Community Members' Perspectives on Inclusion: Membership of Persons with Developmental Disabilities in Community Organizations

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ABSTRACT

Efforts to increase the social inclusion of individuals with intellectual/developmental disabilities (DD) have included recommendations to support membership in community groups and organizations. However, while such recommendations have been made for more than twenty years, there is virtually no information regarding the extent of current membership of such individuals in these community groups and organizations. In this study, surveys were sent to community groups in four states in four different regions of the U.S. inquiring about group membership of individuals with disabilities in general, group members' experiences with individuals with developmental disabilities in their groups, and the benefits and challenges of having individuals with DD as members. Results reflected that the membership of these groups in general is aging so members have to deal with an increasing amount of disability. A wide variety of community groups have members with DD, and members reported many benefits to such membership. The principal challenges included logistical issues of transportation and communication, and some members not being accepting. Implications for community groups, families and disability support staff about how to support group membership experiences are addressed.

INTRODUCTION

Limited community participation and social isolation has long been documented as themes common in the lives of many adolescents, young adults, and adults with disabilities (Abery & Fahnestock, 1994; Bogdan & Taylor, 1987; Burchard, Hasazi, Gordon, & Yoe, 1991; Ittenbach, Abery, Larson, Speigel, & Prouty, 1994). While people might be physically integrated, simply being physically integrated in community settings does not guarantee that adults with disabilities will establish desired social and interpersonal relationships with typical community members (Abery & Fahnestock, 1994; Rosen & Burchard, 1990).

One of the most powerful contributors to the establishment of friendships for persons with as well as without disabilities is regular, ongoing social contact with the same people (Abery & Fahnestock, 1994; Abery, Thurlow, Johnson, & Bruininks, 1990). More specifically, if adults with intellectual and other developmental disabilities are to develop friendships with community members, residential providers and family members will need to insure that these individuals have access to and participate in activities that are likely to result in social interaction and that take place frequently.   Joining a club or group where members interact regularly, such as playing cards or working together on community projects, is much more likely to result in the development of social relationships than attending single passive community events such as sporting events, movies, or other settings in which more substantial and meaningful interpersonal interactions are not regularly occurring.   Thus, for those who wish to promote more social inclusion, many authors have promoted the strategy of people with developmental disabilities joining community associations and groups (Center on Human Policy, 1990; Gretz & Ploof, 1999; Reidy, 1993).   However, although this has been a strong recommendation for many years, there is not a great deal of documentation and/or research regarding what is actually happening in these group membership experiences, either for the people with disabilities or for the community groups.

Voluntary community associations are wide-spread in the United States as well as in other countries. They intersect with major societal institutions such as the family, education, the economy, religion and government. Babchuck and Booth (1969) state that such groups ". .. are a vital part of the fabric of society and play a crucial mediating role in the relations between the institutions of the society as well as providing a link between the individual and institutions."   (p. 44)   People join groups to "find meaning in life, to express their social identity, to contribute to the well-being of others, and to improve their chances in the labor market."   (Bekkers, 2005, p. 439)

Community associations and groups provide the opportunity for both participation and civic engagement, which have many benefits, both for those individuals involved and for the overall welfare of the community. Research studies in such fields as education, urban poverty, unemployment, the control of crime and drug abuse have discovered that successful outcomes are more likely in engaged communities (Coleman & Hoffer, 1987; Sampson & Morenoff, 1997). Civic engagement and social connectedness have also shown to produce such results as better schools, faster economic development, lower crime, and more effective government, and communities with high rates of citizen participation experience a heightened sense of trust and higher levels of communication and coordination (Putnam, 2000). In addition, there are great personal benefits resulting to individuals from such social participation in both physical and mental health, resulting in fewer colds, heart attacks, strokes, cancer, depression, suicide, and premature death (House, Landis & Umberson, 1988; Kawachi, Kennedy & Glass, 1999).

Different definitions and categorizations have been made of the varying types of community groups and associations. Tomeh (1973) states that the terms "formal groups" and "voluntary associations" have been used interchangeably; they both mean organizations in which membership depends on the free choice of the individual, while group severance can be at the will of either party. These groups are organized to "pursue mutual and personal interests of the members so as to achieve common goals" (p. 92).   Types of terms used include: formal groups, organizations, clubs, associations, societies, or special-interest groups.   Gordon and Babchuk (1959) define three types of organizations: (1) expressive groups are aimed at socialization and integration of the adult personality, and include interest and hobby groups, recreational clubs, senior citizens, e-groups, etc.; members engage in activities for immediate gratification and affectual support. (2) instrumental groups are organized to influence the external environment.   These groups seek to maintain or change the

normative order by achieving some condition outside of the organization itself. Examples of these groups may include job-related associations, farmer organizations, business and professional groups, PTAs, political and civic organizations, labor unions, etc. (3) "Mixed" groups include both expressive and instrumental purposes. These include church-related organizations, fraternal-service groups, American Legion groups, etc.

