

Investigating Day Programs for Adults with Intellectual and Developmental Disabilities: A
Provider's Perspective

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Abstract

In this study, the programmatic design of day service programs for adults with Intellectual and Developmental Disabilities is explored using an online survey. Fifteen providers in the Maryland, Virginia, and DC area participated in the study. Questions assessed the level of agreement with statements relating to their respective programs, focusing on relationships to regulatory bodies, commitment to the individuals they serve, and meaningfulness of their activity offerings. Additionally, descriptive information on program size and composition was collected. Providers were also asked to identify their greatest strengths and challenges in serving people with IDD. Respondents indicated a lack of interest in more government guidance, contrasting previous claims that day programs lack specific enough requirements. Additionally, providers indicated challenges related to staffing, particularly in relation to finding quality employees, spreading responsibility evenly among staff, and retaining employees for more than two years. The second most common self-reported challenge was underfunding and lack of resources. Findings indicate a need for further research and policy interventions to support day programs with staffing and funding so that participants can be best served. Additionally, the findings raise questions about how participant engagement in day programs can be measured and improved. Finally, this survey leads to questions about how government regulation can be made most effective in order to protect people with IDD without putting undue burden on providers.

EXPLORING DAY PROGRAMS FOR ADULTS WITH DEVELOPMENTAL DISABILITIES:

A PROVIDER'S PERSPECTIVE

Day Habilitation Programs have functioned as an alternative option to employment for adults with Intellectual and Developmental Disabilities (IDD) who may not be able to be adequately support in an employment setting, or who do not wish to work. Generally, the aim of these programs is “to build the community living skills of people with IDD by increasing their capacity to perform activities of daily living” (Friedman, C., 2016, p. 245). As a society, we dedicate a substantial and increasing amount of funding to day programs. In 2013, day habilitation programs were “the largest form of day service provided by HCBS (Home and Community-Based Service) waivers, comprising more than 80% of projected funding for day services” (Friedman, C., 2016, p. 245). Funding day habilitation programs comprised 18% of total HCBS IDD funding allocated in 2013 (Friedman, C., 2016, p. 245).

The literature on day habilitation programs indicates a variety of positive outcomes for adults with IDD. Studies in 2007, 2011, and 2013 indicated that participating in these programs “reduces boredom, under stimulation, and problem behaviors” and “increase[s] physical and psychological well-being” (Friedman, C., 2016, p. 244). Past research indicates that day programming is preferred by participants over home and institutional settings. Participants reported “increased choice and control over their daily activities” and “increased opportunities for community inclusion” when day programs were in community-based settings (Blick, R. N., Litz, K. S., Thornhill, M. G., & Goreczny, A. J., 2016, p. 362).

A relatively new subtype of day habilitation programs is Community-Based Nonwork programs (CBNW). Community-based nonwork (CBNW) is a type of day programming for adults with IDDs that “includes non-job-related supports focused on community involvement”

(Sulewski, J. S., Butterworth, J., & Gilmore, D., 2008, p. 456). CBNW programs aim to connect people with disabilities to their communities and broaden their social horizons. While this program-type is relatively new, it is steadily increasing. The number of people participating in CBNW programs grew from 44,000 to 114,000 between 1996 and 2004 (Sulewski et al., 2008, p. 459).

CBNW programs allow individuals who may not be able to participate in inclusive, supportive work environments to participate in community-based activities. Inclusive experiences, where individuals with IDD can interact with people without disabilities, increases “sense of belonging” and, according to some studies, “objective quality of life” (Blick et al, 2016, p. 359). Additionally, people in adult day programs with field trips into the community report “having more friends” and additionally have “more advanced language skills” than peers who spend less time in the community (Blick et al, 2016, p. 359).

While these programs have been “growing rapidly” (Friedman, C., 2016, p. 252), some argue that they are problematic because of the limited potential for community involvement and their relatively undefined requirements. Sulewski et al. (2006) report that “primary social interaction [in these programs] is likely to be with other individuals with disabilities and with staff” and that “opportunities to meet and interact with community members not involved in disability services are limited” (Sulewski et al. 2006). Programs themselves have reported difficulty “finding meaningful activities that foster community integration and relationships” (457). The definition and regulation of CBNW programs are often undefined. As per a 2008 survey, “when asked what requirements (minimum staff-to-individual ratio, maximum group size, minimum number of hours in the community or other) were in place for CBNW, over one

third of respondents to this question did not identify any specific requirements” (Sulewski et al., 2008, p. 459).

