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ACADEMIC LIBRARY SERVICES FOR USERS WITH DEVELOPMENTAL DISABILITIES: PARTNERSHIP OF ACCESS AND SYRACUSE UNIVERSITY LIBRARY

KEYWORDS

academic libraries, developmental disabilities, intellectual disabilities, cognitive disabilities, services for people with disabilities, library instruction, minorities, underserved populations, nontraditional students

ABSTRACT

Syracuse University Library and Access partnered to provide library orientations to six Syracuse University students who have developmental disabilities. Access is a service that supports college course attendance for students who have developmental or cognitive disabilities. Students with developmental disabilities are being included in college life more and more. As this occurs, academic libraries will be providing more services to this population. We hope Syracuse University's experience will be useful for other libraries to build on as they develop services. Additionally, we discuss opportunities to improve services for all students by focusing on students with developmental disabilities.

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INTRODUCTION – THE SYRACUSE UNIVERSITY LIBRARY AND ACCESS PARTNERSHIP

Access is a service that supports college course attendance for students who have developmental or cognitive disabilities. Access is a collaboration between University College at Syracuse University and a nearby adult service agency, Onondaga Community Living. Access is funded by New York State Medicaid Day Habilitation funds granted through the Office of Mental Retardation and Developmental Disabilities. These funds typically support adults with developmental and cognitive disabilities in residential or employment situations. Onondaga Community Living proposed this project as an opportunity to support adults in a college setting. It is a novel use of these funds, and one of the first efforts of its kind in the nation.

Access students are non-matriculated adult continuing education students who register for undergraduate courses using an audit designation. Although they are registered for audit, Access students receive the supports necessary to complete course assignments and assessments, sometimes with adaptations and modifications.

Access students are not eligible for admission to the University. They typically do not have high school diplomas or they have IEP (individualized education plan) diplomas, which do not qualify for college admission. Auditing courses with one to one support is an opportunity to pursue learning as an adult student. The one to one support person, called a “campus mentor,” works under the supervision of the Access Coordinator. The Coordinator, Ann Atkins, is a certified special education teacher who attends to the needs of the adult service agency and supports students on campus.

In the Spring of 2007, Ann Atkins contacted Adina Mulliken, who she found listed as the disability services contact in the Syracuse University Library “Welcome Guide” booklet. They discussed library services, such as extra reference assistance and assistive technology, that the library offers for people with disabilities, as well as the library’s general services for all students.

The Coordinator was interested in the library’s instruction program. The students using Access do not work together as a group because one of the goals of the program is to integrate students into the college environment. Therefore, they would come in individually with their mentors. The summer was good timing since

it was less busy for instruction staff. The library was able to offer individual orientations for each student.

While touring the library, the Coordinator saw a display for the University Shared Reading program book, *Mountains Beyond Mountains*. All students enrolled in Freshman Forum at Syracuse University are required to read and discuss this book. The Coordinator immediately suggested that reading this would be a natural opportunity for her students to share experiences and connect with other students on campus. The book then became the focus of the library orientations.

The students were not enrolled in classes during the summer of 2007, so it was an opportune time to more fully orient them to the campus and to practice reading, comprehension, and communication strategies that would support them in their regular semester course work. Collaborating with personnel at Syracuse University Library was a natural opportunity to bring several aspects of this program together, such as: using technology in the library to support student learning, becoming oriented to an important educational facility on campus by *using* it fully – not just *visiting* it, and supporting students to become more familiar working with University personnel.

HISTORY AND LITERATURE SEARCH

Searching the library literature with the keywords “developmental disab*”, “cognitive disab*” or “intellectual disab*” revealed just one source about academic libraries targeting services for students with these disabilities. The databases

searched were IRWI, Library Literature and Information Science Full Text, Library Information Science and Technology Abstracts, and Library and Information Science Abstracts. The one source located, a chapter in *Information Services for People with Developmental Disabilities*, published in 1995, emphasizes the importance of academic libraries serving students with developmental disabilities. The chapter helpfully says that “orientation programs may need adaptation for individual students” (236). However, although the title of the chapter is “Academic libraries and students with developmental disabilities,” the services that are described at specific institutions cover a variety of other disabilities, such as learning and visual disabilities, but actual services that took place for people with developmental disabilities are not discussed. Nevertheless, it is of interest that several of the institutions were offering one on one sessions for students with various disabilities (239-242).

