

Creating Connections: A Community Capacity-Building Project with Parents and Youth with Disabilities in Transition to Adulthood

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ABSTRACT. The transition to adulthood presents many challenges for youth with disabilities and their families. Barriers in the environment often limit the full inclusion of these youth in daily community life. The purpose of this paper is to describe a community capacity-building (CCB) approach to facilitating the transition to adulthood for youth with

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The authors are grateful to the families, youth, and community members that participated and helped to inform this project.

This study was supported by a grant from the Jack and Ina Pollock Charitable Foundation.

Physical & Occupational Therapy in Pediatrics, Vol. 26(4) 2006

Available online at <http://potp.haworthpress.com>

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doi:10.1300/J006v26n04_06

developmental disabilities and their families. A pilot project that used a CCB approach with this population in one community in southcentral Ontario is described. The results of a qualitative, participatory evaluation demonstrate the benefits and challenges of this approach, with themes of increased community connections for youth and a greater awareness of their strengths and capacities. The perceived outcomes of the participants and the “lessons learned” for future initiatives using a CCB approach with different populations are discussed, as well as the fit between community capacity-building and occupational therapy. This pilot project demonstrates that a CCB approach has the potential to assist youth with disabilities to participate within their own communities.

doi:10.1300/J006v26n04_06 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800- HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Community capacity-building, adolescents, disability, transition, occupational therapy

Community can be defined geographically, referring to people living in the same area, or relationally, referring to a group with shared interests and values (McColl, 1998). A community is not static but instead represents the ongoing transactional relationship between persons, objects, and space within the environment (Grady, 1995). A community should provide a setting in which individuals experience a sense of belonging and oneness with others and where they feel safe to explore and achieve their unique potential.

Occupational therapists and other rehabilitation professionals have used different theoretical models to guide their work in communities, for example, a client-centered model (Canadian Association of Occupational Therapists, 2002), an independent living model (Canadian Association of Independent Living Centres, 1989), a community-based rehabilitation model (CBR; Kuipers, Kendall, & Hancock, 2001), and a community capacity-building (CCB) model (Kretzman & McKnight, 1993). Although these models differ somewhat in their theoretical underpinnings and scope, they all aim to achieve a similar end, that of community development. These models have helped to guide occupational therapists to take a broader community-development approach in order to promote inclusive communities that foster the active participation of all community members in meaningful occupations (Banks & Head, 2004; McColl, 1998; Scaletti, 1999; Law, 2002). No reference could be

found to using any of these models or approaches with youth with disabilities who are in transition from adolescence to adulthood.

This article describes a unique experience of occupational therapists collaborating with a group of parents and youth with disabilities on a pilot project to implement and evaluate a CCB forum. The primary role of the occupational therapists in this project was evaluator/researcher. The results of the evaluation and the “lessons learned” by the participants and researchers are presented.

BACKGROUND INFORMATION

The “CCB project” was an initiative conceived through the collaboration of a grass-roots community group and several university-based researchers. The community group was a parent network (herein referred to as the “Network”) comprising families with youth with developmental disabilities. One of the Network’s mandates was to assist youth with disabilities who were making the transition from adolescence to adulthood. Two parents from the Network were team members of this CCB project, and were actively involved in all decisions throughout the project. The researchers were from *CanChild* Centre for Childhood Disability Research at McMaster University, a health-linked research unit funded by the Ontario Ministry of Health whose goal is to maximize the participation and quality of life of children and youth with disabilities and their families in Ontario through research partnerships, evaluation of services, and dissemination of new knowledge. All of the researchers on this pilot project were occupational therapists. There were also two student occupational therapists in their last year of study who conducted the qualitative interviews.

The two groups (Network parents and *CanChild* researchers) identified gaps in the traditional service-provision approaches in meeting the needs of youth with developmental disabilities in their transition to adulthood and to the community at large. These gaps related mainly to the lack of opportunities to engage in meaningful occupations in the adult world, such as employment and recreation (King, Baldwin, & Currie, 2004; Stewart et al., 2001). Despite efforts by pediatric services to get youth with disabilities “ready” for adult life, the young people and their families could not find needed resources and supports for community participation in the adult world (Stewart et al., 2001). Experts in health, education, and social services have identified the need for inno-

vative models that adopt a person-centred and asset-oriented approach to support the transition to adulthood (Betz, 2004; While et al., 2004).

