

## Community Literacy and Friendship Model for People With Intellectual Disabilities

Thomas R. Fish, Paula Rabidoux, Jillian Ober, and Vicki L. W. Graff

Community living for adults with intellectual disabilities rarely translates to full community participation; and reports of loneliness, isolation, and lack of friendships are a recurring theme among individuals and in the literature (Bramston, Bruggerman, & Pretty, 2002; Chadsey & Beyer, 2001; Lunskey & Neely, 2002; Pottie & Sumarah, 2004). Likewise, meaningful and realistic opportunities for literacy and ongoing learning are virtually nonexistent for many people with intellectual disabilities.

There is limited theoretical and practical knowledge of how adults with intellectual disabilities might maintain and/or develop literacy skills beyond school. Although we continue to refine our operational definitions of literacy (functional literacy, cultural literacy, computer literacy) and predict which skills may be necessary for success towards one's life goals, most researchers agree on at least this one point: diminished literacy skills consistently result in a lower quality of life with fewer employment and leisure opportunities for this population (National Adult Literacy Survey, 2002). Though in some cases employers appear to be willing to hire persons with disabilities, employees need to demonstrate essential reading and interpersonal skills. Beyond the employment realm, access to literacy offers adults with intellectual disabilities increased opportunities for inclusion into local community life and culture and is a potentially life-empowering event.

Experts now know that literacy is not a developmental end product but that oral language and written language are interrelated, reciprocal, and potentially lifelong learning endeavors (Teale & Sulzby, 1986). Research results suggest that for children, literacy "emerges" from a range of social and cultural experiences with other people and written language, including story books; magazines; hand-written lists, notes, and signs; and words on television, computer screens, and in movies. This emergent literacy (socially supported literacy interactions) facilitates both oral language and conventional literacy learning (Koppenhaver, Coleman,

Kalman, & Yoder, 1991). Such literacy interactions are often highly motivating and effective contexts for social interaction, communication, and learning (Kirchner, 1991; Koppenhaver et al., 1991; Ratner, Parker, & Gardner, 1993; Watson, Layton, Pierce, & Abraham, 1994).

Field reports from adult education programs consistently indicate difficulties meeting the specific needs of adults with intellectual disabilities due to a lack of community technical assistance (National Institute for Literacy, 1997). In a 1995 monograph by researchers from The Roeher Institute, the focus was on people with intellectual disabilities who sought literacy instruction. The common experiences expressed by participants interviewed included exclusion and segregation from the mainstream; the presumption of illness, discrimination, poverty, and loneliness; vulnerability to abuse; and violence.

Similar to literacy, *social connectedness* (i.e., the extent to which individuals have friendships, engage in social activity, and feel a sense of belonging) positively correlates with a sense of empowerment and with overall quality of life (Lunskey & Neely, 2002). However, adults with intellectual disabilities often lack the opportunities and/or social skills necessary to participate in social events without adequate supports. Since the mid-1990s, individuals with intellectual disabilities have been living and working independently in their communities in unprecedented numbers (Nisbet & Hagner, 2000). Despite this increase, adults with intellectual disabilities rarely participate in local social activities (National Institute for Literacy, 1997). Many fundamental needs of people in this population are neither identified nor supported, and they continue to experience disproportionate segregation, isolation, and loneliness within their homes and communities (Bramston et al., 2002; Chadsey & Beyer, 2001; Minnes, Buell, Feldman, McColl, & McCreary, 2002; Nisbet & Hagner, 2000).

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### Description of the Program

The Next Chapter Book Club (NCBC) is a model for promoting literacy and lifelong learning,

building friendships, and including people with intellectual disabilities into local communities. Clubs meet weekly for one hour in local bookstores and cafés, where members and volunteer facilitators read aloud and discuss a book of the group's choosing. Books in the NCBC library are chosen based on their popularity and readability. Many groups choose to read abridged classic novels such as *The Secret Garden* and *A Wrinkle in Time*. Other groups focus on topics such as sports and review the sports pages of the local newspaper. A group typically meets for 12 to 16 weeks to complete a book, depending on the members' skills and interests and the reading material selected. The program began in 2002 with two clubs in Columbus, Ohio and has expanded to more than 50 clubs in 9 states serving more than 300 members.

At the end of 2004, we had 115 members from central Ohio meeting in NCBCs: 45% were male and 55% were female ( $n_s = 52$  and  $63$ , respectively). They ranged in age from 17 to 82 years ( $M = 38.3$ ). More than 95% of NCBC members were eligible for Mental Retardation/Developmental Disability services through their local county board system. The majority of members were not what is considered *conventionally literate*, that is, able to independently read and comprehend text (Kaderavek & Rabidoux, 2004). To describe the literacy skills of our members, we devised a five-tiered scale (Fish, Ober, & Rabidoux, 2004). Table 1 shows the reading levels of 45 members in the summer of 2004 based on the ratings of one facilitator from each group using the scale within 3 weeks from the start of the group.

These data suggest that 54% of members demonstrated emergent literacy skills requiring social support (Levels I, II, and III) and 46% demonstrated some level of functional, independent literacy (Levels IV and V). Emergent literacy as used here describes the range of activities developed cooper-

atively with interactive partners or in social/cultural contexts (Burns, Griffin, & Snow, 1999).

