

**NN/LM Northwest Pacific Region Award**

**Technology Training for Trusted Sources in Diverse  
Communities Project**

**February 01, 2004 – April 30, 2005**

**Final Report**

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## 1. Summary/Introduction:

Funded by the National Network of the Libraries of Medicine, the Technology Training for Trusted Sources in Diverse Communities project was conducted from February 2004 to April 2005. The project's main effort was to provide technology training on accessing accurate healthcare information to culturally and linguistically responsive Trusted Sources (aka Family Advocates) who worked with families that have children with developmental disabilities in ethnically and linguistically diverse communities. The project was intended to demonstrate that if families receive the information they need from a trusted source of information, they would have the tools they need to understand their child's disability and special healthcare needs. As a result, families will be more responsive to the health care needs of their child, will better understand diagnostic criteria, and will be better able to follow-through on medical advice.

The project provided a total of five training sessions to nine Trusted Sources whose ethnicities were identified as African American, Cambodian, Chinese, Korean, Mexican, Somali, and Vietnamese. Some of the basic training contents include Medline Plus, Pub Med, etc. Claire Lev, King County Resource Librarian and Ellen Howard, Medical Librarian of Harborview Medical Center developed all the training materials. The materials are available on <http://www.librarianstyle.com/rewa>. The training was consistently positive and helpful to Trusted Sources. Trusted Sources indicated that training helped increase their skills and knowledge in how to access the accurate healthcare information for families.

In addition to the successful training provided to the Trusted Sources, we developed a website for the project, provided network opportunities for Trusted Sources, increased the awareness of the contribution of Trusted Sources, and furthered the collaboration among the partnering agencies. As a result of these trainings and resources for the Trusted Sources, many families benefited from receiving healthcare information that empowered them to care for their children with disabilities and special health care needs. One of the success stories was about a Family Advocate's encounter with one Cambodian family. We featured this story in the article written for Dragonfly Newsletter to celebrate what we have accomplished through this project and to remind us that this important work needs to be expanded to serve more Trusted Sources and families in the diverse communities.

2. **Geographic region/number of counties:** All project-related activities were conducted in King County, Washington State.
3. **Collaborations/Partnerships:** The partnering agencies included Associates in Cultural Exchange (A.C.E.), The Arc of King County, Refugee Women's Associates (ReWA), Parent to Parent Power, Harborview Hospital Medical Library, and Children's Regional and Medical Center/Center for Children with Special Needs. The roles and participation from the above agencies were:
  - a. A.C.E.: Served as the lead agency, oversaw the project, hired the project coordinator, consultants, contracted trainers, and coordinated all project related activities.
  - b. The Arc of King County: Provided four Ethnic Outreach staff from African American, Asian, and Latino communities to participate the project to receive training and link to their clients.
  - c. ReWA: Provided four Family Advocates (Trusted Sources) from Cambodian, East African, Vietnamese communities to participate in the training and link to their clients. In addition, the project conducted 5 training at ReWA's newly established computer labs.
  - d. Parent to Parent Power: Provided one Korean Family Advocate to the project, receiving training and linking to families.
  - e. Harborview Hospital Medical Library: Ellen Howard, medical librarian from Harborview was our invaluable trainer for all the training the project provided. She also helped us to recruit Claire Lev, King County Resource Librarian to co-conduct training.
  - f. Children's Regional and Medical Center/Center for Children with Special Needs: Shared with the project their technology training curriculum including "Getting to Know the Internet", "Empowering Parents of Children with Special Health Care Needs: Harnessing the Power of the Internet", and "Library Resources for Families with Children with Special Health Care Needs in Washington State".

Throughout the project period, some of the challenges we encountered were the changes and turnover of staff and limited hours for Trusted Sources to work on the project. During the first quarter, one Trusted Source was not able to join the project due to budget constraints. To remedy the staff shortage, Parent to Parent Power was recruited to assign a Korean Family Advocate to replace the staff we lost. The reason we were able to replace the staff in the nick of time was that the Director of Parent to Parent Power has a long working relationship with the project coordinator and consultants. A critical element to successful collaboration is the trusting working relationships among the agencies and key staff. If we can expand our trusting working relationships with other agencies or organizations in the future, this type of training will benefit more staff in their knowledge and skills enhancement.