The partnership of parents and researchers received seed funding to pilot a CCB project. The CCB project had two main objectives: (1) to support youth with disabilities during their transition to adulthood by bringing community members together at a one-day forum, to discuss the current and potential assets available to youth in the Hamilton community (2) to evaluate the process and outcomes of the CCB forum in relation to meeting the needs of the participants, and to learn and plan for future initiatives.

A CCB approach was chosen as it fit well with the identified issues related to the transition to adulthood for youth with disabilities. It uses an ecobehavioural approach, which recognizes that complex issues, such as the transition to adulthood, are multifaceted phenomena that involve a dynamic interaction between person and environment (Kretzmann & McKnight, 1993). The primary mandate of CCB is to “increase the capabilities of people to address community health issues and to overcome barriers to achieve improved outcomes in their quality of their life.” (Labonte et al., 2002, p. 181). It capitalizes on the assets of the people and the community at large to create sustainability (Frank & Smith, 1999), and has been used successfully with groups of people who are at-risk or disadvantaged (Kretzmann & McKnight, 1993). CCB differs from other approaches to community development as it focuses on identifying and developing a community’s capacities as assets to addressing health concerns instead of a focus on risks, needs, or other deficits. A community’s capacities can include: The extent of community member’s participation and leadership in the community, the skills and resources available in the community and the extent of a community’s social and interorganizational networks (Goodman, Speers, & McLeroy, 1998).

CCB is founded on the principle of engaging individuals and groups in an inclusive and equitable partnership process grounded in true collaboration, which is similar to health-promotion and community-development principles identified in the occupational-therapy literature (Christiansen & Townsend, 2004; Wilcock & Whiteford, 2003; Banks & Head, 2004). Current practice models such as the Person-Environment-Occupation (PEO) Model (Law et al., 1996) and the Ecology of Human Performance (Dunn, Brown, & McGuigan, 1994) place equal emphasis on person, environment, and occupation elements in a dynamic, transactive relationship. These models encourage therapists to realize that

interventions at the environmental or community level can have significant impact on a person's occupational performance.

THE CCB PROJECT

Using the CCB principles of engaging groups and individuals in the process and focusing on strengths to inform the process, the project team planned a forum with community stakeholders in the local community. The purpose of the forum was to identify and capitalize on the strengths and assets of people in the community and to develop action plans that would be responsive to the youth's needs during the transition to adulthood. Recruitment was managed by the parent team members, as they were most familiar with the local community. They sent out invitations to a broad range of people representing different perspectives such as youth with disabilities, parents, and community members.

Evaluation was a critical component of this pilot project. The research team recognized that the evaluation design and tools must fit with the specific situations being addressed by the community project, as well as with the participants' views and learning needs (Dewar, 1997). Using principles for CCB evaluation outlined by Dewar (1997), the project team developed a three-phase evaluation process:

1. *The development phase* took place before the forum, and involved gathering background information about CCB and transition to adulthood, through a literature review; conducting a community inventory or asset map; interviewing community members and planning the forum.
2. *The action phase* was the forum itself, which was held for one day in May 2002. Twenty-five people from the community attended the forum to explore the assets and strengths of community members and young people with disabilities in transition to adulthood and to develop action plans.
3. *The follow-up phase* involved interviews with forum participants about their perceptions of the process and outcome of the CCB forum. These interviews took place one month and again one year after the forum.

Details of each phase are described in the next sections.

The evaluation used primarily qualitative methods to explore the process and outcomes of the CCB approach and to gain participant's

personal insights and perspectives of the experience. A qualitative approach to the evaluation fit best with the exploratory nature of this new initiative, as we had little knowledge about a CCB approach. Given that the focus of the evaluation was on the experiences of the participants, the research team adopted a phenomenological approach to evaluation design and methodology (Patton, 2002). Phenomenology addresses questions about the meaning, structure, and essence of the lived experience of a particular phenomenon (Patton, 2002). For this project, the phenomenon was the experience of CCB.

Participant selection was purposeful in keeping with the qualitative and exploratory nature of the evaluation (Patton, 2002). The research team utilized a maximum variation strategy to ensure that a broad range of participant experiences, positions, and demographics were represented in the evaluation (Patton, 2002).

