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Access to Child Health Information

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The CATCH Project: Central Mass Access to Child Health Information*

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INTRODUCTION

Parents of disabled children have substantial health and social care needs and therefore, a great need for information. Access to health information for parents and health professionals has been revolutionized by the Internet [1]; however, as Blackburn and Read note, "The provision of crucial information to parents of disabled children, at the time when they need it and in a form that they can use, is an intractable problem" [2]. Relevant health information can be difficult to find and is variable in quality [3]. How can medical librarians work with community groups, public health workers, and health providers to assist parents of chronically ill children find and obtain information?

The Central Mass Access to Child Health Information (CATCH) project attempted to address this problem. CATCH targeted eleven public health agencies in central Massachusetts that serve chronically ill and/or developmentally disabled children and their families. Participants varied from early intervention centers to disease-specific agencies (Table 1). CATCH provided these community-based, public health agency staff members with training to locate and effectively use quality Internet health information. CATCH developed a model for outreach and collaboration as well as established new community partnerships for the Lamar Soutter Library (LSL) of the University of Massachusetts Medical School.

TARGET POPULATION AND SIGNIFICANT ISSUES

Massachusetts is home to approximately 221,840 parent-reported children with special health care needs, nearly 15% of children in the state (national average 12.8%) [4]. Previous projects have explored this population's need for health information [5, 6]. The Finding Information Resources and Services through Technology (FIRST) project, funded by the Massachusetts Department of Public Health and located in the UMass Memorial Children's Medical Center (CMC), served the information needs of families with chronically ill children from 1995 to 1999. Parents participating in the FIRST project stated that they need information about their children's health conditions beyond what physicians provide. When the FIRST project ended due to state budget cuts, CATCH filled the gap.

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Supplemental Table 2, Figure 1, and an appendix are available with the online version of this journal.

CATCH targeted public health agencies in central Massachusetts (Figure 1) that serve children with chronic physical, developmental, behavioral, or emotional disorders and their families. To establish relationships with relevant organizations, project investigators identified community-based agencies in the New England Information on Disabilities Exchange (INDEX) database that serve children in central Massachusetts and invited these agencies to participate in the project [7]. Eleven agencies responded positively. Table 1 lists these agencies and their corresponding target populations (650 staff serving 25,000 children).

PARTNERS

The LSL partnered with the CMC Pediatric Family Resource Library (PFRL) and the Massachusetts Network of Information Providers for People with Disabilities (MNIP)/New England INDEX [7]. The PFRL was developed from collaboration between the LSL and CMC. PFRL provided point-of-care information services for parents who used the CMC and was originally funded with a grant from the Massachusetts Board of Library Commissioners in 2002. The MNIP, coordinated by New England INDEX, is a collaborative effort of 110 nonprofit agencies in Massachusetts.

INTERVENTIONS

CATCH (March 2003–June 2005) consisted of four major interventions: (1) in-person site visits to each partner agency, (2) one-on-one and group training, (3) information delivery via a Website, and (4) exhibiting.

In the initial site visits, project staff attended agency meetings and conducted interviews to develop appropriate training tailored for each agency and to solidify the library–agency partnership. Based on this assessment, CATCH project librarians developed training that covered reputable child health information resources and the process of evaluating resources. Project librarians held 14 group sessions with 180 participants. One or 2 hour classes ("Finding Quality Health Information on the Internet and Evaluating the Information") and one-on-one training sessions demonstrating the best Websites for health information (including MLA's "Top Ten" Most Useful Websites [8]), followed by a session on how to evaluate Websites. New England INDEX staff accompanied LSL librarians to training sessions to demonstrate their disability-related databases [7]. A CATCH Website was also developed that included resources evaluated by project librarians and a newsletter to publicize the project [9].

