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# Community-Based Participatory Research Shows How a Community Initiative Creates Networks to Improve Well-Being

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**Background:** Evidence from more than 30 years of research suggests a profound relationship between social participation and human health and well-being. People who hold meaningful roles in supportive social contexts live longer, get sick less often, suffer less disability, and recover faster from life-threatening events. However, despite ample evidence of benefit, the complex phenomenon of social participation has proved difficult to untangle in creating policies or programs for optimizing health in diverse communities. For vulnerable populations, the answer to the question of what contexts invite meaningful participation and improve well-being remains unclear.

**Purpose:** This study explores how diverse participants engage in a supportive network and proposes a theoretic model of community-building for health promotion.

**Methods:** Principles of community-based participatory research were used for qualitative study using in-depth interviews, with a purposeful sample of 28 members of a service exchange program in an urban community.

**Results:** Four primary themes that were related to participation in the service exchange program were identified: (1) motivation for participation; (2) service exchange, or reciprocity, as vital to the program, with distinct benefits in a heterogeneous group; (3) occurrence of personal and community growth; and (4) health promotion and improved well-being. A model of how participation in the service exchange leads to community-building is presented.

**Conclusions:** The model suggests that opportunities for reciprocity are fundamental to healthy community development in heterogeneous groups. Further study of how reciprocity encourages diverse populations to work together to create a landscape of healing may provide a valuable framework for health promotion.

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## Background

That people are social beings is rarely questioned, and mounting evidence from more than 30 years of research suggests a profound relationship between social participation and human health and well-being.<sup>1</sup> Social participation has been examined in multiple forms as an important determinant of health throughout the life course.<sup>1,2</sup> Studies of social participation show that people who hold meaningful roles in supportive social contexts live longer, get sick less often, suffer less disability, and recover faster from life-threatening events.<sup>2–5</sup> Despite ample evidence of benefit, however, the complex phenomenon of social

participation has proved difficult to untangle in efforts to understand more precisely how to create policies or programs to optimize health.

Early studies exploring social participation focused on social support as a source for care from informal networks<sup>6</sup>; however, perceived support, or the belief that support is available, has been shown to be a more powerful predictor of improved well-being than measurable acts of support.<sup>1</sup> A sense of belonging experienced through positive relationships also can buffer stress and promote well-being.<sup>7</sup> Within meaningful relationships, social support evolves to companionship, where the trust that is built through give and take can last a lifetime.<sup>8</sup>

Even more than receiving support, providing support by helping others shows important health effects.<sup>1</sup> Research suggests that people who volunteer, whether through religious or secular groups, are healthier.<sup>9–18</sup> Adolescent volunteers, compared to nonvolunteering peers, engage in fewer risky behaviors and have better social skills, self-esteem, and confidence.<sup>9,10</sup> Adult volun-

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teers aged >65 years report enhanced perceived health and well-being.<sup>11-14</sup> Adults with depression who volunteer show a therapeutic effect of participation through increased social integration.<sup>15</sup> Several population-based, prospective studies demonstrate decreased mortality in adult volunteers.<sup>16,17</sup> Viewed together, these studies suggest that policies promoting volunteerism or social engagement could play an important role in health promotion.<sup>18</sup>

However, social contexts are rarely simple, and several studies on social engagement in heterogeneous communities suggest reasons for caution.<sup>3,18-22</sup> People with lower social status may benefit less from volunteering; for example, in patriarchal settings, women benefit less than men from their volunteer experiences.<sup>20</sup> Not all social interactions are positive, and social engagement with negative interactions may produce harmful effects.<sup>3,18,19,22</sup> Volunteerism can reinforce social-status differences between helpers and recipients, and recipients may not perceive help positively.<sup>21</sup> These observations raise the question of whether volunteers sometimes benefit from their actions at the expense of those they seek to help. For vulnerable populations, the question of which contexts for social engagement invite meaningful participation and improve health and well-being remains largely unanswered.

