advisory committee, have begun to offer a new support group, and have moved closer to meeting the needs of a diverse population by expanding their outreach program.

4. Training

Outreach Activity Data Collection Forms and Outreach Activity Participant Information Sheets were filled out for each of the three workshops within two weeks of workshop delivery. A summary of the data on those reports is as follows:

- Total number of sessions conducted as part of the project: three train-the-trainer workshops
- Total number of sessions in which half or more than half of participants were from minority populations: one workshop included more than half of participants from the Hispanic population
- Total number of participants in the project’s sessions: 31 participants
- Breakdown of participants*:
 - Health care or service provider = 9
 - Health sciences library staff member = 0
 - Public Health Worker = 1
 - Public/other library staff member = 14
 - Member of the general public = 9

*Two participants did check more than one box on the sign in sheet, which noted, “check all that apply.” A number of parent coordinators checked “member of the general public” only, when they are also service providers.

5. Training Sites

Our partners, WSN and WSP2P, identified three specific areas of Washington State as being in greater need of service. These areas included: Grays Harbor County, the Palouse, and Yakima County. Of particular need was a Spanish language or bilingual offering in Yakima County. Focusing on these three areas and projecting how far participants would be willing to travel, the following training sites were selected:

Community Education and Lifelong Learning (CELL) Center, Aberdeen, WA – Large, state-of-the-art technology center in Aberdeen. The CELL Center provided a central location for Grays Harbor, Mason, Pacific, and Thurston County. Those four counties are served by one library system, the Timberland Regional Library. With slightly more travel, it was possible to include Kitsap County. Travel distances and the burden of travel were reduced with carpooling.

Whitman County Library, Colfax, WA – Countywide library system that is a focal point of county activity. Information technology services permitted a multi-station computer lab to be set up in the library's large meeting room. Significant assistance was provided by county library staff, including room set up, ordering of food, and technology issues. Colfax also proved to be a central meeting location for those traveling from out of town.

Yakima Valley Regional Library, Yakima, WA – Large, countywide library system offering a substantial meeting room with a separate, 10-station Gates Computer Lab plus a teaching station. Yakima was a reasonable travel destination for participants. The bilingual program was timely for the library system, which recently expanded its Hispanic outreach activities.

Special emphasis was placed on linking with a public library system and utilizing the facilities available in that library system. Colfax and Yakima offered a special opportunity to create a strong partnership with the public library for present and future activities. Staff from the two library systems provided substantial support to make the workshops scheduled at their facility successful. The Timberland Regional Library did not have a facility in Aberdeen to accommodate the workshop, but the library system provided five library staff members to attend the training, a remarkable commitment of library staff resources. Partnerships with all of the libraries represented at the three workshops continue, and activities will continue beyond the term of the project.

6. Exhibits

No formal exhibits were conducted related to the project. One panel presentation was offered about the project, and one poster presentation related to the project is planned.

Panel Presentation

2004 Gold Rush: The Information Frontier

NCNMLG – MLGSCA – PNC/MLA Joint Meeting

Sacramento, CA
January 28 – 31, 2004
Panel: Outreach: Extending the Frontier
Grant Participant: Margo Harris

Poster Session (copy of poster included in this report)

11th Annual Joint Conference on Health

Wenatchee, WA

October 4 – 6, 2004

Poster Title: “Health Information Access Project: Empowering Parents of Children with Special Health Care Needs”

Grant Participant: Margo Harris

7. Resource materials

A number of items were developed for the project. In addition, a key bibliography was shared with project participants.

- Health Information Access Project Workbook
- *Getting to Know the Internet Guide*
- Library Resources for Families with Children with Special Health Care Needs in Washington State (May, 1999) – Available online - <http://www.doh.wa.gov/cfh/CSHCN/libfinal.pdf>

One item, *Getting to Know the Internet*, is posted to the Center’s web site – <http://www.cshcn.org/resources/living.cfm#internet>.

8. Web sites – N/A

9. Document delivery and references services – N/A

10. Approaches and interventions used:

A detailed timeline for the project was created, identifying the tasks to be completed over the 18-month project period, with approximate completion dates for each task. Tasks were divided among two staff members, the project coordinator and the project assistant. Weekly project staff meetings kept project staff on target.

With three geographic locations identified, project staff began contacting organizations, especially libraries, to identify available training space and facilities. One workshop was intentionally scheduled for late fall and regarded as more of a pilot site or an opportunity to schedule additional time to conduct an effective process evaluation and examine the

training workshop design. The following two workshops were scheduled almost 5 months later to permit redesign of the workshop schedule and workshop materials and to monitor participant success in completing follow-up events. Project staff had low expectations for follow-up activities to be completed during November and December due to holiday schedules.

Because this was a train-the-trainer workshop design with limitations on the number of participants, significant promotion was not necessary. Our two partner organizations identified potential participants, and project staff followed up with invitations. Project staff directly contacted libraries in the geographic areas of interest. It is interesting to note that no library turned down the opportunity to participate in the project in some way.