#### **4. Training:**

- a. The project provided a total of five training sessions to Trusted Sources. One of these sessions was provided to families together with Trusted Sources. There was also a pre-training meeting with Trusted Sources to introduce the project and one wrap up meeting to present certificate of completion to Trusted Sources and gather their feedbacks.
- b. All of our training attendees were from culturally, linguistically, and ethnically diverse backgrounds. Except for the families who speak little English, all of them are either bilingual or multilingual.
- c. The total number of participants in the five trainings, two make-up trainings and one pre-training meeting is 75 (duplicated counts of people who attended multiple training sessions)
- d. Breakdown of participants (unduplicated counts):
  - a) Health care or service provider: 11 Trusted Sources, 3 program managers, 1 coordinator, and 2 consultants.
  - b) Health sciences library staff member: 1
  - c) Public/other library staff member: 1
  - d) Member of the general public: 4 clients of the Trusted Sources

**5. Training sites:** All training sessions were held at Refugee Women's Alliance's computer lab but one at University of Washington Medical Library. ReWA's computer lab is a newly established facility. It is equipped with 10+ brand new computers with Internet access. Computers at UW Medical Library have access to abundant medical and health related information.

#### **6. Exhibits:**

- a. May 17-19, 2004 at Peach Tree City, Atlanta, Georgia. Approximate 60 people from various community organizations and governmental agencies throughout the State of Georgia attended this Think Tank Conference. The majority of the participants were service providers to children with disabilities and special health care needs and their families.
- b. Oct. 01, 2004 Multicultural Family Gatherings at Dimmitt Middle School in Seattle. Number of attendee: approximately 400 people including parents, children healthcare service providers, social services providers, and community members.

**7. Resource materials:** The main resource materials developed by the project can be grouped into four sections:

- a. Training materials developed by Claire Lev and Ellen Howard, Resource Librarian and Medical Librarian. All training material can be accessed at [www.librarianstyle.com/rewa](http://www.librarianstyle.com/rewa).

- b. A.C.E. website <http://www.language-works.org> Access for People with Disabilities provided some basic disability related resources and linkage to National Network of Libraries of Medicine, Medline Plus, Ethno Med, and National Organization for Rare Disorders. Project consultants, computer technician, and the project coordinator designed the web content jointly.
- c. Evaluation tools, including pre-training and post-training questionnaires for Trusted Sources, questionnaires for families, and a few other documents like agency agreement, health care information dissemination records, work timeline, etc.
- d. The project submitted an article to Dragonfly. A copy of the article is enclosed at the end of this report.

The training material was submitted to the National Training Center and Clearinghouse (<http://nnlm.gov/train/>) on May 6, 2005.

#### **8. Web sites:**

A.C.E. computer technician, Dennis Broll, developed new web pages dedicated to the project under A.C.E.'s Language Works websites. Information about the project is available at <http://www.language-works.org>. Click on Access for People with Disabilities, then Tech. Training for Trusted Sources in Diverse Communities. Contents included overview of the project, project collaborators, contact information for Trusted Sources, and disabilities resources and linkages to NN/LM Pacific Northwest website, Medline plus, Ethno Med, and National Organization for Rare Disorders.

After the completion of the development of the website, the project coordinator received 2 phone calls from a parent with a child with disabilities who was looking for school information and a nurse who would like to volunteer himself to work with families with children with disabilities.

This project is one of A.C.E.'s Access Initiatives for People with Disabilities. A.C.E. will continue seeking future funding to enhance their services to families from diverse backgrounds and to expand technology training to them. Web resources and information will be maintained and expanded in accordance with the future project activities. For instance, A.C.E. designed a website for Access for Autistic Youth under a grant. Later, A.C.E. expanded this website to include more resources available to families with children with disabilities through another grant.

#### **9. Document delivery and reference services: N/A**

#### **10. Approaches and interventions used:**

- a. Identifying and scheduling sessions:

At the beginning of the project an introductory meeting for all the Trusted Sources was held to review the project including goals, objectives, and time lines. The Trusted Sources set the training schedule for five training sessions. Because of their high workloads they chose to have the sessions spread out over time rather than in the initial stage of the project. One last session was held for all at the conclusion of the project for discussion, evaluation, planning and for the Executive Director of A.C.E. to provide to certificates of completion. As a result of the discussion, the group desired to hold one additional training session that would include families in the final training was scheduled for April 2005. One of the librarians volunteered to do the training and the Trusted Sources selected families they thought could benefit from a basic training on a few web sites and resources in languages other than English. The trainer geared the training according to the interests of the families.