Finding meaningful and engaging activities is a challenge in day programming for adults with disabilities across the board. In a 2001 study, 100 day programs were observed to determine the level of engagement of the participants. Researchers reported that “adults with severe disabilities were involved in purposeful activities during an average of 48% of the observation intervals” (Reid, D. H., Parsons, M. B., & Green, C. W., 2001, p. 464). In the purposeful activities observed in this study, 75% were determined to be age-appropriate (Reid et al., 2001, p.464).

Additionally, staffing seems to be a consistent issue for day habilitation programs of all types. Direct Support Professionals (DSPs) staff day habilitation programs, and their commitment and competence to participants is critical for successful programming. In the U.S., DSPs have an estimated 52% turnover rate, leading to frequent vacancy and lack of consistency of care. Higher vacancy rates have been shown to negatively impact participant and family satisfaction ratings (Hewitt, A., & Larson, S., 2007, p. 182).

While day habilitation programs, including the newest subtype of Community-Based Nonwork programs, have clear positive effects for adults with IDD who cannot participate in supported employment; however, challenges in staffing, providing meaningful activity, and creating opportunities for inclusive community-building are still present according to current literature. In this study, day program service providers in the Washington D.C. area were asked about the perceived strengths and weaknesses of their programs in order to identify how day programs are faring in this area. Additionally, scheduling, mission, and program design information was collected for each program. This study aims to provide a brief outline of the

current attitudes of Providers, in order to give policymakers and government officials an insight into how programs can be supported best.

Methods

Participants

Directors of Day Habilitation Programs or Community Based Day Programs in the Virginia, Maryland, and DC programs participated in this study. The survey respondents are directors or staff members at 15 different area day programs. While this sample size is small, a recent national survey reported 30-40 consistent respondents (Sulewski et al., 2008), so this sample size not insignificant for a regionally-focused investigation.

Survey Design

Platform. The survey was designed using Qualtrics. It was anonymous, and no individuals or particular programs were tied to the responses given. Qualtrics subscription was provided by the University of Notre Dame.

Questions. The questions in the survey aimed to identify the key ideas, values, and daily schedules of day programs in the DC, MD, and VA area. The survey consisted of 21 questions. The first twelve questions were likert type questions. Respondents were presented with a statement and asked to indicate whether they Strongly Agreed, Agreed, Disagreed, or Strongly Disagreed. The remaining questions consisted of write-in responses and multiple choice question. Write-in questions were used to gain information about self-identified greatest strengths and challenges, activities routinely scheduled at the program, number of program participants, number of staff members, and average shift length. The multiple choice questions asked about the number of reportable incidents in the last 4 months and about challenges day programs face.

Procedure

The survey was distributed via an email to the DC and VA Provider Coalition for service providers for people with disabilities. Not all of the providers in the Coalition provide Day Service support programs, but instructions in the email specifically asked for Day Program Providers to fill out the survey. The survey took about 20 minutes to complete, depending on the length of responses provided for the open-response questions.

Results

Likert Responses

Interestingly, the most significant finding in the likert response section of the survey related to government intervention. In response to the statement “Our organization would benefit from more guidelines and established standards from the state and/or federal government,” 12 out of 15 respondents selected disagree. One respondent strongly disagreed. Only two respondents agreed or strongly agreed with the statement.

In responding to the statement “Our organization struggles to fill open positions,” seven organizations disagreed, one strongly disagreed, three agreed, and four strongly agreed.

In response to the statement “The activities we offer are age-appropriate,” nine programs strongly agreed and six programs agreed. No programs responded disagree or strongly disagree.

In response to the statement, “We take pride in tailoring activities to meet our participants’ needs and match their interests,” eleven programs strongly agreed, three programs agreed, and one program disagreed.

Nine programs strongly agreed and six programs agreed with the statement “Input and evaluation by our participants are always sought after.” Similarly, in response to the statement

“We evaluate and, where appropriate, implement the input from our participants,” ten programs strongly agreed and five agreed.

Day programs also indicated that they would be interested in some level of collaboration with other area providers. Seven programs strongly agreed and eight programs agreed with the statement “We would be interested in hearing activity and scheduling ideas from other programs.”

In response to the statement “Our participants find the activities we offer to be engaging,” six programs strongly agreed and nine programs agreed. In response to the statement “Staff members can identify each individual by name,” thirteen programs strongly agreed and two programs agreed.

Demographic Questions

Demographic questions in the survey collected information regarding staffing, incident reporting, activities offered, and number of participants.

The average shift length for employees of these day programs was eight hours. Three programs reported shift lengths below eight hours, and one reported a shift length above eight hours.

The programs in this study also diverge in the number of participants they cater to. Five programs had less than 20 participants, six programs had between 20 and 40 participants, two programs had between 40 and 60 participants. One program had between 160 and 180 participants, one had between 420 and 440 participants, and one had between 440 and 460 participants. In terms of employees, eight programs employed less than 20 staff members. Two programs employed between 40 and 80 staff members, one employed between 160 and 180 staff members, and one employed between 200 and 220 staff members.