The chapter in *Information Services* states, “If one assumes the term developmental disabilities is the equivalent of mental retardation, it would seem that academic libraries have no students with developmental disabilities to serve...” (234). Many would disagree with this assumption that people with mental retardation do not use academic libraries. The 1999 *Guidelines for Library Services for People with Mental Retardation* published by the Association of Specialized and Cooperative Library Agencies of the American Library Association specifically states otherwise.

Although the broader term developmental disabilities is now often used in place of the pejorative term “mental retardation,” those with cognitive and intellectual disabilities, previously called mental retardation, do use academic libraries.

No more recent information than the 1995 *Information Services* chapter was found about academic libraries that have targeted services for people with developmental disabilities. Informal conversations during American Library Association conferences suggest that some academic libraries are providing such services; however, discussion of it in the literature could not be located.

Several articles were found through the ERIC database about students with developmental disabilities in higher education. The articles describe students who have attended special programs or used services targeted to developmental or cognitive disabilities (Eskow and Fisher, 2004; Gaylord, 1997; Schmidt, 2005), or those less formally supported by parents and employees of a university (Casale-Giannola and Kamens, 2006). Schmidt (2005) reports “a recent surge in the number of postsecondary opportunities for people with mental retardation” (p. A36). He explains that starting in the 1970’s, campus-based programs began supporting people with mental retardation based on the Education of All Handicapped Children Act of 1975, which required that public school systems provide services to all children until age 22 or until they graduate. According to Schmidt, College programs at this time tended to segregate students with mental retardation from the mainstream. However, “by contrast, many of the newest programs put the emphasis on college,” as opposed to the older programs which are financially supported by public high schools (p. A36). Services that are not funded through traditional public high school funding streams may have more freedom to emphasize integrating students into the college experience, as opposed to having

several students spending time with one mentor, effectively segregating the students with disabilities by grouping them together.

As of December 2008, the database ThinkCollege.net (<http://www.thinkcollege.net/>) lists almost 140 opportunities and programs for students with intellectual disabilities. ThinkCollege.net was developed by the Institute for Community Inclusion at the University of Massachusetts Boston, in collaboration with the Center on Disability Studies at the University of Hawaii, and the Federation for Children with Special Needs. It is supported by grants from the U.S. Department of Education, Office of Special Education Programs and The National Institute on Disability and Rehabilitation Research. As of December 2008, only 30 of the opportunities listed are categorized as “inclusive individual supported,” and among these is the collaboration between Syracuse University and Onondaga Community Living. The other programs are classified as “mixed” or “substantially separate,” implying that these programs support students who have intellectual disabilities but they are not fully integrated with the mainstream college population. Their support personnel may also work with more than one intellectually disabled student at the same time. Although inclusive opportunities are not yet common, their prevalence appears to be increasing and in growing demand.

LITERATURE SEARCH: SERVICES TO PEOPLE WITH DISABILITIES IN PUBLIC AND SCHOOL LIBRARIES

Several articles about public and school libraries serving people with “mental retardation,” developmental disabilities, autism, asperger’s syndrome and dyslexia

suggest that academic libraries could learn from the other libraries' experiences. Jennifer Holmes, a public librarian, conducted a needs assessment for users who have developmental disabilities in 2007 in Adams County, Colorado (Holmes, 2007). Another librarian, Dennis Norlin, offered bibliographic instruction sessions targeted toward users with mental retardation (the wording used at the time) at a public library in 1989 (Norlin, 1992). Norlin did pre and post-tests to study the effect of the instruction. Both Holmes' and Norlin's studies make the point that users with developmental disabilities do read, do have sophisticated interests, and do use the library; certainly important points for academic libraries to be aware of.