Data collection methods included the following:

In the *developmental* phase, prior to the forum, a community inventory, also known as asset mapping, was used to gather important information about the current capacities/assets of the community. Asset mapping/inventory is a key element in a CCB approach (Dewar, 1997; Kretzmann & McKnight, 1997), as it is a “tool” that encourages people in the community to focus on capacities and assets rather than problems and “needs.” As a community becomes familiar with its own assets, it can address challenges in a capacity-building approach (Kretzmann & McKnight, 1997). There is no one method for community inventory development, but rather some key guiding principles. An effective inventory should be driven by the purpose of the project, and should be as simple as possible to identify and mobilize individual capacities (Kretzmann & McKnight). For this CCB project, the research team developed a simple, one-page descriptive inventory form for participants to complete four months prior to the forum. These forms were mailed to participants with a self-addressed stamped envelope for return.

Interviews were semistructured in nature, using an Interview Guide that was developed by the research team. Interviews took place in the *development* phase, with key informants, and also in the *follow-up* phase, one month and one year after the forum with consenting participants. The project/research assistant and the student occupational therapists conducted the interviews, which were audiotaped and then transcribed to text for analysis.

Field notes and naturalistic observations were taken during the forum by one researcher and the research assistant. These notes were then transcribed to text and included in the qualitative data that were analyzed.

Analysis of all qualitative data from the interviews, naturalistic observations/field notes and the community inventories was conducted on an ongoing basis by the project team. An iterative process was used to review the data over time, and then modify the interview guides as new ideas or information emerged. In this way, the data collection and analysis informed each other throughout the process. Transcripts were analyzed using an editing/organizing style of qualitative analysis, which involved all researchers first reading the transcripts to search for meaningful segments of text, which were then organized into categories or codes (Crabtree & Miller, 1999). The researchers then developed a coding scheme that described each of the codes, which were all related to the phenomenon of CCB. The coding scheme was tested by two researchers, and finalized, once coding agreement of 75% was achieved. One researcher then coded all transcripts.

THE FINDINGS OF THE EVALUATION

Participants

Twenty-five community members attended the one-day forum. Of these people, 15 provided informed consent to participate in the evaluation component. As well, two people (one parent and one youth) in the community consented to participate in the development phase of the project, but were not able to attend the forum itself. The total number of participants for the evaluation of the forum was 17. They included seven parents (one of whom was a service provider also), two youth with disabilities, and eight community members (a police officer, librarian, a school principal, a grocer, the manager of a community agency for adults with mental illness, a university professor, an occupational therapy clinician and a municipal employee).

Evaluation of Process

The forum was planned by the Network parents. They hired a facilitator who began the day with a description of the CCB approach, and discussion of the assets that people bring to a community. Eight participants filled out community inventories prior to the forum (four youth and four parents of youth with disabilities). The primary purpose of the community inventory was to increase awareness regarding the current assets in the community. The secondary purpose was to encourage dis-

cussion at the forum regarding the community assets identified and additional community assets that may not have been previously identified. The results from the inventories revealed that there was a diverse range of community resources that youth with disabilities and their families were accessing in the Hamilton community. The results were compiled into a graphic for presentation at the forum, and two youth spoke about their inventories and of some of their experiences in the community. The youth were depicted at the centre of their community, with numerous connections fitting like puzzle pieces around the youth. These included informal connections of friends and family, and formal connections with schools and community centers for example. Sources of information that were also identified included newspapers and other media, friends, church bulletins, and the library.

The remainder of the day was devoted to small group work during which participants identified the assets and capacities within their community that could support the youths' participation and began to develop action plans to enhance the transition to adulthood for these youth.

Evaluation of Outcome

Four central themes emerged from the qualitative analysis of the data from interviews, field notes, and observations. Each theme is described in the following paragraphs with supporting quotes from the participants.

Theme 1: Creating Connections

Participants spoke about the value of the workshop in helping to create connections between themselves and other community members.

I met lots of new people and reconnected with some I hadn't seen in a while.

I have my own circle of friends now and the connections have helped me reach further and further out into the community.

Many spoke of the feeling of togetherness and community that is created when people come together for a common purpose.