This community-based participatory case study examines how members from different backgrounds engage with and find meaning in a community-building program serving a diverse population. Community Exchange (Allentown PA) was created in 1999 to engage isolated community members living with physical and mental disabilities in inclusive social networks. Community Exchange brings together individuals from diverse backgrounds, with and without disabilities, to establish a community dedicated to principles of respect, participation, and reciprocity using the time banking model.<sup>23</sup> Members receive credit for each hour of service they offer. All members both give and receive services, broadening personal networks and group resources through reciprocity. With time rather than the value of service as the unit of exchange, Community Exchange minimizes social differences and invites all members to contribute their best efforts, putting into practice the principles of asset-based community development.<sup>24</sup> In this study, Community Exchange members and researchers explore members' experiences to develop a theoretic model of the process of engagement in the program's network that may enhance personal and community well-being.

## Methods

### Research Design

A research team consisting of two organizational leaders and one researcher designed an evaluation to capture the mean-

ing of participants' experiences in a way that mirrored values upheld by the group. The team selected a qualitative case study design and used the North American Primary Care Research Group guidelines<sup>25</sup> for community-based participatory research (CBPR) throughout planning and implementation. A CBPR evaluation plan was presented to the organization's governing body and a research agreement was developed. The research team presented a series of workshops in which members updated the vision and mission and created a "journey map" of ideal participation and organizational expectations used to develop an initial framework for evaluation (Table 1).<sup>26</sup> Workshop participants were presented with qualitative case study methodology for gathering and interpreting member stories.<sup>27</sup> These groups provided feedback and suggestions on the research design of a CBPR qualitative case study using in-depth interviews, and the study was approved by the Lehigh Valley Hospital IRB. The study design involved an initial wave of interviews to establish a thematic codebook and model using grounded theory,<sup>28</sup> followed by a second wave of interviews to explore emerging hypotheses and refine the model.<sup>27</sup> Community Exchange members attending workshops were invited to join the research team. All members who participated in the research team were trained in the ethics of human-subjects research and signed confidentiality agreements in compliance with Lehigh Valley Hospital IRB guidelines.

### Setting and Participants

A group mailing informed Community Exchange's 211 active members of the study. An original purposeful sample of eight members was selected to represent diversity in factors hypothesized to influence member experiences: referral source, activity status, network size, participation style, disability, and demographics (Table 2). The second wave included 23 members and two activity-related groups identified through snowball and purposeful sampling, with an emphasis on people with disabilities, to explore engagement of marginalized community members, until thematic saturation was achieved.<sup>27</sup> From this sample of 31, one participant withdrew for personal reasons, and two interviews were discarded with participant consent because of poor-quality tapes, in that new interviews no longer generated new themes or contradicted

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**Table 1.** Community Exchange participatory evaluation—outcome challenges

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We expect to see Community Exchange members:

- participate in exchanges;
- be willing to both give and receive services;
- understanding that reciprocity is what makes Community Exchange effective.

We would like to see Community Exchange members:

- developing friendships through their exchanges;
- widening their circle of contacts;
- taking initiative in arranging their own exchanges;
- accepting people, including themselves, for who they are.

We would love to see Community Exchange members:

- taking leadership roles that help Community Exchange grow;
- transforming their lifestyles, relationships, and self-perceptions (lives) to embrace a deeper sense of community that comes from Community Exchange;
- becoming catalysts for social change.

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**Table 2.** Demographics and sample (% unless otherwise noted)

	Sample	Total
Members in 2004 ( <i>n</i> )	28	211
Gender, male (%)	28	21
<b>Age (years)</b>		
M	57	56
Range	23–84	23–84
Mental health disability	16	
Physical disability	28	
<b>Duration in program</b>		
≥2 years	96	
<2 years	4	
<b>Network size</b>		
Small, <5	48	
Medium, 5–15	44	
Large, >15	2	
<b>Referral source</b>		
Word of mouth	48	
Healthcare providers	16	
Social service programs	36	

existing themes. Analysis of field notes and audible portions of tape did not reveal new themes or contradictory evidence for the excluded interview.

### Data Collection and Analysis

No members volunteered to collect interviews. Researchers conducted in-depth interviews exploring member experiences with Community Exchange, challenges, meaningful events, and personal growth using an interview guide informed by the preparatory workshops (Table 3). Interviews were tape recorded and transcribed verbatim by Community Exchange transcriptionists.

