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Educating K-12 Professionals and Parents: Finding Health Information for Special Needs Children^{*,†}

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Abstract

A successful partnership model between an academic health sciences library and a K-12 school district to provide librarians, nurses, and special education staff with access to health information to support special needs children and their parents is presented. Train-the-trainer staff sessions and a parent session were collaboratively developed. Funding support was used to purchase iPads for librarians and nurses to deliver mobile support. The results indicate the resources taught are being

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used to find health information and the school librarians and nurses are being sought after to assist in finding health information. Positive feedback from the school district indicates this model could be replicated in similar settings.

Keywords

special needs children; parents; k-12 professionals; school librarians; school nurses; academic health sciences libraries; special education support

Introduction

In recent years K-12 schools have experienced an upswing enrollment of special needs children. In 2001, the National Survey of Children with Special Health Care Needs demonstrated that 12.8% of U.S. children had special health care needs; by the 2005-2006 National Survey that number had risen to 13.9% (U.S. Department of Health and Human Services 2007). In the most recent survey conducted in 2009-2010 the number had risen to 15.1% (U.S. Department of Health and Human Services 2012). Needs range from developmental to physical conditions. For instance, autism rates alone are rising with an average of 1 in 68 children diagnosed with an autism disorder (U.S. Centers for Disease Control and Prevention 2014). Findings from the 2012 Summary Health Statistics for U.S. children are equally as sobering. These show that attention deficit hyperactivity disorder (ADHD) rates are also on the rise with five million children diagnosed between the ages of 3-17: 14% of boys and 5% of girls. The same survey shows over 10 million U.S. children aged 17 years and under (14%) have received an asthma diagnosis at one point during their lives. The Summary Health Statistics also found that 10 million children—13% of all children—were taking prescription medication regularly for at least three months to address a health problem. Additionally, approximately four percent of children missed 11 or more days of school in the past 12 months due to illness or injury (Bloom 2013). Houtrow et al. conducted a secondary data analysis of four data sets from the National Health Interview Survey and found a 15.6% increase in the prevalence of childhood disability from the 2001-2002 survey to the 2010-2011 survey. The same study reported that for neurodevelopmental or mental health conditions the increase was even higher at 20.9% (Houtrow et al., 2014).

These figures represent just a snapshot of special needs children. Based on these sample figures, K-12 professionals need access to reliable health information resources to better respond to these children's health issues in the educational setting. This information is vital not only for professional development in addressing the educational and health care needs of the child, but also to serve as a resource to parents who often look to the educational staff for support and direction.

Recognizing these needs, Schaffer Library of Health Sciences Library, Albany Medical College (AMC) collaborated with East Greenbush Central School District Pupil Personnel Services and Special Education Department (EGCSD) to develop a program that would educate school nurses, librarians, social workers, psychologists and related special education staff to meet the health information needs of special needs children and their parents by

improving knowledge of and access to reliable health information, particularly but not limited to, National Library of Medicine (NLM) resources. School librarians and nurses would also be provided with iPads to enable them to provide support to their colleagues and special needs parents at the point of need; AMC librarians received iPads to be able to provide support using the same device. By partnering the skills and talents of academic health sciences librarians, school librarians, school nurses, and special education experts the project would be able to incorporate the knowledge of each specialization and profession.

Methods

This multiphase project was designed to be a train-the-trainer experience in order for the EGCSd librarians and nurses to be able to transfer the experience to their colleagues and parents of special needs children. AMC librarians developed and provided two train-the-trainer sessions to professional school staff with input from the EGCSd planners. To extend the knowledge gained in these sessions to parents of special needs children a third class was taught to the EGCSd Special Needs Parents Group by an EGCSd librarian and nurse with assistance from an AMC librarian. These three sessions were delivered between November 2012 and January 2013.

Why would these two groups partner together? AMC and EGCSd are located in close proximity to each other in Upstate New York. EGCSd is located in southern Rensselaer County and encompasses 78 square miles covering a diverse demographic population, and is comprised of five elementary schools, one middle school, and one high school serving approximately 4,300 students. Schaffer Library of Health Sciences, Albany Medical College, is an academic health sciences library and an NN/LM MAR Region 1 Resource Library in Albany County. Its mission is to acquire, organize, and facilitate access to knowledge-based biomedical information resources that enable AMC students, faculty, physicians, and other health care providers to advance their education, research, and patient care activities. Both institutions share a commitment to excellence in education and community involvement.

