

Why Should You Start a Next Chapter Book Club in Your Community?

Learning never ends—but some people have more opportunities than others. In the United States, people with ID leave the formal education system with few (if any) expectations that they will continue to learn academically or socially. Those adults who may express an interest in further literacy learning often find themselves referred to adult basic education programs, where staff may be ill-prepared to work with adults with ID. And if someone successfully locates a reading tutoring program, it is generally designed as a solitary learning activity that rarely meets the needs many people with ID have for social learning and community participation. Thus, even when learning opportunities are available, they most often occur without a social context.

History indicates that adults with ID have repeatedly been discouraged from or denied opportunities to engage in nonsegregated, inclusive community life. Although we have made progress in community living, competitive employment, and social integration, people with ID rarely participate in the fabric of community activities, despite living and working in communities (National Institute for Literacy, 1997). As many investigators have noted, living *in* the community is not the same as being a *part of* the community. Community inclusion needs to extend beyond one's residence, place of employment, and education; it must include interacting and forming relationships with other community members as well as belonging to clubs and organizations (Renzaglia et al., 2003). These are among the reasons we started the Next Chapter Book Club in 2002.

The Next Chapter Book Club Model

We believe that active participation in a book club can support community inclusion, self-determination, and literacy learning. The NCBC provides adults with ID an opportunity to make social connections in a community environment, to improve self-esteem and literacy skills, and to continue to learn.

The Next Chapter Book Club Model

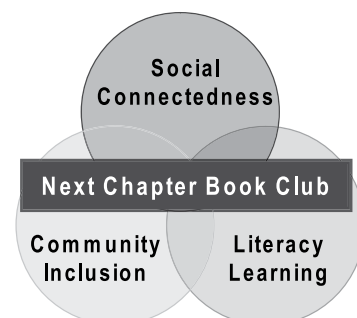


Figure 2

Literacy

We currently have limited theoretical and practical knowledge about how adults with ID might maintain and develop literacy skills beyond school. Research suggests that participation in reading as a leisure activity *declines* significantly for many young adults with ID after they leave the structured support of the educational system (Wagner et al., 2004). In 1995, The Roeher Institute published a series of monographs based on interviews of people with ID regarding their experiences with literacy instruction. The common recurring themes expressed by these participants included exclusion and segregation from the mainstream, the presumption of illness, discrimination, poverty, loneliness, and vulnerability to abuse and violence. These are some of the barriers people with ID encounter when they are interested in learning, literacy, and becoming part of a community. The Next Chapter Book Club promotes increased participation in literacy socialization as one mechanism to address and alter these inequities.

One objective of the NCBC program is to develop an inclusive working model of adult literacy learning for people with ID. While we struggle to define literacy operationally (functional literacy, cultural literacy, computer literacy, etc.) and to predict which skills may be needed for success toward one's life goals (National Adult Literacy Survey, 2002), researchers agree on at least this one point: Lower literacy skills consistently result in a lower quality of life with fewer employment and leisure opportunities. Although adults bring a variety of formal educational experiences to the book club, they all want to learn. They all want to "talk" with friends, have a beverage, and tell each other about their week. The social context of the book club is paramount to adult learning. The social context that surrounds the NCBC—scheduling the meeting with their staff, going to a community meeting place, being an active participant during the book club, purchasing a beverage, and interacting with staff and customers in the café—all support adult-based learning. That's why our model emphasizes the intersections of social connection, literacy/learning, and community. For adults with ID to become members of literacy communities, we must consider reading and writing as socially constructed communicative practices, not as isolated skills to be practiced alone.

The National Institute for Literacy noted, "As the movement for independent living for persons with disabilities grows, the need for better and more competitive literacy skills also increases" (National Institute for Literacy, 1997). Though employers appear to be more willing to hire people with disabilities, employees need to have basic reading and interpersonal skills. Adults with ID continue to be both unemployed and underemployed at a disproportionate rate compared to other adults. For example, in Ohio, the successful closure ratio (getting a job) for a person with ID in the Vocational Rehabilitation system is 16 percent, while the successful closure ratio for all Vocational Rehabilitation consumers is 59 percent (Ohio Rehabilitation Services Commission, 2003). Providing opportunities for literacy learning directly addresses this disparity.