Warriner and Prather (1965) developed a different typology of associations, based on the outcomes for or rewards to members rather than the community function of the group. Their four types of groups addressed the reasons people joined or belonged: (1) pleasure in performance: folk dance, textile painting, discussion groups, etc.; (2) sociability, such as happy hour clubs and birthday clubs; (3) ideological symbolism, such as church and religious organizations; and (4) production, such as the Humane Society, League of Women voters, service clubs, etc. In a longitudinal analysis of membership in voluntary associations, Babchuck and Booth (1969) used six categories of groups: church-related, job-related, recreational, fraternal-service, adult leadership of youth programs, and other (e.g., veterans, cooperatives).

Research into such types of voluntary community associations has often included determination of member demographic characteristics and how these characteristics affect different factors such as longevity of participation and multiple group membership. For example, Tomeh (1973) assessed the likelihood of community group participation among individuals in regards to gender, race, age, education, marital status, income status, mobility, and size of community and place of residence. The demographic characteristics of group members which Babchuck and Booth (1969) studied included age, sex, church affiliation, family status, and work status. Besides these factors, Bekkers's (2005) study of group members also included level of education, hourly wages, urbanization, and political affiliation. However, no study of community groups could be found which had included the factor of disability.

Keys and Factor (2001) studied characteristics of groups of people with disabilities, but these were exclusive groups of people with disabilities advocating for their rights.

What is missing in the community association research is information about the extent of participation by people with disabilities in community groups and associations. From the perspective of national and local community organizations, no information is known about the extent to which persons with disabilities are currently included in such groups, and what the experiences of those groups are with inclusion of members with developmental disabilities. While inclusion in such groups has been recommended by advocates for people with disabilities, there is no research regarding the perspectives of ordinary community members regarding both the benefits and challenges of inclusion of people with disabilities in their groups.

From the perspective of disability research, studies of the community participation of individuals with intellectual and/or developmental disabilities living in the community often include data on such community activities as shopping, movies, restaurants and other activities such as volunteering. Among the options for community participation, some studies do indicate that some service recipients participate in community groups and organizations (e.g., Amado, DeGrande, Boice & Hutcheson, 2010; Hewitt, Larson & Lakin, 2000). This information from the disability research perspective results in information such as what percentage of group home residents participate in community groups and associations. However, there is virtually no systematic research on the experiences of these individuals with disabilities in these groups.

At the same time, to our knowledge no study has been done of national community service organizations themselves regarding the extent of membership of people with intellectual disabilities (ID), other developmental disabilities (DD), or any kind of disability. That is, it is not known what percentage of community groups and associations have members with disabilities. While some groups

such as Kiwanis have started special groups or types of chapters for people with disabilities, the current study was focused on the inclusion of individuals with disabilities in regular chapters.

. Some authors on disability supports have provided specific recommendations regarding supporting group membership. For example, Reidy (1993) made specific suggestions for how to support individuals with DD in becoming members of groups, from her direct experiences of working to support individuals to join such clubs and associations. However, her recommendations did not derive from systematic research of attitudes of community members themselves who were members of such groups and what they had to express about their experiences.   It would be worthwhile to determine if inclusion is valuable from the perspective of community members, and if so, what could be done to strengthen, expand and support such membership from the perspective of these other group members.

Research regarding deinstitutionalization, community integration and mainstreaming has often focused on the question of impact to the individuals with disabilities of such inclusion, including both positive and negative benefits   (e.g., Heal, Haney & Novak Amado, 1988; Hewitt, Larson & Lakin, 2000; Stancliffe & Lakin, 1996).   It is a fairly new and recent phenomenon to evaluate the impact on ordinary community members of inclusion of individuals with disabilities. This more recent body of literature has assessed the benefits and contributions which people with disabilities make to ordinary community members, as well as the challenges of inclusion, and theoretical models are still evolving concerning this impact on community members. For example, there is some literature (e.g., Amado, 2011; Carter, 2007) concerning the benefits and challenges of including individuals with developmental disabilities in faith congregations, as well as research on co-worker impact when people with disabilities are included in employment settings (e.g., Chadsey & Linneman, 1997; Rusch, Wilson, Hughes, & Heal, 1994).   Studies regarding inclusion and mainstreaming in schools of children include the benefits which regular education students gain from the mainstreaming of special education students (e.g., Villa &

Thousand, 1999).   There is also research regarding the benefits to families of having a child with disabilities (Blacher & Baker, 2007; Hastings & Taunt, 2002; Summers, Behr & Turnbull, 1989). Contrasting a half century of research regarding negative impact on families of having a child with intellectual disabilities, Blacher and Baker note the paucity of research regarding the positive impact on families of having a child with disabilities, and that this topic has been researched only in the last decade. In conceptualizing a theoretical model for determining positivity, Blacher and Baker proposed three levels for determining positive impact: (a) the absence of negative views, (b) "common benefits" (despite disability, parents experience many of the same joys of raising a child with disabilities as families experience with children without disability) and (c) "special benefits" (there are unique benefits experienced by families of children with disabilities that are not experienced by parents of children without disabilities).