Exhibiting provided another opportunity to advertise the project and enlist project participants in using resources (Table 2). Exhibits consisted of a portable

Table 1
Targeted agencies

Agency	Number of staff and clients	Services provided
Metrowest Children and Adults with Attention-Deficit/Hyperactivity Disorder	1 staff	Support groups, referral, education for children with attention deficit hyperactivity disorder
UMass Early Intervention	55 staff; in 2002, 62,404 hours of home visits, 44,756 hours of child group, 10,200 hours of parent group, 4,764 hours of developmental screening, 15,768 hours of developmental assessment	Developmental assessment and screening; child and parent groups; physical, occupational, and speech therapy; social work; education
Autism Alliance of MetroWest	2 staff	Support and education for children with autism and pervasive development disorders
Family Services of Central Massachusetts	10 staff	Child care education, resource, referral
Crohn's and Colitis Foundation	3 staff; 185,000 children and adults in New England; 10% are children under 18	Medical information and referral, support groups, and seminars
Sunshine Haven Charles River Arc	20 staff; 9 residents ages 3–25 220 staff; 300 families	Residential home for disabled children Respite family support, recreation, after school, school vacation, and weekend programs for children with mental retardation, autism, Down's syndrome, and cerebral palsy
Pernet Family Health Center Center for Development	36 staff; 2,500 + birth–3 yrs. 200 staff; thousands of clients, birth to 8 years	Early intervention Early intervention, child care, teen parent support, home visiting, respite funding
Gardner Visiting Nursing Association	130 staff; 1,938 visits in the past 6 months (221 children)	Maternal and child health home care
Child Development-Worcester Head Start	12 staff	Plan and implement health services and health education
Totals	652 agency staff; 25,000 agency clients	

display of project materials and a computer for demonstrations.

EVALUATION

Evaluation methods included ongoing participant feedback during site visits and training sessions, immediate written evaluation following each training session, and an electronic evaluation form for longer-term follow-up evaluation. At each training session, staff were asked to document their subsequent use of information resources via the brief online form [10]; however, only six electronic evaluations were submitted. The authors learned from this experience that ongoing personal contact was more effective than electronic modes of communication in gathering additional data from participants. Like all health providers, these public health workers were overloaded and stretched for time. They had scarce attention available for project reporting. A significant challenge for CATCH project librarians throughout the project was to gain the time and attention of busy public health workers. Subsequently, a simple one-page paper evaluation was used after each training session (Appendix). Via these evaluation mechanisms, agency staff indicated strong support for the training: 98% (n = 175) of the 180 respondents answered "yes" to the 4 questions referring to successful completion of session objectives. The evaluation highlighted that the best feedback about the project from agency staff would only be obtained through ongoing, consistent personal contact by CATCH librarians.

RESULTS

For agency staff, training led to greater awareness of MedlinePlus [11] and MLA's "Top Ten" Most Useful

Websites [8]. As a result of this training, agency staff referred parents to these resources via the CATCH Website and the reference services offered by pediatric library staff. For the LSL and its partners, the project provided awareness and marketing for resources and services available from the LSL, the PFRL, and New England INDEX. CATCH also served as a model for other LSL outreach projects, particularly the e-Mental Health Project and GoLocal Massachusetts [12, 13]. CATCH enabled the LSL to become the Massachusetts Department of Education's Early Childhood Resource Center (ECRC), starting in July 2003. As the ECRC, the library features a variety of materials for the early childhood community, early childhood educators, and parents. Two of the CATCH agency participants are subsequently involved with the ongoing operation of the ECRC project. Finally, the CATCH project fostered new relationships with local and state public health agencies, prompting requests for similar training by non-CATCH pediatric agency groups that had learned of the project.

FUTURE DIRECTIONS

Since the official launch in 2003, feedback about CATCH has been positive. The LSL has incorporated the projects and services provided through CATCH into its regular outreach services. The library was also able to use project data to substantiate reallocation of funds from a newly created vacancy in another library unit to create permanent staffing for the PFRL. Therefore, the library continues to support learning by public health practitioners, community day care workers, other health care providers, parents, and caregivers of chronically ill children through scheduled and "on demand" assistance to support their information needs.

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