Twenty-eight interviews and field notes from two community events were included in analysis. For the first wave of interviews, grounded theory was used to develop a thematic codebook and preliminary model.<sup>28</sup> Themes and model were revised iteratively throughout the second wave using immersion and crystallization strategies.<sup>27</sup> Documents developed during workshops provided material for triangulation and internal validation of the model. The research team trained two Community Exchange members to participate in the analysis and coding of interviews. At least two coders, one researcher and one Community Exchange member, reviewed each transcript using inductive and deductive coding to extract themes from interviews in NVivo version 6.0. Coders met to reach consensus on coding discrepancies. All interviewees reviewed coded transcripts to clarify, highlight, or exclude any interview portion and provide feedback on themes and model. The research team solicited community feedback for further member review. The model was presented to the organization's governing body, resulting in minor revisions. The revised version was then presented at a community-wide event, where the model was accepted enthusiastically.

### Results

Four primary themes related to participation in the service exchange program were identified: (1) motivation for participation; (2) service exchange, or reci-

procity, as vital to the program, with distinct benefits in a heterogeneous group; (3) occurrence of personal and community growth; and (4) health promotion and improved well-being. These themes were synthesized to develop a model of how participation in the service exchange leads to building a community.

### Motivation for Participation

At its most basic, Community Exchange is a complementary currency that creates a framework in which members can offer and receive services from each other. Members joining Community Exchange may be motivated instrumentally (by a need for services): "In several respects, it's made my life more comfortable in the sense that when I call on people for transportation or to run errands they come and I don't need a car." In contrast, another member describes a need for companionship: "Getting to know people, really that's my goal. You know, just to associate with them and have a little fun. It's such a good feeling considering the condition I'm in."

Some members perceive their current participation as an "insurance" policy that gives them the confidence that help will be available to them in the future: "The unused dollars would go into a bank so that any time we needed a service there would be money in the bank." Another member describes: "I knew that you all were there. I knew that I could rely on somebody, even if I needed to call in the middle of the night. I knew that somebody would be there and that was the biggest blessing."

**Table 3.** Interview guide

#### Telling our story: a participatory evaluation of the community exchange

Tell me how you heard about/became involved in Community Exchange?
Tell me about some of your early experiences with Community Exchange?
Prompt: Early success?
Early discouragement?
Did you have doubts?
What made/helped you keep going?
Tell me about the most meaningful or challenging experience you have had in the Community Exchange?
Prompt: What surprised you about this experience?
How did this experience challenge you/change you?
Who was involved in this experience?
In what ways do you envision continuing or expanding your involvement in the Community Exchange?
Prompt: What do you imagine your involvement might look like in 1 year?
What might encourage you to expand your participation?
What might get in your way or keep you from being more involved?
How do you imagine your involvement might help the Community Exchange grow?
Do you have anything else that you would like to add?

## Service Exchange and Reciprocity

The benefits of service exchange or reciprocity are inclusion, individuals taking on new roles, respect and appreciation for others, and a network of friends. Reciprocity allows those who have been socially isolated or stigmatized to build relationships, as one member describes her experience:

I was alone and frustrated. I volunteered as Meals on Wheels deliverer for a year but that was too taxing for me healthwise. I also volunteered in a library and at the Clubhouse . . . but found no real benefit—I remained isolated. Today, I found people in the Community Exchange program who understand my situation and have similar situations as well. We have teamed up as a group and individually in pairs. We can shop together and attend social functions, something I haven't done in years. I also am able to get music lessons. In return I make phone calls and send cards to those who have lost a loved one in their family.

This member finds a willing network of partners, her own team, working together to offer each other both instrumental and social support without distinguishing those who give from those who need services.

Reciprocity encourages people to take on new roles. One participant who likes to give says,

Actually I feel more comfortable providing than receiving. Because it's the old story I would rather give than take and so when I came to people's homes and was able to do things for them that was great, but when it came to coming back to me, I felt a little bit uncomfortable. And once I got comfortable with the people who were offering me the time, it was nice.