Much more research is needed about community members' attitudes and effective inclusion strategies in social settings such as neighborhoods, clubs and community organizations.   The current study was under-taken as an initial effort to gain information concerning the extent to which persons with disabilities are currently included in community groups, what the experiences of those groups are with inclusion of members of developmental disabilities, and if such inclusion is beneficial to community members, what can be done to expand such membership.   For example, do community members experience both positive impact and negative impact? Do they experience "common" benefits, the same benefits as having any member in the club, as well as "special" benefits in having a member with disabilities join their organization?

There were three principal purposes for this study:

1.   To gather information about the extent of inclusion of people with developmental disabilities in community service organizations, clubs, and groups, from these organizations themselves.

2.   To determine the perspectives of non-disabled group members on the inclusion of people with

developmental disabilities in their organizations, including the positive outcomes and

benefits as well as challenges or barriers.

3.   Based on any challenges to inclusion of persons with developmental disabilities in these

organizations, as perceived by organization members, to identify any supports which human

services provider agencies and families can offer to expand membership in those

organizations and to support successful experiences for the member with developmental

disabilities and for the other group members.

These purposes were intended to result in concrete recommendations both for human services agencies and for community group members themselves about successfully including individuals with intellectual/developmental disabilities in their associations.

METHODOLOGY

In order to have a broad sample of community organizations to survey, within the study scope possible, four different regions of the United States were identified, and one state in each of these regions was selected for a study size of four states.   Since to our knowledge no such study had previously been conducted, we selected states that had high ratings on their measure of "social capital." Putnam (2000) defines the core idea of social capital theory as "that social networks have value." (p. 19).   Social capital means the connections among individuals, the reciprocity and trustworthiness that arise from those connections, and the idea that our lives are made more productive by our degree of social ties.

Since the number of states to be studied was going to be selective, we wanted to choose states in which we felt membership of people with disabilities in community organization membership might have the highest chance or possibility of being present. If membership of people with disabilities in community organizations was happening, we wanted to maximize our chances of finding groups in which it might actually be occurring, and gather information from organizations that had direct experience with members with developmental disabilities. Thus we picked states already high in social capital, theorizing that such states would provide us the greatest chance of finding such organizations.

Using various scales in Putnam's (2000) foundational study of social capital ("Bowling Alone") we selected each state in each of the 4 regions of the U.S. that had the highest scores on his Social Capital Index. (Putnam's social capital index was compiled from measures of trust, organization membership, volunteering, voting, and socializing with friends.) This process resulted in the selection of these four states: Washington for the west, Minnesota for the mid-west, Massachusetts for the Northeast/east, and Florida for the south.

In order to obtain lists of community organizations to survey, again we also sought to find organizations which already had a high degree of social capital, assuming that these groups might have the greatest possibility of membership of people with disabilities. We also sought a broad range of different types of organizations. The decision was made to use "Adopt-a-Highway" lists from each state to gather a wide selection of different types of community organizations. These lists include a broad variety of community groups, and each of these organizations had already made a commitment to be responsible for the cleaning of a various section of a highway; hence, they already reflected one type of social capital.

Entities on Adopt a Highway lists include a broad range of sponsors. After obtaining lists from each state, in order to end up with the types of community voluntary organizations intended for this study, we excluded the following types of sponsors that were on these Adopt-A-Highway lists:

1. families

2. businesses

3. military units, including ROTC

4. employment associations, business fraternities or professional associations such as engineers

5. churches unless it was a specific church group

6. fire or police units

There were many youth groups on the lists but we wanted respondents old enough to answer written questions concerning their experiences of inclusion of members with disabilities; thus, we included 4-H, Future Farmers of America and Boy Scouts but not Cub Scouts.   These exclusions left a broad range of community groups or organizations, including service organizations, political parties and chambers of commerce. From this remaining group, a random selection method was used of selecting every 7th group listed. If the seventh group listed was not eligible, the next eligible group listed was used, until a study group of 100 organizations in each state was compiled.   In two states, we included a slightly higher number (e.g., 105) because doing so meant all of the eligible community organizations on the Adopt A Highway list for that state could be used.   We then surveyed these groups using mail surveys and phone interviews.