Training occurred at the three workshop sites, and focused on a “how to teach” approach. The project coordinator and project assistant facilitated each workshop. A bilingual consultant participated in the Yakima workshop. Participants attended in pairs, and pairs switched roles during the workshop to experience the lessons as a student and as a teacher. Participants also had an opportunity to be a teacher for the entire group and introduce a library or parent web site to the group.

The work of the project was completed by the project coordinator and project assistant, sharing all responsibilities. A project consultant was used for one workshop that was delivered in a bilingual format. The same consultant developed the Spanish version of the workshop materials.

Web site development was not a part of this project. Training materials developed for the project are posted on the Center’s web site – <http://www.cshcn.org>.

11. Evaluation

The project was evaluated in a number of ways. Participants critiqued all aspects of the initial workshop from the length of time scheduled, to the computer facilities, to the training approach. The workshop was significantly redesigned after receiving this feedback from the initial training.

A pre- and post-test was conducted for the two-hour skills session of the workshop. Knowledge gains were demonstrated at all three workshops. A written evaluation was completed at the end of the workshop and responses compiled.

Participants have received regular email correspondence inviting additional feedback. A Follow-up Activity Report was completed by many of the participants. In addition to specific information about the activity offered, the form included additional questions to gain feedback about the value of the workshop training in delivering follow-up activities.

Project staff are confident that the project objectives were well met. Based on its use in the 2nd and 3rd workshop, the training curriculum designed for the workshops and posted

to the Center's web site is an effective tool for parents and professionals to utilize when seeking health information on the Internet specific to special health care needs. The curriculum has been shared and complimented by other organizations serving a similar audience.

Three workshops were delivered during the project. One workshop was offered in a bilingual (Spanish/English) format and the training curriculum was developed in a bilingual format. While some clients speak Spanish only, their service providers are bilingual and preferred the bilingual format.

The original proposal indicated that ten community-based training sessions would be conducted by the participants in the three project workshops. To date, nine classes have been conducted, but additional one-on-one training sessions have taken place. Other activities were conducted that proved to be of benefit to the audiences involved, including: library staff in-service presentations, additions to library video and print collections, Internet links added to library web sites, library staff invited as guest speakers at parent meetings, and library staff exhibiting at parent events. While there isn't an exact match with the objectives outlined in the project proposal, the clients served support and appreciate the project being tailored to their needs.

12. Problems or barriers encountered

- While project staffing was adequate for the project, the project relied on a number of other individuals to participate in the project – parent coordinators and library staff. Funding for participants was a challenge, especially for a number of library systems. Staff resources and travel budgets are limited, and libraries had to be convinced that the project was worth the investment. Paying a stipend for parent coordinator participation was key. Providing additional resources, video and print, was of value to libraries. Breakfast and lunch served at each workshop was also an effective strategy.
- Library staff and parent coordinator turnover was a problem throughout the project. Even with confirmation of participants, we continued to have a problem with “no shows” at the workshops. With a purposely limited number of participants at each workshop, no shows impacted the dynamics of the training. At one location, all of the librarians arrived, but two parents did not. The training was heavily focused on participating with and future planning with a partner. Missing a partner was problematic. Realistically, the parent coordinators are parents of children with special health care needs. A child's health status always takes precedence, even if it results in a parent's inability to attend.
- Training materials design was carefully accomplished, but still required substantial revision after delivery of the first workshop. The definition of children with special health care needs was omitted from the workshop materials,

which affected the understanding of participants. Assuming too much knowledge or too little knowledge about participants proved to be challenging.

- Providing each individual with a computer was actually a problem in our workshop design. Having pairs share a computer resolved that challenge and improved the workshop experience in the second and third workshops.
- The post-training plan that included follow-up activities to be conducted by trained participants within six months following the training workshop was not workable for most sites. A six – twelve month time range is needed at most sites.

13. Continuation plans

One goal of the project was to establish an ongoing relationship between public libraries and our two partner organizations, WSN and WSP2P. From the start, project staff understood that the project would operate for 18 months and expire. The success of the project has motivated both partners to continue to encourage their parent coordinators to keep active. The link to the public library has been a key strategy, and the library will remain constant in all communities. A number of activities have ensured the continuation of the project. One parent coordinator has been named to a library's Advisory Committee. One library has started a new parent support group that meets at the library. Parent groups have had librarians as speakers. Those activities will continue regardless of the existence of the project.

Library staff have agreed to continue to include the needs of families who have children with special health care needs in their planning. The library budget will continue to cover staff serving as guest speakers at parent meetings, writing newsletter articles for parent publications, and exhibiting at special events, especially to promote summer activities for children. The number of families that see the library as a resource, both for online resources and offline resources, will continue to grow. The number of families that view the public librarian as a key health information guide will also grow.