In contrast, a natural receiver describes his new role:

Not only is this an organization where you as a member receive certain services but there has to be an exchange involved where I would have to reciprocate. The more I thought about it at the time, I knew there were a lot of things that I needed, but I couldn't think for myself what I could offer. But it turned out that I was in a position as a retiree to be able to offer all kinds of services, some of which I did not realize that I was capable of performing.

As members stretch themselves to honor the community's expectation of reciprocity, they learn to have respect for others. Respect sometimes comes as a surprise, as one member remembers:

I thought, well, heck, I see and she doesn't see, so right there is probably stuff I could do to help her. I wasn't quite sure what she could do to help me and it turned out that she helped me as much or

more than anybody in the Community Exchange. She's like a tornado when she comes in the room. That's really wonderful and we've gone out together and I really enjoyed going out with her.

As members get to know each other through exchanges, they find opportunities to appreciate others' gifts, including the gift of friendship:

I learned to value friendship more. I have a friendship with her. I look forward to seeing her every week. I look forward to . . . going to her concerts. I look forward to having that. It gives me a sense of purpose, you know, and I also feel that it gives her something in return. She was once a teacher, instructor, and I just want her to know that she's not forgotten.

Relationships emerge out of a network where everyone has opportunities to both give and receive, and to be recognized for their contributions. Service exchange allows members to get to know each other "based on sharing," as one member explains, "By the end of the task we have a good discussion, we learned something about each other, and whatever had to be fixed was fixed." Another member describes Community Exchange as "a website of friends, people who are ready and willing." Another member says, "It's not just a group you belong to, it's a whole philosophy," and "it's a wonderful way of life."

## Personal and Collective Growth Through Engagement

Relationships within the network create an environment of both personal and collective growth that is fueled by member engagement. In one member's words, in Community Exchange, "You grow, you see yourself growing and you see other people growing and that's what's so good about being involved." Many members mentioned an increase in their self-worth as contributors, like one wheelchair-bound participant: "It did a lot for my self-worth, learning I could do mailings, I could do phone assurance for people that were homebound or did not get out much. I learned that there are many different things that I could do." Others described personal growth through the opportunities they received from others, such as learning a new skill: "I've always looked at the piano and I've always wanted to play. I just think it's a waste to see a piano and no one knows what to do with it. It's not impossible. I learned from scratch." Members identify important opportunities in giving back to others: "I thank God for this service, because when I also give, it makes me feel great inside."

Several stories describe emerging leaders engaging in activities that strengthen the group as a whole, including recruiting new members, developing programs, offering classes, and organizing events. Collec-

tive growth promotes an attitude of member-driven leadership: “We’re a self-supporting program and we have to make it work, because if we do not do it, it is not going to work.” The network as a whole becomes stronger as more members begin to engage in complex tasks together, ranging from organizing meals and leisure activities to gathering a community of help when people need it. Ownership and leadership move Community Exchange from a social service program to a true community, a rich context for learning and growth: “It was really amazing that everyone, older people, even younger people coming together and really sharing with one another. It was the family atmosphere that I felt from that, the gathering made me really interested in Community Exchange.”

Community Exchange establishes a powerful mechanism for social engagement or, as one member explains, a way of “having a stake in the community. I want to get to know people. I want them to know me.” A context that welcomes engagement from all members “stirs the pot,” another relates, generating an activated community: “People have abilities and it’s nice that people are willing to share their talents with other people. I think that attitude should be promoted, encouraged, to more or less help stir the pot and get people more active.”

### **Health Promotion and Improved Well-Being**

Members describe benefits from participation in Community Exchange ranging from access to affordable services, to meaningful relationships, to community mobilization. Direct exchange increases access to health-promoting services: “I always thought massages were something I’d love to get but couldn’t afford. Then I met CS and DB—ah, what bliss!” Members help reduce barriers to care by providing services such as transportation to medical appointments and respite care for families:

I was looking for organizations that I could get help keeping company with my mother who has Alzheimer’s. I was looking for something that I could afford and the reason I was attracted to Community Exchange was that it was basically a situation where they said you would trade time for time. I can afford time but I can’t afford cash.