In February 2012, a planning team was formed to examine the feasibility of a partnership between EGCSd and AMC. The planning team was comprised of representatives from both institutions. The team was co-chaired by the Assistant Director for Education and Outreach from Schaffer Library, AMC and the Director of Special Education and Pupil Personnel Services, EGCSd. The other planners from AMC were the Associate Dean of Information Resources and Technology, the Information Specialist, Research, and the Instructional Technologist and from EGCSd the high school librarian and the high school nurse. Two in-person meetings were conducted with the remaining planning supplemented by e-mail and phone conversations. Each group brought their strengths to the table. The AMC librarians shared their expertise in health sciences resources. As librarians and nurses, the EGCSd participants have the foundations in their respective disciplines to apply what is taught in the train-the-trainer sessions to provide consultations to their EGCSd colleagues and to parents.

While the initial contact occurred between the two co-chairs, the training format originated with the EGCSd planning team members who identified their perceived health information

needs. Prior to the project, the Committee on Special Education (CSE) teams would either get diagnoses in a prescription form from a student's physician or from a brief psychiatrist's report. Instructional and support staff would search Google to get more information, but the reliability of the information found was unknown. A review of the school libraries and health offices homepage indicated that the high school and middle school had health sections. The high school library page had a health page which listed three NLM resources: MedlinePlus, PubMed Central, and the National Library of Medicine homepage. The use of these websites was unknown.

To validate the proposal a needs assessment survey using Survey Monkey was developed by the team. The committee decided to ask questions pertaining to current information seeking skills as well as perceived needs. Respondents were asked how often they referred parents to websites for healthcare information and if so, which websites were they most likely to recommend. They were also asked how important they thought finding health information is for parents. The planners wanted to know how important searching for health information is in the school setting, how often the educators searched for health information, and where do they look first. This survey was distributed via e-mail to 83 school nurses, librarians, social workers, psychologists and related special education staff. A total of 73 surveys were completed for an 88% response rate. The team felt the results, discussed in the Results section of this article, strongly supported the goals of this project.

To further validate the need, searches were conducted in PubMed, CINAHL, ERIC, Google Scholar, and LISTA to determine if there have been similar collaborative projects reported in the literature. There are many studies in the education and human resources literature to support the train-the-trainer model. These studies have concluded that this model both a cost-effective and efficient method for providing sustained training that empowers the new trainers (Jackson 2012; Marks et al. 2013; Suhrheinrich 2011). While there were no direct studies found that matched this project, there were some studies that are relevant to the goals. There is evidence that health information access for school professionals and parents can improve classroom outcomes and provide support to teachers and parents. A study in *Archives of Pediatric Adolescent Medicine* found that school professionals have concerns regarding the classroom management of children with chronic diseases that can be reduced by having access to health information from health care professionals (Olsen et al. 2004). A 2011 study of classroom teachers, including special education, found that when school nurses were available for consultation, there were "... fewer early releases, increased communication, less time spent on health issues, students with chronic illnesses are safer, and there is a resource available for health information." (Hill 2012). The desired outcome, that school professionals will have improved knowledge of health information, appeared to be supported. Additionally, a *Pediatrics* study found that when a child is initially diagnosed the greatest needs for parents include access to information and support from professionals (Rahi 2004). Another study indicates that parents perceive that school nurses, school counselors, and school social workers are extremely important in promoting health (Kirchofer 2007). While not specifically targeting our goals, the underlying message from these studies is that access to health information can support educators and parents.

Based on the results of the survey and literature review, the team felt there was enough data to support the validity of the project. The project was submitted to and approved by Albany Medical Center Committee on Research Involving Human Subjects Institutional Review Board (IRB). Funding to support this project was pursued and received through a National Network of Libraries of Medicine (NN/LM) Middle Atlantic Region (MAR) Outreach Award.