Mail Surveys

  The mail survey format had been piloted with five community groups, and pilot information indicated that when community members were asked about membership of people with developmental disabilities

in their organizations, interviewees often responded with information about various types of disabilities. Consequently, the final survey asked about membership about people with numerous types of disabilities, and then more specific information about members with developmental disabilities.   The survey content consisted of questions about the size of the group in general, numbers of members with different types of disabilities, length of membership of individuals with DD, and benefits and challenges of membership with people with DD.

A survey was mailed to each of the selected community organizations, and if an email address was available, it was also emailed.   When surveys were returned as "no such address," if a phone number was available, that contact person was phoned to determine current contact information for the group or contact information for the group was sought on the web. After the initial mailing, a second round of surveys was also mailed. We continued to attempt to have surveys returned from as many groups as possible, including additional phone calls and emails.

Phone Interviews

Survey respondents were asked on the mail survey if they were willing to also be interviewed by phone.   The phone interviews asked for more in-depth information about the experiences of the group and group members about what members with DD had brought to the group, what the challenges were, if they got support from human service agencies, and what they found helpful or not helpful. Phone interviewees were also asked to contact individuals with DD who were members, to ask for their willingness to be interviewed about their experiences, and to be put in contact with us.

Information is reported on these 3 study parts: mail surveys, phone interviews of community organization representatives, and phone interviews of individuals with DD (or their family members) who were organization members

RESULTS

The number of organizations contacted was 415.   This number is slightly higher than 400 (100 for each state) because in two states including a slightly higher number meant that all eligible organizations on the state's Adopt a Highway list could be contacted, and also because of difficulty with contact information in the initial 100 selected.

Of these 415 Community Organizations contacted, 101 responded, a 24 percent response rate.   An additional five organizations returned surveys indicating the group had disbanded or were declining to participate.   The number of surveys returned by state was Florida: 13 (10%), Massachusetts: 19 (20%), Minnesota: 40 (37%), and Washington: 29 (27%).   Results below are reported for the mail surveys, phone interviews, thematic analysis of responses by community group members of benefits and challenges, and interviews with members with disabilities.

Mail Survey Returns

Of the groups which returned surveys, approximately two out of three (67 of the 101 organizations) reported that they had members with disabilities.   Out of the total membership reported, the percentage of people with disabilities in organizations that have members with any kind of disabilities ranged from: 1.2% in Washington to 3.7% in Minnesota, 5% in Massachusetts and 10% in Florida.

The types of disabilities reported are shown in Table 1.   Two types of groups, Big Brothers/Big Sisters and Best Buddies, reported very large numbers of people with disabilities. The organizational

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basis of those two organizations is primarily members volunteering for others, including for a very large number of people with disabilities.   Hence, because their organizational nature is different than other types of community organizations, their information is not included in Table 1 (how many groups have how many individuals with different types of disabilities) but is reported in the information in Table 2 about the number of groups with members with DD.

Thirty-one organizations responded that they had no members with disabilities (Florida: 5, Washington: 9, Minnesota: 14, and Massachusetts: 6).   The types of organizations reporting no members with disabilities in some states included seven Kiwanis or Key Clubs, four university Fraternities/Sororities, 3 Rotary Clubs, 3 Lions clubs, five outdoors clubs (e.g., Pheasants Forever; 4-H; Sno-Riders), and nine "other" (e.g., Zibibi OES Foundation, Knights of Columbus, Masonic Lodge, Historical Society, TOPS, PALS Club).   However, other states reported having members with disabilities in most of these very same organizations.

Groups with people with disabilities were in communities both large and small, as were the groups that did not have people with disabilities. The groups which had individuals with disabilities tended to be slightly larger than groups without people with disabilities.

There was a wide variety of types of disabilities reported among these groups' membership. Many survey respondents wrote comments on their surveys or expressed in interviews that their membership was aging, and thus they are having to deal with an increasing amount of and different types of disabilities.   For example, some individuals have been Kiwanis or Rotarians for 30 years, and are continuing their membership; so fellow members have to deal with increasing physical impairments, vision and hearing losses, and also memory loss and Alzheimer's.

Of the 67 organizations with members with disabilities, 21 reported members with developmental disabilities.   These groups are listed in Table 2. To determine the number of groups with

"developmental disabilities" we added together any responses in the survey categories of "mental retardation" (term used at the time of the study), "cerebral palsy", autism, and developmental disabilities. XXX

<u>Phone Interviews</u>

Representatives of twenty-three of all of the 101 survey-responding organizations were interviewed by phone (23 percent). Of these 23 groups interviewed, 11 had members with DD. These 11 groups were able to identify three people with developmental disabilities or their family members who could also be interviewed.