b. Promotion/marketing

Because of the goals and objectives with the emphasis on training the Trusted Sources promotion and marketing was not a formal part of this project. The Project Coordinator, Consultants and Trusted Sources told others about the project on an informal basis. The Project coordinator promoted the project by displaying NN/LM promotion material at different events she went. For example, the Multicultural Gathering for Families with children with developmental disabilities at a resource booth.

c. Training

The Trusted Sources set the timing and dates of the 5 training sessions. The project consultants did all arrangements for the training sites and notification and reminders to the Trusted Source. Four of the trainings sessions were conducted at Refugee Women's Alliance. This site was used not only because of the availability of the computer lab but also because of the convenient location and parking availability. One session was conducted at the University of WA Medical Library so everyone could become familiar with the resources of the Medical Library. The Librarians organized the training sessions according to the stated objectives of the grant, the questions and needs raised by the Trusted Sources and the vast amount of knowledge possessed by the 2 librarians. They made every attempt to make the training appropriate and useful for a wide range of trainees. They also conducted makeup sessions for those who missed sessions.

The final session conducted in April 2005 was done at the request of the group for the purpose of doing a special session to include families. One of the librarians conducted the training on a volunteer basis. She organized it according to the identified interests and needs of the families. It was set up at Refugee Women's Alliance because the families were familiar with that site.

d. Personnel and Staffing: The original Trusted Sources were selected for the project because of the two agencies (The Arc of King County and

Refugee Women's Alliance) history of working together and because the staff from these two agencies are seen by families and others as Trusted Sources. The Trusted Source from Parent Program was selected later because they showed their interest and familiarity. There were some changes in the staff over the year because of normal staff turn over and other unexpected changes at the agency level. The consultants were chosen because they are well known in the community for their work with agencies serving refugee and immigrant families and families of color and their long time experience in developmental disabilities services. The project coordinator was hired because of her expertise, familiarity with all aspects of the project, and her affiliation with A.C.E.

- e. Web site development: The web site was developed and designed by the project consultants and computer technician from A.C.E. The purpose of the web site was to showcase the project as a part of A.C.E. **Language Works!** and Access to people with disabilities programs at A.C.E. The web site plan included basic information about the project as well as links to developmental disabilities services and access to health care information. It was designed to be easy to access and to provide basic information.

#### **11. Evaluation:**

The project was evaluated based on the following two indicators:

- a. Trusted Sources Pre/Post Survey for 9 trusted sources: and a group feedback discussion in addition.
- b. Family Pre/Post Training Surveys for 45 parents/care givers

The objectives were to provide technical training to the trusted sources so that they can gain knowledge on how to access to medical information and resources through the Internet and then pass it on to the families they serve.

Based on the results generated from the group feedback and the Trusted Sources surveys, the project has achieved it greatest objectives in many ways:

a.1. Training sessions have increased the skills level of the Trusted Sources in using Internet and the knowledge of websites that provided accurate and appropriate medical information and resources. At the end of the project, seven (7) out of Nine (9) indicated that they had increased the use of Internet and access to the healthcare resources websites and could identify at least two (2) useful websites.

a.2. All Trusted Sources reported the training and resources they received have increased their ability to meet the health care information need of families they serve.

a.3. All Trusted Sources desired the families they served to have similar training and a more advanced level training for them selves in the future project.

b. For the family survey, we felt that it was not relevant for the evaluation purposes due to the fact that most families who were originally completed the pre-survey, 41 out of 45 targeted parents, were not the ones the Trusted Sources shared the health care information to. Many of the Trusted Sources shared and visited other families who were not originally selected to be part of the project and nor did they fill out the pre-survey. However, those families benefited greatly from the project as well.

Factors contributed to the facts that post-surveys could not be done for the same families were:

b.1. Some families moved to other places.

b.2. Families went to visit the Trusted Sources for the things they needed only. Therefore, they would not ask for help if health issues were not concerns at that time.

b.3. The majority of the Trusted Sources worked on limited hours. They were not able to visit families solely for the purpose to deliver health care information that might not be what families asked for. They tended to respond to either crisis or calls from those who are in need.