The funding received was used to purchase the iPads. In developing this program, it was also important to the planners to build in a mechanism to support the school librarians and nurses in delivering health information needs to other school professionals and to special needs parents seeking advice. To this end, EGCS D librarians and nurses were equipped with iPads to enable them to provide additional mobile access at the point of need in a private setting. AMC librarians were also equipped with iPads to be able to provide support in finding health information to the EGCS D librarians and nurses using the same device.

Course planning started in the summer and fall of 2012. The planning team worked together on developing three training sessions. AMC librarians developed and taught two train-the-trainer sessions to professional school staff. The first K-12 professional class taught on November 2, 2012 was "Finding Reliable Professional Information on the Web". This session targeted school librarians, nurses, social workers, and psychologists. The content covered using a clinical question to define a search and then searching PubMed, the Trip Database, and Google Scholar. These resources were selected since the attendees had a firm foundation in health sciences based upon their backgrounds in healthcare and counseling.

The second K-12 professional class, "Searching Consumer Sites" was taught on January 25, 2013. This session targeted the same audience, but also special education teachers and other participants on CSE teams. The focus was on evaluating web information and an introduction to consumer resources, including MedlinePlus and PubMed Health. During this class, the high school librarian provided a brief overview of the district's library website to show where the session resources had been integrated into the current content. As a result, the class also provided a marketing opportunity for the school librarians.

A third class, "Evaluating Websites" was held on January 8, 2013 and was created by the high school librarian and high school nurse with assistance from an AMC librarian. This consumer health information session was delivered to the EGCS D Special Needs Parent Support Group. This session covered evaluating websites as well as consumer resources. The sites selected reflected a broad range of resources, including MedlinePlus, PubMed Health, Kidshealth.org, and school resources. Originally, this class was supposed to have been held after the second K-12 professional class, but a change in the district's calendar necessitated a change in the class date. As a result, an AMC librarian met in December 2012 separately with the high school librarian and nurse to review resources for inclusion in the parent session.

The resources covered in these sessions were selected based on the district's needs, with NLM resources being the main focus, but not the exclusive content of each session. Fee-based resources were excluded so as not to incur future expenses. Table 1 lists the resources

covered in the staff sessions. The resources taught to the East Greenbush Special Needs Parent Group was a subset of the consumer resources session taught to the health professionals. For continued access at the end of the project, age appropriate resources were added to the school libraries websites. The AMC instructional technologist also added the resources taught to the home screen of the iPads. NLM resources were compiled in one folder and the non-NLM resources were placed in a second folder on the iPad for easy access. The sites were added by saving them to the home screen, then dragging the icon into the appropriate folder. This step was another way to promote continued use of the resources by the school nurses and librarians.

The sessions were evaluated using an audience response tool during the two educator sessions, a paper survey at the end of the EGCSN Special Needs Parents Group meeting, and three follow-up surveys in April 2013 using Survey Monkey: one to all 83 Pupil Personnel Services staff, one to nurses and librarians, and one to the EGCSN Needs Parent Group members who attended the session. Since the K-12 professional surveys were sent to all Pupil Personnel Services staff who received the needs assessment, not all the respondents attended the sessions. The planners were able to extrapolate further data by limiting the responses to those who indicated attending the classes

Results

The results from both the needs assessment and the train-the-trainer sessions were encouraging. It is evident that the educator and parent groups each walked away with new resources to use and knowledge of where to seek assistance when needed. To gain a complete picture of this project, it is equally important to view the qualitative data that came from the participants' comments and observations.

Seventy-two respondents (98.5 %) felt that searching health information was either very important or important in their setting, with 46 (62.9%) searching for health information either on a daily or weekly basis. However, while 66 respondents (90.3%) believed that health information was either very important or important in educating parents, only 13 (17.7%) respondents referred parents to websites for healthcare information either daily or weekly. When they do, 36 (50.7%) referred parents to a society or an association website, 22 (30.9%) referred them to a search engine such as Google or Bing, but only 4 (5.6%) referred them to a government website such as MedlinePlus. To find out where the respondents themselves searched for health information, an open ended question was included. The school staff indicated they predominately searched Google (40 respondents/56%) and WebMD (24 respondents/33%). Despite having NLM resources listed on the high school library webpage, only one respondent indicated searching an NLM resource and that was PubMed. Two respondents indicated using the high school website, but it is unknown if they used the linked NLM resources.