<u>Thematic Analysis of Surveys and Phone Interviews</u>

Survey and interview responses were analyzed according to the constant comparative method (Glaser & Strauss, 1967) of qualitative analysis, which involved analyzing and categorizing survey responses into specific themes. Potential categories of themes were identified, and then coded according to the frequency of mention. Individual responses were categorized into the relevant theme, and the total number of responses that fit into each theme, or category, was calculated. Responses analyzed thematically included areas of benefit and areas of challenges and barriers. Information is also reported for living arrangements of the members with developmental disabilities, assistance from group homes, and the benefits and challenges reported in the phone interviews of the individuals with disabilities and/or their family members on their experiences as group members.

1. <u>Benefits to Community Members of Group Members with Developmental Disabilities</u>

The benefits which were most frequently mentioned on the 21 mail surveys where groups had members with DD were: recognition that individuals with disabilities have talents, abilities, and are able to participate and contribute (24%); tolerance/acceptance of individuals with disabilities (19%), learning experience (14%), and friendship (19%).

Of the 19 people who responded in interviews to this question of benefits, every single response reflected some learning, awakening, or change in perception.   Examples of comments included: "it was an awakening that they are regular people", "more like us than not like us," and "realize they have a lot to contribute."   Other examples included:

- "[It] made you aware of the fact that although they can't speak and have trouble moving that they still think, know what you are saying, and like to participate."

- "As I expressed to her one time, it is so nice to have you in the club – before when I saw someone in a wheelchair I was shy, but I have learned to pull up a chair and be eye-to-eye and can just talk to her."

- "That their limitations are less than what they are first seen."

- "[I think we have all] learned to be more relaxed with someone with that type of a disability."

- "It helps people to understand their own limitation."

 2 Barriers/Challenges Reported by Community Members of Members with DD:

    With the groups which had members with DD, there were a variety of barriers or challenges reported, both on surveys and in interviews.   However, the most frequent survey response to this question was "none" (24% of responses).   The barriers most frequently reported on the surveys fell into four major categories: transportation (19%); planning & accessibility (19%); acceptance from some members (e.g., afraid of them) (14%); and behavior of person with disabilities (calling/emailing too often, not wanting to pay for themselves) (10%).

    The people that were interviewed also reported all of the above four barriers and challenges experienced, but with more frequency and also reported a greater variety of barriers.   These were the barriers reported in interviews: the individual's behaviors or abilities (22%), acceptance from other

members (22%), adapting or matching activities to the group so the person could participate (22%),

transportation (11%), accessibility (6%), and communication with group homes (6%).   Examples of

the challenges about specific abilities or characteristics of the individual included: "Working through

socially awkward situations was a challenge," and "It is a challenge for them to get across what they

mean." Here are some typical comments about challenges of adapting or matching activities to the

group: "It was a challenge ensuring safety and finding service projects the member could participate

with, " "Finding a job that met the student's interest and ability to perform a task was a challenge" and

"That was a challenge to always have someone nearby to answer questions for her."

   Four people interviewed responded to the question about barriers or challenges by giving specific

examples of how attitudes and the capabilities of other members changed over time:

1. "One lady who was rather uppity [who had a lot of] money [and] lived another style of style.
    Now, she says, "Wow, Mary is a neat lady and has lots to offer …"

2. It took a little bit on everybody's part not to get angry (and) take a step back and a deep breath
    before getting angry (to remember she has a) child mentality rather than [that of a] 50/60 year
    old woman.

3.   It wasn't smooth the whole way and there were grumblings along the way, but that was the few
    rather than the many.   They (the grumblings) got fewer and fewer as time went on.   She was
    willing [to do jobs that others didn't want to do; for example] we did favors for a banquet [and it
    was] tedious work [but was] right up her alley.   She can sell tickets and count money [and] she
    does well sitting and doing that type of thing."

4. "When you have members who have been in for 50/60 years, [they said things like] she
    shouldn't come, she isn't going to know what is going on, who is going to take care of her
    walker? But [then other] people spoke out, "well Dolly has a walker and no one said anything
    about Dolly."

   Three people interviewed also expressed concerns about what would happen if they increased the

number of people with disabilities in their group.   For one group, the biggest challenge was

communication with the group homes in town, and if more people with disabilities wanted to participate,

that would be difficult.   A second group picks up the dues for a member with Down's Syndrome, but if they recruited a lot more people with disabilities that would be a problem.   In a third group, the respondent noted that the members with disabilities are not quite as active in coordinating activities or taking leadership positions, so that if there were a lot more members with disabilities, other members might get bitter if they had to pick up more of the slack.