Access to literacy offers increased opportunities for inclusion into local community culture and is potentially a life-empowering event. The NCBC program provides this opportunity for adults with ID to continue to engage in literacy and social activities. At the same time, it helps to build necessary skills to obtain and maintain future employment opportunities. Several researchers have noted that book interactions, such as those the NCBC provides, are often highly motivating activities and an effective context for social interaction, communication, and literacy learning (Kirchner, 1991; Koppenhaver et al., 1991; Ratner et al., 1993; Watson et al., 1994). The expectation of the NCBC model is

that members will continue to learn through participation in the club and will improve their sense of self-worth, because the program recognizes that they may be interested in and capable of learning.

We recognize that for some participants, independent literacy skills may not emerge. Historically, this has been an argument against inclusion of literacy activities for people with ID; that is, if conventional independent literacy is an unlikely outcome, then participating in literacy activities is illogical. We counter this claim by suggesting that participation in activities valued as part of our culture and human experience requires no definitive level of achievement to make the activity more or less rewarding or significant. Consider, for example, the value to the athletes, coaches, families, and spectators who participate in a Special Olympics competition. One could argue that the achievements of the Special Olympians, on a personal and social level, are every bit as significant as the world-record accomplishments of elite athletes. The magnitude of the achievement in terms of seconds and yards does not diminish the magnitude of the personal and social achievement for the competitors or the spectators. Similarly, we suggest that whether or not a member will become a conventional reader should not minimize the importance of interactive literacy activities (serving as the member's literacy partner and removing any barriers limiting this member's literacy participation). Participating in literacy at any level can improve quality of life, increase social interactions and relatedness, and improve communication skills. As one facilitator said, "You don't have to be able to read to enjoy a literary experience."

Both facilitators and members have realized increased reading ability and interest in reading. One member, Patty, is a forty-three-year-old woman who lives with her sister. After transporting Patty to and from her book club for six months, Patty's sister commented that she was amazed at how much more Patty had been reading since being in the NCBC. She noted that Patty was reading billboards and traffic signs as they drove to and from the book club, something she had never done before. Gary, a sixty-year-old man who had little formal educational experience, stated, "This is what I've wanted to do all my life: Since I've been in the book club, I've been learning."

Literacy does not merely mean being able to read. It also entails an understanding of the purpose of reading, the pleasure one experiences from reading, comprehending the stories, and being able to relate them to one's own life.

—Nicole B, co-facilitator, Columbus, Ohio

Literacy and ongoing adult education must be recognized as a basic human right for all people, with services starting at birth and continuing throughout life. The NCBC is an innovative program designed to integrate literacy and learning into social contexts for folks with a wide range of abilities. NCBC also seeks to empower members within their own communities, while increasing public awareness, self-esteem, and risk taking.

Shane is very high functioning and a good reader. He's an only child, and when we were new to the community, he joined the NCBC because he wanted a chance for more social interaction and to make friends.

—Wanda S, parent and legal guardian, Hilliard, Ohio

Social Connectedness

Similar to literacy, social connectedness—the extent to which people 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 (Lunsky & Neely, 2002). Interpersonal connections, friendships, and belonging play important roles in an individual's emotional and physical well-being. It is well recognized that our social activities help define us as people and promote self-esteem.

Similar to declines in literacy skills, participation in social activities, such as talking on the phone with friends and spending time with friends after work, also declines significantly for young adults with ID after they leave school (Wagner et al., 2004). Since the mid-1990s, individuals with ID have opportunities to participate in their communities in unprecedented numbers (Nisbet & Hagner, 2000); however, adults with ID often lack the social skills needed to participate in these events. The themes of social isolation and reduced support for people with ID recur in the literature (Lunsky & Neely, 2002; Pottie & Sumarah, 2004; Bramston et al., 2002; Chadsey & Beyer, 2001), regardless of family income or social background. Decreased support and fewer opportunities for activities result in a diminished quality of life.