## **12. Problems or barriers encountered:**

- a) Promotion/marketing: no problems encountered. This project did not have a specific focus on promotion or marketing.
- b) Training: we did not encounter major problems except some minor barriers in the training. In one training event, we experienced technology difficulties. However, with the technology support person at ReWA, we were able to get on our training soon. Rescheduling training for those who missed sometimes took a longer time to coordinate and conduct the training. However, we were able to provide make-up sessions to Trusted Sources who missed any scheduled training.
- c) Personnel/staffing: no problem encountered for the project. For the collaborating agencies, a couple of incidents happened to a manager and a Family Advocate. They were on leave for a couple of months. We had to pick things up after they were back to work again.
- d) Web site development: no problems encountered.

## **13. Continuation plans:**



Through the project, we learned that many Trusted Sources were interested in learning how to access health care information. We believe that many bilingual/bicultural workers in the social services would be interested in learning these skills and knowledge as well. We intended to explore further opportunities to bring this wonderful technology training to others. One of our action steps is to create a Cultural Broker Network. The Cultural Brokers are like Trusted Sources called in this project. The Cultural Broker Network project will identify, recruit, and train bilingual/bicultural staff. In addition, it will provide a network opportunity for them to share resources and solve problems. This training effort will be expanded to serve more Cultural Brokers and eventually benefit families they work with through future projects.

#### **14. Impact:**

Four major benefactors of this project include:

- a) Families of children with disabilities and special healthcare needs: when they seek for health related advice, Trusted Sources were able to research and select relevant, accurate information for them. Many of these families speak very little to no English. They rely on someone who speaks their language to interpret information written in English. In our case, the Trusted Sources were able to interpret and search for information written in their language, for example, Spanish to share with them.
- b) Trusted Sources increased their skills and knowledge on accessing accurate and reliable healthcare information. A couple of Trusted Sources who were not previously trained in using computer took this opportunity to advance their computer knowledge and skills. The training taken place at University of Washington's Medical Library also broadened their views on how abundant healthcare related information is available on the Web.
- c) Partnering agencies benefited from furthering their relationships with one another.
- d) This project introduced UW Medical Library to the Trusted Sources as a great source to broaden their knowledge and understanding of medical and health care information.

#### **15. Recommendations for improvement:**

The project coordinator and consultant were not successful getting much written feedbacks on Children's Hospital training material: "Getting to Know the Internet". The Trusted Sources, constrained by limited working hours and challenged by reading and writing English that was their second language, were unable to perform the task we requested.

Instead of writing us the feedbacks, they told us what they thought about

the Children's training curriculum. They commented:

- It is a very good handbook for new Internet users or new computer users.
- We like the resources websites and glossary that were listed in there.
- They are very helpful for parents who have (or not have) children with special health care needs. In addition, there are helpful tips for evaluating the Internet resources. However, ESL students or parents found it difficult understanding terminology used in this handbook.

#### **16. Responses to follow-up questions (attached):**

##### **FOLLOW-UP QUESTIONS**

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

The first goal of improving the ability of the Trusted Sources to use the Internet and access health care information for families was met. The Trusted Sources attended the high quality training sessions and were better able to provide health care information to families. At the beginning of the project there was a large difference in the computer and Internet skills of the Trusted Sources but all felt more confident at the end of the project. Those with more skills were more apt to provide more information than those with lesser skills.

During the course of the project there were some changes from the original 9 Trusted Sources who started the project. All who were in the project even for part of the time received some training and reported a higher level of confidence in using the Internet resources to locate health information. This included 2 new Trusted Sources who replaced others who were no longer serving as Trusted Sources. The two newest ones were able to attend the extra training session, which was done in April 2005. They both stated they learned from the training and would be able to use the basic information they learned to help families.

The second goal could not be fully measured. This was because the original decision to select families from caseloads was not realistic. Families did receive culturally and linguistically relevant health care information from The Trusted Sources but the families were not necessarily from the original group. All the Trusted Sources respond to families on the basis of the immediate needs of the family. Many of the immediate needs were not necessarily about health

**2. What significant lessons were learned would be of interest of use to others conducting outreach projects? Which strategies were the most effective in implementing the project?**

This project focuses on serving the culturally, linguistically, and ethnically diverse service providers and families. It also involved with many collaborating agencies. One of the most effective strategies we used to implement the project is being flexible. It means:

- a. Being flexible to provide extra training. Provided make-up sessions for those who missed the previously scheduled training.
- b. Supporting Trusted Sources, often individually, during the training sessions because of their different skill levels on using the computer.
- c. Understanding that, for Trusted Sources, English is their second language. Although they are proficient in speaking English, writing most often remains a challenging task to them.