To meet these information needs of library users with developmental disabilities, several articles about public and school libraries recommend sources for collection development. High/low books are frequently mentioned in the literature (Holmes, 2007; Juozaitis, 2004; Akin 2004). High/low books are intended to be high interest and low vocabulary. They can be adult oriented. Holmes additionally recommends English as a Second Language and Adult Basic Education books, as well as children's books if the user prefers them. Bloomquist gives detailed collection development recommendations for children with autism (2005). Many articles recommend collecting audio books or other commercially available alternative formats (Akin, 2004; Bloomquist, 2005; Gorman, 1999; Holmes, 2007; Retledge, 2002; Weingand, 1990).

Akin describes a number of teaching strategies geared toward autistic students (2004). Although targeted toward younger children, some of the strategies might be

adapted for autistic library users in higher education. Similarly, Halverson describes techniques for communicating during a reference interview especially with students who have asperger's syndrome, some of which might be useful for older students as well (2006). Gorman gives a rich explanation of dyslexia and strategies for a school library to develop collections and to teach kids how to use the library, which certainly can be helpful for academic librarians (1999).

Finally, the library OPAC and web design is mentioned by Holmes, as well as Gregor and Dickinson, as a barrier for people with developmental or cognitive disabilities that should be improved. Holmes states, "A catalog that is easier to navigate and understand would benefit all patrons, not just those with developmental disabilities" (2007). Gregor and Dickinson, who work in the field of human computer interaction, developed a simplified interface for an email application (2006). They tested the application with older adults and found that "learning was significantly facilitated" compared to a traditional email interface (2006). They additionally describe helpful web interface features for people with dyslexia and other cognitive difficulties (2006). Although academic librarians providing instruction sessions for students with developmental disabilities are not likely to develop such complex applications, similar features could be considered while creating or selecting web pages and other online resources.

LITERATURE SEARCH: SERVICES TO PEOPLE WITH DISABILITIES OTHER THAN DEVELOPMENTAL DISABILITIES IN ACADEMIC LIBRARIES

The literature about learning disabilities, speech disabilities, and other disabilities in academic libraries contain advice that can be useful for providing services to students with developmental disabilities as well. Forro describes library staff taking the initiative to create and use a word board to communicate with a user who had a speech and mobility disability at Michigan State University Library (2002). This precedent could be particularly helpful for some students with developmental disabilities. A word board can be as simple as words written on a piece of paper that the user points at to communicate, though Forro's library designed something more elaborate. Similarly, in the public library context, Holmes points out that people with developmental disabilities may use communication devices or have difficulty speaking, and that library staff should be prepared to communicate in this situation (2007).

Applin's advice for proactively providing accessible bibliographic instruction for students with various abilities and disabilities (1999) also includes ideas that would be relevant for students with developmental disabilities. She emphasizes "multi-sensory teaching" and explains, "anything that is taught should include short, specific, verbal instructions or explanations; simple, large, visual representations; and immediate, hands-on experience" (1999). Carter makes similar recommendations and explains that it is important to use a universal design that would work for users of all abilities rather than simply reacting at the last minute when a user or professor requests an accommodation (2004).

The literature describes at least one academic library, Oxford University Library, taking on the role of providing alternative format books, including in house creation of alternative format, to make originally print books equally accessible to users with disabilities (Harris, 2007). Alternate formats are important for users with developmental disabilities in particular. Alternate format can include various formats, such as analogue audio books on CD, print books that are scanned and OCR'ed for use with Kurzweil 3000 or other text to speech adaptive technologies, ebooks from commercial vendors (although these are often inaccessible to assistive technology), and the newer DAISY format which can combine some advantages (including searchability and natural sounding voice) of the other formats. At Syracuse University, as at many other institutions of higher education, an office for disability services provides these accommodations. In the future, the advantages of integrating such services into academic libraries may be a consideration in moving toward a more universal design.

The authors of the present article found that some of the recommendations in the literature agreed with our experiences and many of the recommendations could be useful for Syracuse University Library as we continue to work to improve our services.

PREPARING TO SERVE A NEW GROUP OF STUDENTS

One goal of the orientation at Syracuse University Library was to have the students learn about library resources and services. It was decided to create a handout

which would guide the students to ask questions for specific resources at each of four reference desks in Bird Library.

The library's head of instruction and the instructional services librarian agreed to support the project. Librarians for several subject areas: art, music and maps, also offered assistance with the handout and tours.