Meaningful engagement within a supportive community helped a young woman suffering from depression. After a series of frequent hospitalizations, she began to volunteer regularly at the Community Exchange office: “Coming here, it’s crucial for me to get out and be productive and have some place to go and just to get up and get dressed.” She describes how she has stayed out of the hospital for 9 months, the longest period in many years. Later, she relied on her Community Exchange network during her mother’s terminal illness.

Her quality of life improves with her contribution and sense of belonging, and as she develops a supportive network, she enhances her resilience in times of stress.

One member explains the value of an activated, member-driven community that can solve complex problems: “The idea is to turn the community into a self-help unit that will spread.” For this member, the community “self-help unit” made it easier to stay independent at home for 6 years before entering a nursing home, by filling gaps for his dedicated family:

I was desperate for help in putting my socks and shoes on and my poor son was just being run ragged 7 days a week. That was solved quite quickly by telephoning a number of people and discovering their goodwill and their willingness to commit to doing this kind of thing. Those connections really have lasted.

When he did move to the nursing home, he relied on his network to bring him “real food” and companionship. In turn, he represented Community Exchange at a planning session for palliative care services.

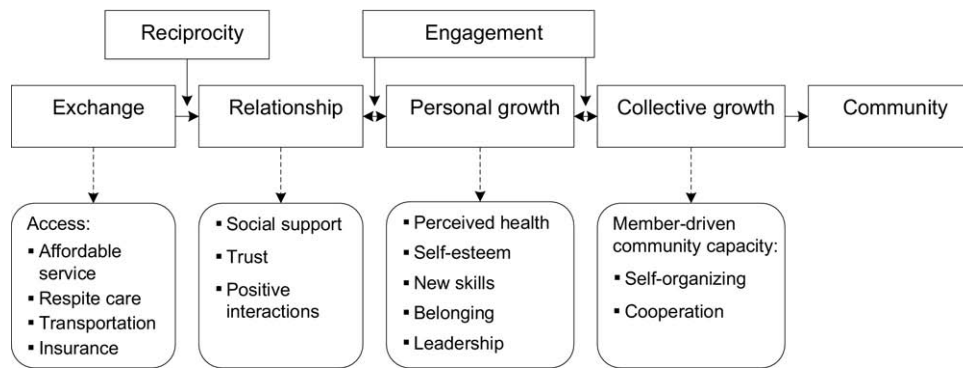
The connectedness provided by the Community Exchange is experienced as health-promoting. As one member eloquently expresses it:

The idea of the extended family in our society today I think is healthier than almost anything else we could implement or change to make our society healthy again. . . . I don’t know but if we could learn the value of each human being and what we can do to make our life and the whole better, the whole would benefit.

### **Community-Building Model**

From the rich and varied stories told by Community Exchange members, the research team developed an integrated model of community building that suggests how participation builds community that may promote individual and community well-being for a diverse group of participants. In this model, exchanges lead to relationships that in turn create community (Figure 1). Progress through the model is not linear for most participants, and it is influenced by the group norms of reciprocity and engagement. Reciprocity allows many members from different backgrounds and different abilities to meet each other as equals and develop relationships. Stories of how engagement promotes both personal and collective growth in the context of relationships suggest a dynamic process that appears to benefit both mainstream and disabled participants. Finally, as individuals realize their potential and the potential of people around them, they can come together as a community of cooperation to meet each other’s needs and solve complex problems.

Members attribute an improved sense of well-being to different levels of the model. From simple exchanges,



**Figure 1.** Community-building and hypothesized benefits for improved well-being

some members access health-promoting activities and decrease barriers to healthcare and related services. Personal growth through engagement improves personal resources such as self-esteem, confidence, and leadership in addition to improving connections through decreased prejudice and increased trust. Collective growth, the increased capacity of the group to solve complex problems together, results in an activated community that can mobilize diverse resources. Although this study cannot directly link social participation in a service exchange program to health outcomes, the variation in stories shows that individuals find different paths to healing, suggesting a nonlinear, dynamic pattern, in what Miller calls a “landscape of healing.”<sup>27</sup>