3. Types and Role of Living Arrangements/Staff of Group Members with DD

In order to obtain some information about the types of individuals with DD who were members of these groups, and their situations, the phone interview included a question about living arrangements. Not all group representatives were able to provide information about the living arrangements of those individuals with DD that were members.   However, of the groups that did provide this information, these were the living arrangements:

- Three groups that had a total of 4 members with DD reported that those 4 individuals lived on their own

- One high school group that had 6 individuals with DD as members reported that they lived with their parents and family

- Three individuals in three different groups lived in group homes:

    1. one comes to meetings without staff and is picked up by other group members

    2. one had originally lived in a supported apartment and now lives in a group home; that person
        is picked up by other group members

    3. one comes to meetings with agency staff

4. Assistance from Group Homes

Several survey and interview responses reflected the group member's need for more information and/or support about members with disabilities. For example, one respondent noted, "We are not necessarily informed enough to deal with some of the disabilities."   For a group member who lived in

a group home and was accompanied by a staff member to meetings, the role of group home staff was very important.   The community group representative interviewed reported there were not really any challenges because of the assistance provided by the staff.   "He always had a person [aide] with him [and] he blended in [with the rest of the members] just fine.   The person that came with him was someone from the home, she drove him over and got the wheelchair in. She participated [talked, ate, etc.] in the club as well, usually anyone who comes to the meetings participates.   She always helped him keep his papers straight [because his motor abilities were hard and] sometimes he had trouble talking and she would help interpret for him … that helped us and him."

A Knights of Columbus member who was interviewed complained that the group home staff requested he monitor how much the person with DD ate at group meetings.   This made him very uncomfortable, and he received assistance from an advocate in communicating with the group home that this was not an appropriate request.

 Phone Interviews with Individuals with Disabilities/Family

Three group representatives were able to obtain permission from members with disabilities to be interviewed. These individuals were:

1. the mother of a girl who is in Girl Scouts

2. a woman with cerebral palsy who is a member of the Lions' Club

3. a man with autism who is a Big Buddy for a high school student

The benefits of group membership reported by the individuals with DD, and/or what they liked about being group members included: social interaction, the diversity of activities in which to participate, and using their skills in the community.   What they reported was:

- "I gained friends, increased my knowledge and self-confidence, and carrying out my lifetime purpose. That purpose, as I see it, is to show everyone that I come in contact with that my disability is only secondary to who I am first – a person."

- (from Mom) "I like that it allows her to do a lot of mixing with other people. As you get to be high school age you are not so socially integrated if you are mentally delayed, and your peers tend to be mostly special education. She is quite integrated in Girl Scouts."

- "I love using my skills to help others and to be part of the community."

The barriers and challenges reported by these individuals included: that some group members had initially "grumbled" about their being part of the group; that although they were integrated, they did not always experience being included; and that transportation was a challenge.

These individuals also reported on the benefits to other group members. The woman with cerebral palsy reported, "Of course, there were the stares and the mumbling about what could I possibly do in the club. After all, I couldn't speak nor feed myself. People didn't know how to act around me and were skeptical. With my speech impediment, I can't even help ease their "fears" by engaging in conversations with them. I think that there are always some that never change, for whatever reason. On the whole, however, things go quite well. After they see me picking up garbage after an event, or chucking corn at our Annual Corn Feed, or making a point in a meeting, they see that I just want to be like everyone else." The mother of the Girl Scout reported that "For the last two years, our girls have been role models for other troops . . My girls are becoming leaders."

DISCUSSION

This study was the first we know of to gather information about the extent and nature of membership of people with disabilities, and specifically people with developmental disabilities, in community organizations. Information was obtained from groups in four states. For those wishing

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to support membership of individuals with disabilities in community organizations, and for community organizations themselves who wish to include individuals with disabilities in their membership, there were several important factors identified.

One of the most revealing pieces of information gathered in this study was the high number of groups which reported an aging membership.   For instance, there were groups of Kiwanis or Moose Lodges which had members who had belonged for more than 30 years.   They are increasingly dealing with issues of hearing loss, vision loss, increasing physical impairment, and memory loss including Alzheimer's.   These groups reported that they are learning to accommodate increasing degrees of disability out of a commitment to their life-long members.   The capacity of these groups to accommodate individuals with life-long disabilities is therefore increasing.   As one interviewee reflected, "[Challenges included] sight lost and inability to drive and act independently. These challenges caused withdrawal from some activities but when cognizance was present, there remained the benefits of support through participation and encouragement." Another example was reported above about the woman with cerebral palsy joining who uses a walker being compared to another long-time member who now also uses a walker.