Based on the interest demonstrate in the needs assessment survey, it is not surprising that the two staff sessions were well attended, especially considering there were other activities available to the staff during their allotted professional development time. The first session, which was limited to librarians, nurses, social workers, and psychologists, had 28 attendees

and the second session which was open to the entire Pupil Personnel Services and Special Education Department had 40 attendees, almost half of the original 83 who received the needs assessment. The EGCS D Special Needs Parent Group session had six attendees, which was significantly fewer. However, the average attendance at these meetings is usually eight, with a high of fifteen. Some of the factors which impacted attendance for this session included the winter weather and an illness going through the district. The session was also held during the first week back after the holiday break while children were still adjusting to being back in their routines. This reason was anecdotally suggested by one of the parents to a planner. The reliance on consistent scheduling for special needs children does add a challenge to planning parent activities.

The post session results received through SurveyMonkey provided strong support for the project, although the response rate was not as high as the needs assessment survey. Of the 28 staff who attended the first class, 22 (79%) responded to the survey; 24 (67%) of the 40 who attended the second class responded. Fifty-five (66%) staff responded to the survey sent to the all special needs and related staff. Reviewing the results, it is important to note that not all staff responded to all questions.

Survey results were very encouraging for continued work with K-12 professionals, especially in terms of recognizing NLM resources. Of the 55 total respondents a total of 15 (27.2%) would recommend PubMed, but 31 (56.3%) staff did not answer this question. When narrowed down to just the 22 respondents who attended the “Finding Reliable Professional Health Information on the Web” class, more than half (13 respondents/59%) would recommend PubMed to a colleague looking for professional healthcare information. These figures indicate that of those attending the class, the majority walked away with a better understanding of how PubMed could benefit their work. Additionally, there was a definite increase in staff recognizing NLM resources with 12 out of 21 respondents (57.1%) identifying MedlinePlus as an NLM resource. When asked where they go first for information, 17 (40%) out of the 43 who responded to the question still replied Google, but since the sessions, seven (16%) included sites covered in the classes and previously not mentioned in the needs assessment. One of the objectives was to introduce the education staff to freely available resources; this data shows that the objective was met.

Equally as encouraging are the results of staff searching multiple resources covered after both staff sessions. Table 1 represents those that have either searched or plan on searching NLM and other free resources covered. The resources represented were taught in either one or both sessions. These results definitely show that the educators are consulting a wider variety of resources than before the sessions. It is also interesting to note that the NLM resources have been used the most since the class compared to the non-NLM resources.

The results are also promising that staff will recommend the health information websites covered in the “Searching Consumer Resources” to parents. Twenty-three K-12 professionals responded that they would or might recommend sites to parents (see Table 2). Again, the NLM resources would be recommended the most. Two respondents noted that it would depend on the information needed. While PubMed may seem unusual to include with this group as there are more consumer-focused resources available, there are parents who

search it to find information on their child's condition. A parent who was unable to attend the parents group session specifically asked if PubMed was covered because she regularly searched it for information concerning her son's condition and felt the school staff should be aware of the resource as well.

Five out of six parents who attended the EGCSN Special Needs Parents Group session completed the follow-up survey, Four (80%) respondents indicated that the number of times that they have searched for health information has increased since the class. Three (60%) parents used PubMed and PubMed Health since the class. Additionally, four (80%) parents have either used or are planning on using the high school library's online health resources. Also encouraging is that one parent has already asked a school psychologist for searching assistance and four more haven't asked for assistance finding health information yet, but will if needed.

The EGCSN nurses and librarians who received iPads to facilitate finding health information for staff and parents completed a separate survey to capture the support they delivered. Of the 12 respondents, eight (72.7%) have been asked for assistance from teachers, eight (72.7%) by parents, two (18.1%) by teaching assistants, one by a school social worker, and one by the school psychologist. Six (50%) have helped EGCSN staff 1- 5 times, Two (16.6 %) between 6 - 10 times, and two (16.6%) more than two times. When asked how many times they have assisted parents, seven (58.3%) answered 1 – 5 times and three (25%) answered 6 – 10 times. Since the professional development sessions, two (16.6%) respondents indicated these numbers have increased. The high school librarian has also noticed an increase in health related ILL requests since the sessions.