There were a lot of different people from different elements of society, different facets of life, and I think that they felt good because they realized that they all had the capacity to give and to help.

It was just so interesting for me to hear what people within the community, who may not have ever been associated with disabilities before, were bringing to those small groups.

Theme 2: Raised Awareness about Capacities and Gifts

Participants spoke of a change in their perceptions and attitudes about people with disabilities.

They're ordinary people too, they happen to have disabilities but they're more alike to us than they are different, and to hear them talk about citizenship, you know, just being involved, having a job, earning some money, having friends. . . . Looking at people's abilities instead of their disabilities.

Many of the participants spoke of the profound effect that the facilitator had on their perceptions of people with disabilities.

Her passion for living, and that there is no restraint to anybody if you don't want them. I remember that much, yeah. Very inspiring.

Theme 3: Lessons Learned

The diversity of the individuals invited to the forum created an interesting mix of people and much potential for the scope of the forum. The different perspectives and types of disabilities that were represented at the forum needed to be acknowledged. Participants liked having the young people with disabilities speak about their experiences.

I remember really liking either two or three people there . . . young people . . . who had their own different placements and we talked about their experiences. I really liked that, I thought it was really well done.

Clients are part of everything they do. And so you don't have a meeting talking about clients when clients aren't there.

Although diversity of participants was felt to be an important element of the forum, some people felt that the scope of the community that was involved was too broad.

When you're doing the whole city, people who attended the workshop don't have anyone else who attended the workshop working

where they work, whereas if it's in a neighborhood, you can walk across the street or next door, and other people have been affected the way you've been affected.

The parents from the Network recognized that the 'personal touch' was necessary to get community members who weren't familiar or comfortable with youth with disabilities to come to the forum. Because of time constraints, they could not get in touch personally with everyone they wanted.

Maybe some of the people we did invite who didn't come, I mean some of them obviously had conflicts on the same day, but I think that with some of them, if we'd have been able to sit down and talk to them would've thought (Oh yeah. I do want to be a part of this).

People would have liked to see more participants at the forum, but they knew that time was tight in preparing for and inviting community members.

I think that there should have been more involvement around some of the people in the community that are already doing it. Just means that other agencies of people, because why invent the wheel when it is already there? Let's work together to see how we can build it and expand on it and make it better.

The importance of having an effective facilitator, who has been there and has a good understanding of CCB is essential for a successful forum, especially the first one.

[The facilitator's] example of the incredible potential that people with disabilities have that is often overlooked; and people just don't take the time to stop and listen, enough to real lives. Everything is there.

For the occupational therapy researchers and students involved in the project, a review of log books and journal entries throughout the project revealed some important "lessons learned."

Reminder to self needed that our role is evaluation for the parents' project. It's not our place to lead or suggest. Be participatory.

We are finding with this project it may be faster to take a task and get it done one's self, but that would take away the power and leadership . . .

[This project] is client-centred, working in partnership, enabling participation, learning and changing through occupation.

Theme 4: Making It Happen

Participants spoke about their renewed beliefs in and commitment to inclusion following their involvement in the CCB project.

Having participated in [the CCB project] has made me more responsible and aware as a community member. I have more confidence to approach people with disabilities. I speak to the girl with a disability at my bus stop now and I have noticed that since I have broken the ice, other people talk to her now too.

One of the parents that I met at the forum came and found me at the library where I work and asked if her daughter could come and work there. We had never done anything like that before but I felt responsible to make it happen. I had heard this woman's story at the forum and I had seen her with her daughter at the library before.

My daughter has received several invitations to participate in community activities since our involvement in the forum. She was asked to help with the make-up in an elementary school play production. I think that more people that live around here know she exists now. Maybe they see her as a person who can contribute.

DISCUSSION AND CONCLUSIONS

This pilot project involved the development and evaluation of a CCB approach to enhance the transition to adulthood for youth with disabilities in one city in Ontario, Canada. The partnership of parents and occupational-therapy researchers proved to be very effective in bringing research and social action together. The evaluation of this project addressed both process and outcomes using qualitative methods. The results indicated that the *process* of running the one-day community forum appeared to be successful. The amount of time to prepare for the forum and invite community members was short, and this was a "lesson learned." Timing and budget constraints definitely impacted on the process. Other lessons learned about the CCB *process* from this initiative included: Start small in the community and grow; include people with

different disabilities and perspectives, but recognize upfront that there are differences in the community's perceptions and comfort level with youth with different types of disabilities; leave time for action planning and follow up on action plans to help people get started.