### Profile of an NCBC Member

Paul was a 45-year-old man who had been a member of the NCBC for one year. He lived at home with his 70-year-old mother. At age 5, Paul's teachers stated that he would never learn to read; however, Paul did learn to read along with his older brother and was reading aloud before kindergarten. Paul was enrolled in special education classes through high school and graduated at age 19.

Until 10 years ago, Paul worked very little outside his home. For several years he was employed by a large corporate mailroom and was very satisfied with this position, which utilized his keen attention to detail and reading abilities. In the 2 years preceding this study, Paul was laid off from the mailroom. He then worked in an industrial enclave that did not require any reading skills and was somewhat less satisfying.

In addition to his favorite books on presidential history and mysteries, Paul read the newspaper every morning. He also enjoyed such television game shows as "Jeopardy" and "Wheel of Fortune," which drew on his literacy skills and knowledge. Paul said that he had been reading even more since joining NCBC. Paul's favorite parts of being in the club were "reading out loud together and talking about all the food in the book" and the refreshments in the café.

Paul's mother noted that he often needed to be "drawn out" in social situations. Because "he has always loved to read," the NCBC offered Paul a comfortable activity in which to socialize.

### Program Uses Volunteers and Meets in Public Places

Two volunteers trained by NCBC staff facilitate each club. Current and recent volunteer facil-

**Table 1** Description of Reading Levels of 45 Next Chapter Book Club Members in 2004

Reading level	Members rated	
	<i>n</i>	%
Level I: No letter recognition or understanding of written language	9	20
Level II: Recognizes and understands letters	7	16
Level III: Reads and understands single words	8	18
Level IV: Reads and understands sentences	6	13
Level V: Reads and understands paragraphs	15	33



**Figure 1** The Next Chapter Book Club model.

itators include high school and college students, parents, professionals, retirees, and people with disabilities. Co-facilitators establish a positive working relationship with each other and provide monthly feedback about the club to the program coordinator. The primary responsibility of each facilitator is to maintain an atmosphere where members are free to participate in any way they can and to express themselves. Facilitators are taught to use strategies that support the communication and literacy abilities of members.

Many traditional book clubs meet in secluded, sedate environments, such as libraries or individual homes. In contrast, NCBCs meet in visible, busy environments, where people gather to enjoy various social activities. Neighborhood bookstores, cafés, and coffee shops serve as “host sites,” within which members report feeling comfortable and included in typical adult activities. Host sites also benefit from an expanded customer base.

The reciprocal relationships among the primary NCBC constructs, namely literacy learning, social connectedness, and community inclusion, lay the foundation for the social validity and efficacy of the NCBC. As literacy and learning facilitate interactions with others, they also broaden exploration of one’s community. Social interactions and social connectedness significantly enhance literacy and learning and are essential components of a vibrant community life. Active community participation and community inclusion foster the retention of literacy and social skills as well as social learning (see Figure 1).

The NCBC project members consider reading and writing as socially constructed communicative

practices in order to develop an inclusive literacy paradigm. Thus, to best address the needs of adult learners with a variety of skill levels, we consider situational supports, including the social, functional, physical, and emotional contexts of literacy events, so that both oral and written communication and language are supported.

Building friendships and interacting with others are central to the NCBC model. Facilitators demonstrate appropriate interactions, maintain conversations focused on themes from the literature they are reading, and extend conversations (e.g., “Jane, did you know that Bob likes to paint, too?”). Volunteer facilitators are taught to engage individuals who may otherwise avoid participation in groups, particularly engaging in conversation. Exchanging phone numbers further encourages social interactions among members and extends their connections beyond meetings.

Participation in neighborhood communities distinguishes the NCBC project from many other educational and recreational literacy programs for adults with intellectual disabilities. Meeting in neighborhood bookstores, cafés, and coffee shops, members have opportunities to engage meaningfully in their communities and practice a wide array of skills in the natural environment, such as ordering and paying for beverages, conversing with host site staff, and browsing through the establishment. As members become accustomed to their role as contributing persons in a neighborhood, they achieve greater community independence and rely less on facilitator support. An additional beneficial effect of this open visibility is increased public awareness of people with intellectual disabilities. We have received positive responses from host site staff members and customers, with several customers expressing interest in participating in the NCBC.

These clubs are forming throughout Ohio and the rest of the United States. We are currently extending several aspects of the project, including using peers as facilitators; developing evaluation tools to assess changes in literacy, social connections, and community inclusion; and researching aspects of the program, such as the use of volunteer versus professional facilitators, the effects of a more intensive meeting schedule, and the inclusion of members with and without disabilities.

Clearly, people with intellectual disabilities have the right to participate as full and equal members of society in order to maximize their independence, productivity, and quality of life. We have

started to demonstrate that active participation in a book club supports community inclusion and life-long learning. Interviews of members following completion of a book have indicated that they found the NCBC experience highly satisfying and fun. Our call to action is for families and professionals in the disability field to embrace activities such as the NCBC and seek similar opportunities for people with intellectual disabilities to pursue learning, literacy, and community participation.

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## Authors:

**Thomas R. Fish, PhD** (E-mail: fish.1@osu.edu), Director, Social Work & Family Support Services, 257E McCampbell Hall; **Paula Rabidoux, PhD**, Chief of Speech/Language Pathology; 323 McCampbell Hall; **Jillian Ober, MA**, Program Coordinator, 327 McCampbell Hall; **Vicki L. W. Graff, BEd**, Program Manager, 257A McCampbell Hall, The Ohio State University, Nisonger Center, 1581 Dodd Dr., Columbus, OH 43210.