## Discussion

Members describe how their connection to Community Exchange enhances their quality of life and sense of well-being at all levels in the model, from the social support of exchanges, to personal benefits of social engagement, to the collective capacity of a community of cooperation. Consistent with the community model developed in this study, game theory suggests that cooperation evolves in a nonlinear, dynamic fashion through reciprocity and trust.<sup>29–31</sup> However, in complex human systems, communities may achieve cooperation and cohesion through systematic exclusion of those who are different.<sup>2</sup> This model demonstrates how diversity and reciprocity help to create a sense of cohesion and trust by bringing people together across differences. Positive effects of participation in the network appear accessible to members with disabilities as well as to those without, largely as a result of reciprocity. Reciprocity helps to create a landscape of healing, an environment in which individuals can engage the cooperation of others for their mutual benefit and well-being.<sup>27</sup>

The community-building model described in this study highlights the key concept of asset-based community building as described by Kretzmann and McKnight.<sup>32</sup> By inviting all members of the community to partic-

ipate equally, Community Exchange opens a possibility for mutual engagement that mobilizes assets without exclusion.

The model described in this study, although exploratory, may provide useful insights for how healthcare systems can partner with community-building programs to improve service delivery. The expanded chronic care model, for example, emphasizes the im-

portance of population health promotion through activated communities that create supportive environments for change.<sup>33</sup> Population health concerns the health of whole communities: “the spirit of population health becomes evident whenever a community expresses its care and concern for all of its members.”<sup>34</sup> Population health strategies have made partnerships for health promotion and healthcare delivery increasingly prominent. Partnerships are complicated, and case studies caution that without attention to expectations of participation, power-sharing, and reciprocity, partnerships may unintentionally perpetuate rather than reduce inequality and distrust.<sup>22</sup>

Time banks such as Community Exchange that focus on reciprocity may successfully engage vulnerable populations in community-building to improve health. Time-banking advocates in both the U.S. and Britain have emphasized the connection between service exchange programs and health through co-production: “an explicit and dynamic collaboration between the ‘client community’ and the helping professionals.”<sup>35</sup> By developing ways in which patients have opportunities to co-produce the help they need, healthcare institutions enhance their own resources for caring, remove the stigma of neediness from patients, and promote community capacity.

Time banks have partnered with medical services to expand support networks, generating impressive results for both patients and healthcare institutions. One hospital group’s time bank ran an Asthma Help Line that reduced emergency visits for participating patients by 39%, hospital admissions by 74%, and overall costs by \$200,000 over 2 years.<sup>35</sup> Programs that did not explicitly focus on reciprocity, however, failed to produce results distinguishable from more traditional volunteer programs.<sup>36</sup> Without understanding the dynamic nature of reciprocity, relationships, and engagement, initiatives may continue to separate those who are willing to give from those with needs to be met.

Limitations of the study include the limited sample reaching few dissatisfied or new members and none who had left the community. Although involving orga-

nizational leaders in the research team communicated the value of collaboration to members, their presence may have elicited more positive stories because of social desirability. Some members nonetheless appeared reluctant to elaborate on their personal growth or contributions, possibly because of modesty or difficulty describing complex experiences. Personal benefits may be underestimated as a result. Further research should explore whether the model described generalizes to other contexts.

Without directly exploring health outcomes, this study can only suggest how community-building programs based on reciprocity might promote population health in diverse communities. Next steps include investigation of health outcomes in Community Exchange using mixed-method and social network analyses. Further study will include practice-based interventions to explore the feasibility and potential outcomes of implementing time-banking models in clinical settings serving vulnerable populations. Also, further research may distinguish whether helping others, receiving assistance, or a balanced combination produces stronger health benefits for individuals and the communities they live in.<sup>37</sup>

In increasingly heterogeneous communities, the question of how people can come together to trust and help each other is fundamental to our social fabric. Focusing attention on how the lived experience of inequality interferes with social cohesion and discourages meaningful participation from marginalized populations will continue to improve community-based partnerships for health. Further study of the impact of social participation on health that uses a dynamic model to explore how cooperation, trust, and social participation create a landscape of health and healing may provide a valuable framework to promote health and well-being in diverse communities.

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