When asked how they had helped, 10 out of the 12 nurses and librarians responded. One responded indicated that she had not assisted other staff or parents since the class. They were instructed to select all the choices that applied. The response breakdown clearly indicated that finding health information on a condition was the biggest need with ten respondents (90.9%) selecting that option. Seven (63.6%) respondents were asked help in finding articles on a medication Developing a search strategy, including selecting the appropriate resources was indicated by 2 (18.1%) respondents. One (9%) respondent helped retrieve articles from another library. Finally, one (9%) spent time helping a staff member locate information for curriculum development. While supporting curriculum development was not a project objective, it was an unintended positive outcome.

The results from the surveys demonstrate that the goal and objectives of this project were overall successful in educating K – 12 professionals and special needs parents in finding reliable health information.

Discussion

The results of this project can be judged both quantitatively and qualitatively. While attendance and evaluations tell part of the story, there is an anecdotal side that touches upon the intangible and unexpected benefits that grew out of this collaboration. The figures are

telling as they demonstrate that the resources are being used by the target audiences, but the other outcomes are also worth sharing.

The project was very successful as an initial partnership. As demonstrated, the evaluation results show that K-12 professionals and the parents of special needs children plan to use the resources to find health information. The survey results previously reviewed also indicate that the school librarians and nurses are being sought after to assist in finding health information. In June 2014 an informal poll of the nurses indicated that requests for information are still being received, especially at the beginning of the 2013-2014 school year when the students were returning. This timing is understandable, given the staff are learning the students' needs.

As this project developed from concept to implementation it became clear the application was broader than originally anticipated. The resources taught were also of interest to educators for inclusion within the middle school and high school curriculum. For example, a number of attendees indicated that NLM drug information resources, such as the Drug Information Portal and PillBox, would be useful for students required to research medications and other substances. Health information can be used for multiple purposes within a school district further expanding the instructional benefit beyond the initial goal.

Another positive result was the marketing to school personnel of the school library resources, including promoting the value of the librarians. The high school nurse consults with the high school librarian on search strategies and resources that were covered in the classes. After the last staff session, an elementary school librarian thanked the AMC librarians for promoting the EGCSd librarians as resources to school staff. By including the high school library website in the instruction, the EGCSd librarian was able to meet with a broad audience of educators at the same time. Resources covered in the classes were added as age appropriate to the district library webpages. Additionally, Columbia High School is now an affiliate member of the NN/NLM MAR, so the librarians will directly receive notification of trainings and resources.

Co-training with nursing, social work, psychology and teaching staff was also identified as a benefit. Although their jobs intersect, they do not usually participate in professional development opportunities together, because the health staff has specialized training and the teachers have reading and curriculum training. These sessions provided an opportunity for everyone to be together.

For anyone wishing to replicate this program, cooperation between institutions is the key to success. AMC and EGCSd project planners worked well together, respecting each other's strengths, knowledge, and contributions to the project. This collaboration has continued even though the project has ended through resource sharing and communication of other learning opportunities. During planning, it is important to recognize that each institution might have different purchasing and information technology requirements and to leave enough time to ensure that these are met. If the project partners are flexible and are willing to work together, then the outcome should be as positive as our experience.

Despite the success of the project, there are study limitations which should be noted. This project took place within one school district so the sample size was small, especially with the librarians, nurses, and special needs parents. The district has five librarians and seven nurses, so a broader sample incorporating other districts would provide additional data and support. Additionally, there was no needs assessment done for the East Greenbush Special Needs Parents Group. Should this project be replicated that may be an enhancement to consider. More in-depth study of the parents needs is warranted.

Although this project was local in scope, K-12 support is a current national initiative of the NN/LM. As such, there are an increasing number of projects in this area that are being conducted, but not reported on as of yet. For instance, MAR has funded five projects in the last two years to support K-12 professionals, including this project (Barger 2013). They have received positive feedback from educators during K-12 educator and school librarian conference exhibits who were pleased to learn about the resources available to them (Collins 2014). Similarly, the NN/LM Mid-Continental Region (MCR) reported exhibiting at the Utah Educational Library and Media Association 2014 Spring Conference to favorable response. The teachers were especially pleased that using NLM resources would free them to spend more time educating the teachers (Bramble 2014). As these initiatives grow, more success stories will presumably be available through the literature.