One of the learning objectives was to practice reading using a variety of strategies: partner reading or taking turns reading a book aloud, using books on tape, and using Kurzweil 3000. Kurzweil 3000 is software that will highlight words on the computer screen and simultaneously read them aloud. It has simple, on screen, cassette player-like buttons. One copy of Kurzweil 3000 is located in the general reference area and another copy is in a private room for students preferring greater privacy or quiet. The Coordinator suggested using the reference area to prevent students from being isolated in an area for people with disabilities.

Another goal of the orientation was to help staff become comfortable working with students who have disabilities and who sometimes communicate differently from other students. Some of the students talk slowly, some need to type rather than speak aloud, and some point at letters, pictures, or words on a board to communicate. The mentors facilitate communications where necessary.

Three websites on etiquette for communicating with people who have disabilities were reviewed (see Appendix A). A brief compilation of these was emailed to the library's public services staff, along with a copy of the handout and the offer that

questions, such as any difficulties with Kurzweil 3000, could be referred to the disability services librarian if needed.

STUDENTS' AND LIBRARIANS' EXPERIENCES

The Coordinator distributed the handout to the students and their mentors as part of a larger binder of summer activities. The first segment of the orientation asked students to contact one of two librarians to arrange a tour. Early in the summer, one student contacted the instruction librarian and came in for a tour. This librarian reported that experience was very positive, although the student was perceived by library staff to be rather shy. The librarian additionally observed that the student seemed inclined to work independently, similar to many undergraduates. In fact, that particular student does not speak aloud to communicate. He types or he can point at a word board. The student's mentor may need to be relied upon more to facilitate further communication with this student. Also, librarians could take initiative to write word choices or "yes/no" on a sheet of paper to play a more active role in the conversation.

The librarian found that the mentor was helpful for both student and librarian in breaking the ice. Although these tours were arranged to orient students to the library, they also provided an opportunity to orient staff to the students. Both parties may need this initial support from the mentor. As Causton-Theoharris and Malmgren contend, an important role for mentors is to encourage people who do not have disabilities to become comfortable interacting with people who have disabilities (2005).

Another student contacted the disability services librarian. She and the music librarian gave this student a tour. The disability services librarian found it was somewhat challenging to understand whether the student was engaged. This is not unusual during orientations with new students. The mentor was very helpful in making the librarian feel more comfortable. The student communicated by showing enthusiasm about using the computer, so they spent extra time on the computer.

Librarians did not get tour requests from the remaining four students. It is not clear if the students chose not to take advantage of the opportunity for personal reasons, or if difficulties arose preventing the mentors from making the opportunity available. As with typical college students, not everyone takes advantage of orientation opportunities. Students initiated contact later in the semester when the need arose.

For example, the disability services librarian met with one of the other four students and his mentor when they had difficulty using Kurzweil 3000. The University's Office of Disability Services helpfully provided the electronic book in a different format, which solved the problem.

Another student approached the reference desk with a request to use Jaws to access an online article. Several staff attempted to assist, but finally recommended the student return when the disability services librarian was available. The disability services librarian did not hear from the student. However, Jaws, a text reader for blind users, requires learning extensive keystrokes and would not have been

appropriate for their needs. This points to the need for training or signage to make all staff more aware of range of technology available and its intended purposes.

Two of the students, through their mentors, asked for background reading to prepare for their courses in the fall. The disability services librarian suggested some books and materials, including videos, PBS and BBC publications, and other materials of high visual or general interest. General knowledge facilitates learning from college lectures that presume this prior knowledge. Many students with developmental and other disabilities have gaps in their education. This librarian learned that collecting such materials could be a useful accommodation for the future.

RESPONSES TO THE ORIENTATION

The handout encouraged students to contact librarians when they finished the activities to discuss their experiences. Students did not respond directly to that request. However, one of the students and his mentor met with the disability services librarian during the fall. They shared the student's written answers on the handout, which were done very thoughtfully. Other reference librarians reported that students had asked for assistance with the questions on the handout, as intended.

The same mentor explained that emailing or calling the librarians to arrange appointments was difficult. To access email, she and her student usually had to be in the library anyway in order to use the computers. It was more practical for them to

ask at the reference desk to see if the librarian was available. Other Access students occasionally did this as well.