Jeffrey was in assisted living since age fourteen in Port Clinton. Our parents died, then his roommate died, his case worker retired, and his care provider left town, so Jeff moved to Franklin County. He had no friends or peer relationships after moving here. Friendship Connection groups were 'cliquey.' Jeff joined the NCBC mainly for the social interaction; the reading was a bonus.

—Dean F, brother and co-facilitator, Blacklick, Ohio

NCBC members make social connections as part of their book club experience. Family members and facilitators report that the NCBC members have “made lasting friendships.” These friendships often extend to the volunteer facilitators: “We have all become real friends and, to a great extent, have positively changed each other's lives” (Suzanne F).

Stephanie is still in high school in a work program for social graduation. She works in the Sylvan Learning Center three hours a day pulling reading materials for classes. But she had lost contact with her friends, so she joined the NCBC mainly for the social skills.

—Stephen F, father, Westerville, Ohio

Community Inclusion

Evidence strongly indicates that a sense of social or community belonging correlates with overall quality of life. Research on the social isolation of people with ID routinely suggests increased leisure-time opportunities and utilization of the local resources as sources of support to address this isolation (O'Brien & O'Brien, 1993; Lunsky & Neely, 2002). However, despite our knowledge about the importance of connection to community, adults with ID continue to experience disproportionate segregation, isolation, and loneliness within their homes and communities (Bramston et al., 2002) and rarely participate in community activities, despite living and working in the community.

It's extremely important to be in the community doing what other people are doing, instead of just sitting at home, which can contribute to depression. The NCBC is pretty phenomenal...there are so few educational options after school ends.

—Peggy M, parent and legal guardian, Columbus, Ohio

To address these disparities, authentic community inclusion needs to extend beyond education and involve interacting and forming relationships with community members and belonging to clubs and organizations (Renzaglia et al., 2003). However, the research consistently suggests that these needs (of people with ID) are rarely identified or supported, and people with ID are in fact *not* regularly included as members of their communities (Nisbet & Hagner, 2000; Minnes et al., 2002). Local participation in community activities has also been significantly associated with improved social skills, positive affective demeanor, and increased levels of independence (Hunt et al., 1992). Other benefits of active local community participation for people with ID include increased economic productivity; improved health, well-being, and family functioning; higher life satisfaction; and more appropriate social interactions (Gracia & Herrero, 2004; Bramston et al., 2002). Adults with ID are more likely to experience success and build problem-solving skills if they are given the opportunity to apply skills in real-life community settings. In this natural community environment, social and literacy skills take on greater meaning (Renzaglia et al., 2003).

The NCBC model directly addresses many of the needs previously described. Clubs encourage the full inclusion of people in the cultural and social fabric of American society (Rehabilitation Act, 1973). They are held in community bookstores, cafés, and coffee shops—natural gathering places that have become increasingly popular in the last five years. People come to them to meet friends, buy a cup of coffee, do homework, read a book, and enjoy a variety of social activities.

People still go to bars to hang out and meet friends. Yet, the bookstore and coffee house scene may have a wider (and healthier) appeal to “come in and stay a while” without the pejorative connotation. (It’s hard to imagine taking your laptop computer into a bar to check your email or reading a newspaper or magazine, without someone hounding you to buy a drink or order food. Similarly, you can go to Borders or Starbucks anytime of the day or night. Try going into a bar in the middle of the morning and see how people react.) People in bookstores and cafés can be productive or lazy or whatever they like. There’s no expectation to be rowdy (like at a bar) or quiet (like at a library).

Local NCBC host sites provide an atmosphere in which members report feeling comfortable and included in typical adult activities. In these settings, staff and customers also meet and engage with NCBC members in natural contexts. Many members (and support staff) report pleasurable anticipation of NCBC meetings so that they might browse through the bookstore, select refreshments, and converse with host site customers and staff. As members become accustomed to their role as a contributing member of a neighborhood, they achieve greater community independence and rely less on facilitator support. Some members had never ordered their own drink before joining the NCBC, because it was always done for them.