14. Impact

The project had a very real impact when it introduced two groups – library staff and parent coordinators – that were largely unfamiliar with one another. Few parent coordinators had actually thought of seeking health information at the library or asking librarians for help with Internet searches. Some parent coordinators struggled to complete complex health information searches on their own, with limited skills and limited success. Parent coordinators now envision libraries as places to:

- Access computers when families have none at home
- Consult experts to guide an Internet search
- Find print and video resources that may help them in their health information research

- Find professionals interested in supporting their health information needs and willing to add to the library's collection or make the library web site more helpful

15. Recommendations for improvement

The train-the-trainer model was an effective strategy for this project, but with a larger budget, we could have provided training to more participants. The target audience for each training was 12 participants total – six librarians and six parent coordinators. We could have increased that number or increased the number of workshops delivered. With additional funding, it would be useful to re-deliver the workshop to our first site, Aberdeen, WA. While that site served somewhat as a pilot site, they didn't receive the full benefit of an effective training. With the inability of two parents to attend the class, follow-up activities from that site have been limited.

The funder needs to permit funds to be spent on travel and food, even if the funding is available as a stipend, not actual reimbursement of costs. If traveling a distance, overnight accommodations need to be offered or reimbursed in part. Depending on the audience, childcare costs may also need to be paid.

16. Responses to follow-up questions (attached)

FOLLOW-UP QUESTIONS

1. Were your original project goals and objectives met? If not, why not?

This question is answered in part in Section 11, Evaluation and Section 13, Continuation Plans. To a large extent, our goals and objectives were met. Any changes in objectives occurred when tailoring to participant need was necessary. Expanding time lines and accommodating our target audience were a high priority.

2. What significant lessons were learned? Which strategies were most effective?

The most significant lesson learned is that public libraries are underutilized by our target audience, an audience with high, ongoing health information needs. Introducing that audience to librarians and bringing them to a library was the most effective strategy.

Participants make commitments, and sometimes cannot keep commitments. Working with parents who have children with special health care needs requires patience and flexibility. All the parent coordinators in our audience are parents of a child with special health care needs. Their child comes first, and that sometimes means they cannot attend the training. Be flexible and have a back up plan. Overbook if necessary, and permit participants to stay in the project even if they were unable to attend the training. Conduct telephone or individual trainings for participants unable to participate at the actual workshop.

Training participants had better ideas than we did for the design of the workshop and skills session. Listen to and incorporate their feedback. Share revised materials with all participants post-workshop.

No matter how much communication you share, it is not enough. Don't assume email works all the time. Mix communication strategies – email, telephone, and print.

3. If you were to start all over again, what, if anything would you change about your goals, project plans, etc.

We might have conducted a pilot version of the training before delivering it to the three project sites covered by the proposal. A “dry run” might have shown us some of the challenges and areas needing improvement. While we utilized in-house review, that wasn't sufficient to develop the product we needed.

At the outset, we assumed we wanted computer facilities that offered a computer per participant. That was not a useful strategy for our workshop. A shared computer was a major reason for the success of our second and third workshops. For our training design, we would plan for computer sharing from the start.

We saw community-based or group Internet trainings as the desired outcome and set a goal of ten trainings. That was not the same vision shared by our participants. More

accurately, that was not the initial need of our participants, but it may make more sense in the weeks and months ahead. Most of our parent coordinators were not ready to schedule or participate in a community-based training. The librarians were prepared and ready to implement that objective.

We would revise our expectations for partner contributions. While both our partners, WSN and WSP2P, participated equally and strongly, WSP2P has a larger presence throughout Washington State and more coordinators available for a project such as we designed. We would have relied more heavily on coordinators from WSP2P and supplemented with parents from WSN.

4. What advice or recommendations would you give to anyone considering a similar outreach effort?

If your goal is health information access, include public libraries in your project. A medical librarian may also be a good addition to your advisory committee or someone who could serve as a key informant.

Don't assume that "everyone knows how to use the Internet" or that everyone even knows how to use a computer. Do know that your public librarian is willing and able to help.

Define your issue well. Because our "expertise" was working with parent coordinators, it was easy for us to assume that the librarians knew the term "special health care needs." As one key informant said, "They are librarians. They know everything." Define any critical terms or concepts that are the focus of your outreach activity so all participants are on common ground.

Spend a little time explaining the role of the participants in your project. Parent coordinators were interested to learn about librarians and the use of a reference interview as part of a librarian's skill set. Our librarian participants also shared their limitations (self-imposed or library system-imposed) on providing health information versus medical advice. Librarians were fascinated to learn about parent coordinators and the whole world of special health care needs. For many librarians it was new information and a valuable learning experience.

Share your project's story. To date, the project has been accepted for a brief report in the Practice Notes section of the journal, *Health Education & Behavior*. A poster session on the project has also been accepted for presentation at the Joint Conference on Health, Wenatchee, WA, October 4 – 6, 2004.