Secondly, the range of groups which had members with disabilities and with developmental disabilities was striking.   Almost all types of groups had members with disabilities and with developmental disabilities, including the different types of groups categorized in the community association literature.   For example, the range of groups that had members with developmental disabilities reflected Gordon and Babchuck's (1959) three categories of expressive, instrumental, and mixed groups, as well as Warriner and Prather's (1965) four types of groups based on members' reasons for joining: pleasure in performance, sociability, ideological symbolism, and production. The groups reported in this study which had members with disabilities also fit in five of Babchuck

and Booth's (1969) six categories: church, recreational, fraternal-service, other, and adult leadership

of youth programs (one man with autism interviewed was a Big Buddy); the only category missing

in this study from their typology was job-related groups.

For any group that did not have a member with DD, there was in almost every case, the same

group in another state which did have a member with such disabilities, including Kiwanis (Key

Club), Knights of Columbus, Lions, Moose, and outdoor groups (hiking club, saddle club). The only

exceptions in our surveys, of groups that did not have people with DD, were some specialized

groups such as university fraternities/sororities and Masons. There might of course be examples of

these groups which do have members with DD in other groups or in other states than those four

surveyed here.

Third, the responding group representatives did report many types of benefits of including people

with DD in their groups. The primary benefits reported on surveys were recognition that

individuals with disabilities have talents, abilities, and are able to participate and contribute;

tolerance and acceptance of individuals with disabilities; a learning experience; and friendship.

Interestingly, in phone interviews every single response about benefits reflected learning, awakening

or change in perception. Comparing with Blacher and Baker's (2007) theoretical model of

positivity, the interview responses were all in the "special" category of benefit. The only benefit in

the "common" type of benefit – benefits which one would gain from any other member – was

"friendship," reported in 19% of surveys. That is, almost all of both survey and interview responses

were about the special and unique contributions of having a member with disabilities, but people

with developmental disabilities could also share in the common benefit of friendship with other

members. There were also some responses in the "absence of negative views" category of positivity,

since 24 percent of respondents noted there were no barriers or challenges.

Fourth, group members do extend themselves for members with developmental disabilities, including providing transportation.   This is important for families and for staff in group homes or other residential services to know.

Fifth, the information gathered about challenges and barriers and how groups addressed those reflect several issues or "lessons" for residential agencies if they are to support inclusion of the people with disabilities in community groups. Apart from sheer logistics, almost all of these lessons reflect that community associations and groups have a different culture or different ways of operating than many group home/supported living situations, and that when support is provided by residential support staff they need to be aware of this "culture clash."   The following six issues reflect supports which residential agencies will need to address:

a. Transportation

Transportation was the most frequently mentioned challenge, by surveyed group members and by people with disabilities who were interviewed. Examples of challenges reported were: making sure the person could attend meetings, group members picking up members with disabilities, and finding someone to give them a ride to and from the meetings.

b. Email

Many organizations these days communicate with members by email.   This is a challenge for individuals with disabilities living on their own who do not have email, and there is a challenge to maintain consistent email contact with individuals who live in group homes.

c. Last minute changes/communications

    Often groups make last minute changes in meeting times, places, or other information for get-togethers.   Besides the fact that this information is often sent out by email, some groups reported that it was difficult when members lived in group homes that were inflexible about last-minute schedule changes – for example, when staff or transportation schedules were set in place a week or more in advance.

d. Turning the community group into a "program"

    Some interviewed group members reported feeling uncomfortable when they were asked to do things with their member with DD that was of the nature of a human services "program."   For example, one member of the Knights of Columbus was in the role of a mentor/friend for a member with DD; he was asked by the person's group home to monitor what the individual with DD ate at Knights meetings.   This made the mentor Knight very uncomfortable.

e. Community organization members often do need support

    In many situations, group members without disabilities can use support from family members or residential support staff for addressing issues that are challenging or difficult. For example, one member with DD was making too many phone calls to his sponsor in the group.   When the sponsor let the group home staff know, they supported the member with DD to cut down his calls.   One survey respondent said, "we are not necessarily informed enough to deal with some of the disabilities"; so, providing needed information would be important.

<u>f. Sensitivity is needed regarding each group's capacity to include and support individuals requiring special accommodation</u>

It is natural to expect that if a particular group is accepting of one individual with disabilities, then more individuals may wish to join or an agency might want to encourage more people to join. However, in the past, human services professionals have recommended limiting the number of individuals with disabilities in any particular group or community, to limit congregation of too many people with disabilities in one organization and to promote greater assimilation of the individuals with disabilities who are already members (Wolfensberger & Glenn, 1983).   It is important to note that this study reflected that community group members themselves also recognize their limitations in being able to include a greater number of people with disabilities.   The concerns they expressed were quite practical ones: picking up an individual's dues, difficulties in communication with group homes, and the fact that people with disabilities were not always as active in activities and leadership as other members, so that could present a greater work-load to members without disabilities.   These comments were spontaneously provided during interviews and were not in the interview script.   It is also possible that the benefits reported here by other group members about having members with disabilities in their organization results from the fact that most of the groups had only one or a very limited number of members with disabilities.   More challenges may have been reported if there had been a greater congregation of individuals with disabilities in any one chapter.