The successful elements of the process, which were recommended for future initiatives included the following:

- Hiring a facilitator who has a strong knowledge and comfort level with youth with disabilities and CCB. Most of CCB literature suggests that the facilitator should be from within the community, but this project suggests that the knowledge and experience of the facilitator are also important;
- Using the personal touch to invite community members;
- Asking as many people as possible to complete a Community Inventory ahead of time, so you have a good sense of the capacities and assets that are out there;
- Planning a follow-up forum, six to nine months after the first forum.

The *outcomes* of the project were evaluated using qualitative interviews and field notes/observations. The results indicated that this CCB project appeared to be successful in achieving the primary objective of the project: To support youth with disabilities during the transition process using a strengths and asset-based approach. Specifically, the findings from the interviews after the forum demonstrated that the CCB forum helped the community members in a number of ways. They felt that they now had more awareness of the capacities and assets of youth with disabilities in their communities, and they recognized that they had something to offer as well. With this increase in their own awareness, participants also gained a greater sense of their own roles in including these youth and in increasing their community's capacity to continue to support them. Participants spoke about feeling accountable to these youth, not leaving the job of including them to someone else but taking on part of the responsibility themselves. Another benefit of the forum was the new connections that were developed and maintained in the community, which the parents and youth felt were important for their quality of life during this transition to adulthood. Focusing on the capacities of the community and raising the community members' awareness, of the assets that the youth bring to their community, created a positive climate for change and an atmosphere of opportunity among those who participated. Forums have been previously shown to be

effective methods to bring communities together to raise awareness, to achieve a common purpose and to promote collaboration (Wesley, 1995; Buysse, Wesley, & Skinner, 1999). Using a CCB approach to planning, implementing, and evaluating the forum further enhanced its relevance to the youth and community participants by actively involving them in the process and by guiding them to reflect on their experiences and the actions that followed from that day.

The project team also identified some positive outcomes for themselves. They gained a great deal of knowledge about CCB as a viable approach to address the complex issue of the transition from adolescence to adulthood for youth with disabilities. For the occupational-therapy researchers and students, this project demonstrated the value of a CCB approach for addressing complex issues facing clients and community members at large. The project and the evaluation efforts focused on the capacity of people in one community, instead of the more traditional approach of addressing the specific challenges and needs that the youth with disabilities presented. The focus of attention shifted from “problems” to capitalizing on the abilities and capacities of the youth, their parents, and the community during the transition to adulthood. This approach promotes opportunities for youth with disabilities to develop capabilities instead of requiring them to prove themselves capable before being included (Grady, 1995). By creating opportunities for community members and agencies to work together, people in a community are empowered to enhance their own capacity to support all of their members in making their own unique contributions. As such, this becomes a cyclical process; the more community members are fully participating, the richer the community becomes.

The results of the evaluation of this capacity-building approach fit with emerging models in health care and occupational therapy that view health and disability as a dynamic and complex interaction between person and environment (Stewart & Law, 2003). Social models of health acknowledge that disability must be considered within a social context in order to achieve meaningful change in the lives of persons with disabilities (Vreede, 2000). Research needs to focus on increasing knowledge of local concepts, beliefs, and practices, which are fundamental to positive change in communities and individuals (Vreede, 2000). This pilot project demonstrated that a partnership between researchers and parents can promote social change in a local community.

The main limitations of this evaluation were the small number of participants and short time frame. However, given the exploratory, qualitative nature and small budget of this pilot project, the depth of

information that was gathered from these participants answered our questions satisfactorily. In qualitative research, generalizations are not expected, but the research team felt confident that the results were representative of the experiences and perceptions of the study participants. These pilot study results support similar research with larger groups and different community populations.

One of the benefits of this small study was the opportunity if offered for occupational therapists to work closely with parents and youth. The collaboration provided rich and valuable experiences that enabled everyone to develop a better understanding of the potential power of community-based approaches for youth with disabilities and their families.

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