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

If we were to start all over again, we would make a few changes on the project. They are:

- a. Conduct the 5 training sessions within 3 months' period. Each training session after first one would begin with reviews and lessons learned from the previous session.
- b. After completing the training for Trusted Sources, we will ask each Trusted Sources to invite 2 families to join 2 more training. This time, the Trusted Sources will come and learn with families together and serve them as a mentor.
- c. We will need to increase our budgets to allow Trusted Sources to allocate more time to work with the families for the project.

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

This project requires a lot of collaboration, understanding and working experiences among linguistically, ethnically, culturally, and ability diverse staff and agencies. For those who would like to conduct similar training or outreach project like this one, here are some lessons we learned and would like to share.

- a. Commit themselves to providing culturally and linguistically competent services by working collaboratively with community agencies that target to serve the underserved population.
- b. Be willing to listen to the bilingual and bicultural staff's recommendations. Be flexible and willing to make changes as the project moves forward.
- c. Conduct consumer focus groups to assess their needs.

- d. Allocate additional funding to support the language needs of the participants who have limited English proficiency.

### **Article submitted for Dragonfly**

In 2004 an important project was started in the Seattle/King County area. This project was called as Technology Training for Trusted Sources in Diverse Communities. The aim of the project was to improve the use of the Internet by a group of advocates and outreach workers identified as “Trusted Sources” to access health information and in turn provide culturally and linguistically relevant information for families raising children with developmental disabilities.

The project was made possible through the collaborative efforts of several local agencies. The Associates in Cultural Exchange hosted and led the project. The Trusted Sources were Family Advocates and Outreach Specialists from The Arc of King County, Refugee Women’s Alliance, and Parent to Parent Power. These individuals had experience in working with families with children with disabilities and special health care needs and were bilingual and bicultural. They all provide direct services to families in the following communities: Vietnamese, Korean, Cambodian, Chinese, East African, Spanish speaking and African American. In addition two librarians, Ellen Howard, Medical Librarian of Harborview Medical Center and Claire Lev, Resource Librarian from the King County Library system planned and conducted the training for the Trusted Sources. Lastly Children’s Medical Center and Hospital shared their curriculum of “Getting to Know the Internet”.

During the project the Trusted Sources learned Internet and Medical Library health care resources and were better able to assist families. The following story is an example of the impact of the project on a family. This example highlights how a Cambodian family benefited from the health information provided by their Family Advocate (trained Trusted Source) from Refugee Women’s Alliance.

The family is composed of a 23-year-old mother, her 8-year-old son, 3-year-old daughter, and a grandmother. The mother has good English skills, but the grandmother who is the main caretaker of the children knows little or no English.

The family was referred to the Trusted Source by a Public Health nurse who was concerned about the little girl's development and the family's lack of follow-up and seeming disinterest in her. The Trusted Source also found that the family showed no interest in any treatment or care for the child and had a fatalistic attitude about the potential of the little girl. The mother and grandmother focused on the older child as he was developing well without any problems. Even with a good relationship, the common language and a cultural understanding of the family's attitude, the Trusted Source found

that she was not able to motivate the family to take an interest in the little girl or to seek any medical or therapeutic care for her.

However, things began to change very rapidly when the Trusted Source returned from the first major project training session on internet resources - how to find and use websites and other available internet resources. In the session that day the Trusted Sources were introduced to the website Medline Plus. Besides a thorough introduction to this web site all trainees were given a brochure and bookmark about Medline Plus. When the Trusted Source saw the mother of little girl later that day she told her about the website and gave her the bookmark as the mother seemed interested in checking out the website. The mother had recently enrolled in a training program to become a Pharmacy Aid and had a class assignment to check out and research a question on the web. The mother chose to research Cerebral Palsy (the diagnosis given to the little girl). In doing that exercise for her class, she became very interested in learning about Cerebral Palsy and started printing up information to take with her to the child's doctor's appointment.

Reading the information on this website and receiving other written information from the doctor, checking other websites and successfully completing her assignment of her class began to change the understanding and the attitude of the mother. She became much more interested in her daughter and began to talk and play with her. She was able to talk about Cerebral Palsy and her child's doctor and the Trusted Source and was able to follow up with needed therapies. The family, including the grandmother, began to show more interest in the little girl not just in the older boy.

This story was shared and showed all involved in the project that it takes both the trusting relationship between the advocacy and outreach staff and a family as well as training and knowledge to achieve the desired outcomes for children and their families.