Perhaps the most telling indicators of success are the anecdotes and thanks that have come back to the project planning team. The district's nurses reported using the iPad to search Pillbox to find information regarding students' new medications. The EGCSO Director of Special Education and Pupil Personnel Services received several e-mails after the "Searching Consumer Sites" session thanking her for the class and indicating its usefulness. The success of this collaboration is perhaps best summed up in an e-mail the high school librarian received from a teaching assistant with a request for an article she had found after using one of the resources she learned about in class:

"Thank you so much for getting this. It will be a big help with one of the students... I learned a lot of valuable websites to use to help with the children in the class. I plan on doing more research on the children I work with to better help us understand them."

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Table 1

Resources Searched Post-Sessions by K-12 Professionals

Have you searched any of the following since this session?:	Yes	No	Don't Remember	Plan to, but haven't had the need	Total Respondents
Finding Reliable Professional Health Information on the Web: November 2, 2013*					
PubMed (http://www.PubMed.gov)	12	7	0	4	23
PubMed Central (http://www.ncbi.nlm.nih.gov/pmc/)	10	8	2	3	23
Google Scholar (http://scholar.google.com)	6	13	0	4	23
ClinicalTrials.gov (http://www.clinicaltrials.gov/)	2	15	1	5	23
Sweet Search (http://www.sweetsearch.com/)	2	15	0	6	23
Trip Database (http://www.tripdatabase.com)	0	18	0	5	23
*The survey was distributed to 83 personnel. Of the 53 respondents, 22 indicated they attended the class. Actual class attendance was 28.					
Searching Consumer Resources: January 25, 2013**					
MedlinePlus (http://www.medlineplus.gov)	9	9	0	7	25
PubMed (http://www.PubMed.gov)	9	12	0	4	25
PubMed Health (http://www.ncbi.nlm.nih.gov/pubmedhealth/)	8	10	1	4	23
Drug Information Portal (http://druginfo.nlm.nih.gov/)	6	13	0	5	24
Healthfinder.gov (http://healthfinder.gov)	5	16	0	3	24
FamilyDoctor.org (http://familydoctor.org)	2	18	0	3	23
Child Health Plus (http://www.health.ny.gov/health_care/child_health_plus/)	2	17	0	5	24
U.S. National Library of Medicine (http://www.nlm.nih.gov)	2	15	1	6	24
Agency for Healthcare Quality and Research (http://www.ahrq.gov/consumer/)	1	21	0	3	25
National Center for Complementary and Alternative Medicine (http://nccam.nih.gov/)	1	18	0	5	24

**The survey was distributed to 83 personnel. Of the 53 respondents, 24 indicated they attended the class. Actual class attendance was 40.

Table 2

Recommended Resources for Parents by K-12 Professionals

Would you recommend any of the following sites to a parent?	Yes	No	Maybe	Total Respondents
Searching Consumer Resources: January 25, 2013 [*]				
MedlinePlus (http://www.medlineplus.gov)	12	1	10	23
PubMed (http://www.PubMed.gov)	12	3	8	23
PubMed Health (http://www.ncbi.nlm.nih.gov/pubmedhealth/)	12	2	9	23
Drug Information Portal (http://druginfo.nlm.nih.gov/)	9	3	11	23
Child Health Plus (http://www.health.ny.gov/health_care/child_health_plus/)	9	5	9	23
Healthfinder.gov (http://healthfinder.gov)	8	6	9	23
FamilyDoctor.org (http://familydoctor.org)	8	5	10	23
U.S. National Library of Medicine (http://www.nlm.nih.gov)	8	5	11	24
National Center for Complementary and Alternative Medicine (http://nccam.nih.gov/)	7	6	10	23
Agency for Healthcare Quality and Research (http://www.ahrq.gov/consumer/)	6	6	11	23

^{*} The survey was distributed to 83 personnel. Of the 53 respondents, 24 indicated they attended the class. Actual class attendance was 40.