Hence, residential services, other agencies or families providing support to individuals joining groups will need to address transportation, email, last minute changes, and providing sufficient support and information to other group members. Supporters will need to be sensitive to not trying to turn the group into a human services program and not congregating too many individuals with disabilities in any one group.

Lastly, for members of any community service organization, this study provides evidence of the positive and unique benefits gained from membership of people with disabilities. In addition, it is valuable to know that as long-time members age, groups will be dealing with an increasing amount of disability. The information from this study provides several practical recommendations to association members about including persons with disabilities, including: (1) ask for support if it is needed to address a specific problem or issue; (2) appreciate that accommodations might have to be made for transportation, communication by email, and last minute changes in such things as meeting times or locations; (3) limit the number of people with disabilities in the group proportionate to the group size and capacity for support; (4) do not accept requests (or see how certain requests could be accommodated) if honoring the request would make members uncomfortable or would not fit into the "culture" of the group; and (5) recognize that not all members of a group are the same and some may be more accepting than others, and that several groups reported that initial negative or fearful attitudes and acceptance improved over time.

Of course the number of groups studied and people interviewed in this study is small compared to the thousands of community organizations which exist. In addition, we were selective in choosing both the states and the organizations studied. Hence, the results reflected states that were higher in social capital measures and the organizations responding were perhaps more likely to be groups that had individuals with disabilities. It is also possible that the groups responding to the surveys were those that had members with disabilities and/or those with positive experiences. More extensive, varied, and larger studies would provide more information, such as a random sample study of all the groups listed in the Encyclopedia of Associations. However, despite the size limitations, the study results demonstrate that people with developmental and other disabilities are and can be quite successful members of community service organizations, and that their membership can bring rich

benefit to the other members, as expressed by those other members themselves.   Lastly, there is quite practical assistance which group homes, other support agencies, and families can provide and should learn about assisting the individuals they support to be active members of these organizations.

Future research can address far more extensive study of such issues as the benefits and challenges of group membership to individuals with disabilities, whether group membership provides benefits to them similar to the benefits gained by non-disabled individuals, whether there are differential factors affecting longevity of membership, and how groups and agencies address challenges and barriers. More extensive research will also provide more information on the perceptions of common and unique benefits and challenges to non-disabled group members and the factors affecting successful group participation for members with and without disabilities.

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Table 1. Group Membership – People with Different Types of Disabilities: Number of Groups and Individuals in Those Groups

	Total		FL		MA		MN		WA	
	Gp*	Ind	Gp	Ind	Gp	Ind	Gp	Ind	Gp	Ind
Mental Illness	5	5	2	2	1	1	2	2	0	0
Traumatic Brain Injury	3	4	1	1	0	0	2	3	0	0
Spinal Cord Injury	3	4	1	2	0	0	2	2	0	0
Physical Impairment										
Hearing Impairment	26	106	2	11	6	27	8	42	10	26
Vision Impairment	15	26	2	3	2	4	3	3	8	16
Other Physical	21	45	5	11	3	4	6	7	7	23
Developmental Disabilities	15	37	2	3	1	1	8	26	4	7
Cerebral Palsy	4	4	1	1	0	0	2	2	1	1
Mental Retardation	8	12	1	1	1	1	5	9	1	1

*("Gp" is the number of groups that responded that they had members with disabilities; "Ind" is the number of individuals they reported were members)
Data from organizations that reported numbers of members with each type of disability. Does not include Best Buddies or Big Brothers/Big Sisters.

Table 2: Groups with Members with Developmental Disabilities

Massachusetts
1. Degree of Pocahontas (DD = 1)
2. Canal Association (DD = no #s)
3. Big Brothers/Big Sisters (DD = 30+)
4. Big Brothers/Big Sisters (DD = no #s)
5. Best Buddies (DD = no #s)

Washington
1. Lions Club (DD = 1)
2. Christian Fellowship (DD = 2)
3. Hiking Club (DD = 1)
4. Key Club (DD = 3)

Florida
1. Knights of Columbus (DD = 2)
2. The Florida UFO Group (DD = 1)
3. Moose International Lodge
   (# unavailable)

Minnesota
1. SADD (DD = 6)
2. Lions Club (DD = 1)
3. Sertoma Club (DD = 1)
4. Jaycees (DD = 1)
5. Moose Lodge (DD = 4)
6. 4-H Club (DD = 6)
7. Health/Community Service Group
   (DD = 5)
8. Saddle Club (DD = 1)
9. Big Buddies (DD = 5)