This mentor had worked with another student during the summer. She reported that movies with subtitling did not work as well because she frequently needed to stop and read the subtitles for this student. She also reported that asking questions at reference desks did not work well for this student because the student is nonverbal. In the future, the disability services librarian intends to make sure some movie options for the orientation do not have subtitles. She also intends to further encourage nonverbal communication, such as using a word board, whenever mentors and students demonstrate this preference.

Having students with developmental disabilities in mind, the library's Principal Bibliographer purchased an audio copy on CD of *Mountains Beyond Mountains*. However, since the students using Access were registered as audit students, they could not check out library materials. The issue of how much access to grant audit students implicates larger issues for the University. Therefore, the Access Program obtained their own copy of the audiobook and used it in the library. Circulation statistics show the library's audiobook was checked out seven times during the fall semester, suggesting it was useful for other students at the University.

One Access student showed a strong preference for oral readings. Her campus mentor read assigned readings aloud. The orientation guide prompted the mentor to support her student in using headphones to listen to the audio book copy of *Mountains Beyond Mountains*. The student displayed great displeasure, tugging at

the headset and grimacing. Reading the material aloud, in the company of a companion, was clearly an important part of the reading experience for this student. However, e-books that are read in a natural voice can have excellent voice quality. Perhaps using an e-book with natural voice in a location where headphones are not necessary would work for this student in the future. One of the goals of the orientation and the college experience in general is to support students in becoming more self-directed and more fully aware of opportunities to access community life. A natural goal for a student who loves to be read to, such as this student, is to make this activity less staff dependent. E-books could become an important resource for such students.

CONCLUSIONS

Students with developmental or cognitive disabilities are beginning to be included in college life more and more. As this occurs, academic libraries will be providing more services to this population. Therefore, an awareness of services that can be useful for them is important. We hope that this discussion of Syracuse University's experience will be helpful for other academic libraries as they create their own services.

Additionally, there is an opportunity to improve services for all students by focusing on students with developmental disabilities. Students with learning disabilities are the largest group of students with disabilities on many college campuses and they

are often a significant percent of the entire student body. Therefore, increased knowledge on the part of library staff about Kurzweil 3000, which is intended for users with learning disabilities, has potential to be useful to many students in addition to those with developmental disabilities. Furthermore, providing learning materials, as well as library reference services, in as many formats as possible, such as the print and audio versions of a book, or in-person as well as online research assistance, can be helpful for many students.

Finding ways to encourage more communication on a drop in basis, even though staff will not always be available, is likely to be convenient and practical for many library users in addition to those who have developmental disabilities.

Recommended etiquette for communicating with people who have developmental disabilities is really just a review of librarians' usual reference interview skills, with emphasis on listening

In the experience of the authors, many library staff welcome the chance to work with students who have developmental disabilities and are quite willing to treat this minority group with the same expectations and respect as any other cohort of students. The staff at Syracuse University Library certainly learned about some service improvements that can be made in the future. Overall, the collaboration between the library staff and the students and professionals involved with Access and Onondaga Community Living was educational and enriching.

APPENDIX A

Websites About Etiquette for Communicating with People who have Disabilities

Center for Accessible Living. Disability Etiquette.

http://www.calky.org/resources.htm#Disability_Etiquette (accessed February 25, 2008).

Mazrui, Jamal. 2007. GENERAL ETIQUETTE For Interacting with People with Disabilities. <http://www.empowermentzone.com/etiquestt.txt> (accessed February 25, 2008).

Kansasworks.com. Ten Commandments of Etiquette for Communicating with People with Disabilities

https://www.kansasworks.com/ada/disability/dis_controller_dsp.cfm?page=9201&calling_file=dis_controller_dsp.cfm&hash=B6A10C19D220DD5673884FAA8A8F1C48

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Holmes, Jennifer. 2007. Serving an Invisible Population: Working with Patrons with Developmental Disabilities. *Colorado Libraries*. 33, no. 4: 35-40.

Institute for Community Inclusion at the University of Massachusetts.

ThinkCollege.net: Postsecondary Education for Students with Intellectual Disabilities.

(<http://www.thinkcollege.net/>) (accessed February 25, 2008).

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