She likes gathering at a grown-up place—Borders Café and Panera. She calls it ‘going to her meeting.’

—Karen B, parent and legal guardian, Dublin, Ohio

Many NCBCs meet in central spaces within host sites, where public traffic is at its highest. One example is at Target stores, where the cafés are usually located right next to an entry/exit doorway. This exposure contributes to increased public awareness of people with ID and has elicited positive responses from customers. Several customers have approached the NCBC group and expressed interest in participating in the NCBC.

A young woman was at Espress Yourself Coffee House today when we began gathering for our book club. She shared that she had observed us several times in the past and liked what she saw. She is the owner of a dance studio, and we will be meeting to discuss her working with us as a volunteer theatre instructor, dance instructor, musical expression instructor, something. This is a great opportunity for us to be able to provide additional choices for our clients, and we have our participation in the book club to thank for this contact. It is amazing what the exposure to the community is bringing our way.

—Jean T, former affiliate program coordinator and co-facilitator, Valparaiso, Indiana

While the NCBC provides important opportunities for community inclusion, it represents only a beginning. The NCBC is merely a structured platform that allows people with disabilities to meet and participate in mainstream society. It is not spontaneous. We would like to see people with disabilities hanging out with their friends on their own and hope that will eventually happen with greater frequency. For now, however, such factors as dependence on others for transportation and limited experience initiating and maintaining friendships tend to curtail spontaneous activity.

For people with disabilities, community inclusion means more than simply living in the community. It should translate to going wherever one wants, whenever one wants to go there. Figure 3 illustrates the critical success factors for people with disabilities engaging in community activities.

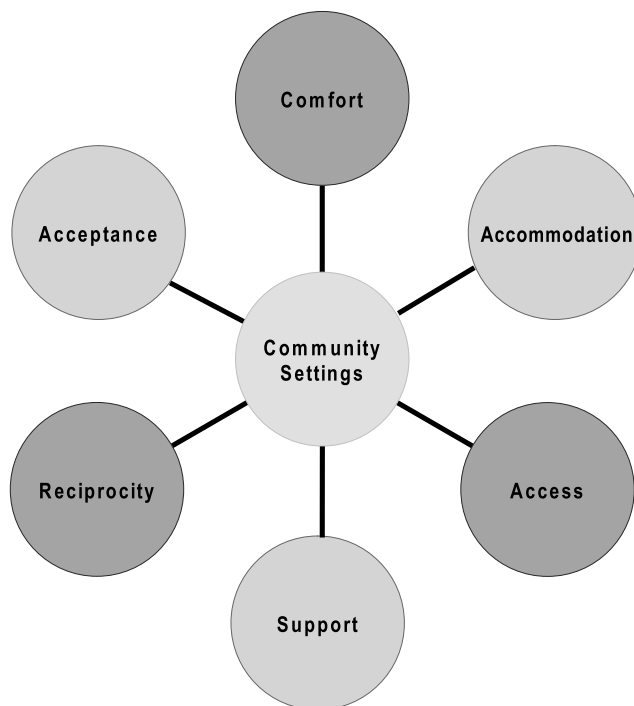


Figure 3—Critical success factors for people with disabilities engaging in community activities

To create opportunities for people with disabilities to engage meaningfully in community activities, the Next Chapter Book Club depends on the following factors and strives to enhance them in community settings:

- Comfort: attractive, friendly, and relaxed environment
- Accommodation: interaction with host site staff to meet members' needs
- Access: physical facility and transportation to meeting locations
- Support: developing friendships with other members and facilitators
- Reciprocity: members and facilitators helping themselves and each other
- Acceptance: by other members, facilitators, host site staff, and customers

Reciprocal Relationships in the NCBC Model



Figure 4—The Next Chapter Book Club model

The Next Chapter Book Club is effective because of the reciprocal relationships among its three major components. 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. Like the three legs of a stool, no one component is more important than the others.

I really like this place a lot, with the friends, the book, and the drink!

—Van, member, Columbus, Ohio