Programs also identified the number of reportable incidents their organization has had in the last four months. Two programs identified having no reportable incidents, eight reported having between one and five reportable incidents, two had between five and ten reportable incidents, and one had ten or more reportable incidents. Both of the programs that reported no incidents had twenty staff or less, and five of the eight programs that reported between one and five incidents had twenty staff or less.

Day programs reported a variety of different activities that are routinely offered to participants. Six programs offered art and volunteering respectively. Four programs offered music. Three programs each offered group exercise activities and visits to museums. Additionally, activity offerings were analyzed based on the extent to which they engaged participants in their current communities. Of the seven programs that listed the specific community-based activities routinely offered, the average number of community-based activities offered per program was 2.2 (s.d. 0.7). Additionally, six respondents reported offering “community integration activities” or “community outings,” but did not specify what particular opportunities were offered.

Greatest Strength

When providers were asked to identify the greatest strength of their respective programs, seven referenced their commitment to a “person-centered” approach. Four programs responded with themes relating to activities offered and community-based focus of their programs. Three programs cited their greatest strengths as either their qualified staff, choices presented to participants, or the low turnover rate for employees. Two programs referenced their small size, qualified management, clinical and therapeutic offerings, and commitment to individuals as strengths. Single programs each named strengths in facilities, focus and specialization of

activity, vocational opportunities, consumer satisfaction, consistency, and high ratio of staff to participants.

Challenges

When asked to check off the challenges that they consistently face, 33% of providers indicated they struggled with hiring enough staff members. 60% of providers reported difficulty in retaining staff members for more than two years. 53% reported challenges with funding. 33% reported challenges with government compliance. 27% reported challenges in Finding Age Appropriate Activities. No programs indicated that none of the listed challenges applied to their programs.

Greatest Challenge

When asked to identify the greatest challenge faced, eight providers responded with a concern related to staffing. Of these responses, five were related to attracting enough employees, two were related to offering a competitive and livable salary to staff, and one mentioned retaining employees for longer than two years. Additionally, five programs identified funding issues as the greatest challenge for their program. Of this number, two programs specifically mentioned difficulties with access appropriate technology necessary for the daily operation of the programs. Two programs identified finding appropriate activities and finding participants respectively as their greatest challenge. Additionally, two programs referenced a lack of support from management and government compliance respectively.

Discussion

Fifteen adult day service programs in the DC, Maryland, and Virginia area responded to an online survey discussing strengths, challenges, and program design. Their responses explore important policy areas relating to government regulation, staffing, funding, and offered activities.

In addition, the shift toward person-centered programming is evident from providers in this survey.

A particularly interesting finding was the significant response of programs that disagreed with the following statement: Our organization would benefit from more guidelines and established standards from the state and/or federal government. Based on previous literature, day programs, particularly Community-Based Nonwork programs, are often criticized for not having specific enough standards. In the 2008 national survey, “one third of respondents [...] did not identify any specific requirements” relating to ratio, group size, and minimum hours in the community (Sulewski et al., 2008, p. 459). Current findings indicate that most providers would not like more requirements for their programs. This finding could potentially be explained simply by the six years in between these two surveys, in which more regulations and monitoring processes may have been established. Maybe, in trying to regulate and define CBNW programs, states have swung too far in the opposite direction, leading to overbearing requirements and overregulation. In identifying the greatest challenges for their programs, one provider cited “over-regulation” and another wrote “keeping up with the daily requirements set forth by governing bodies.” However, it could also be that there still is a lack of regulation, but programs do not desire more government intervention. More research is needed to determine exactly what type of government regulation is optimal for both providers and participants. State resources should be directed toward finding a balance between ensuring the safety of people with disabilities while also creating a system of guidelines that is amenable to providers.

Another finding with policy implications relates to staffing, which was the most frequently cited “greatest challenge” for providers. When programs were asked to choose which challenges applied to their program, nine programs indicated issues with retaining employees for

more than 2 years. This challenge received the highest response rate. Additionally, five programs, one third of respondents, indicated difficulties in hiring enough staff members. For the write-in responses, while two programs just generally identified “staffing” as the greatest challenge, other respondents provided insight into the specific elements of staffing that are challenging. Two programs reported overburdened staff; one provider wrote “each staff person wears many hats/shoulders a lot of varied and essential tasks,” while another observed “frequently things aren’t done to a perfect standard or get lost somewhere along the way due to the heavy [staff] responsibilities.”

Two programs also directly referenced the salary of the staff. One program noted that “the high performing employees want higher pay.” Additionally, one program referenced “retaining employees” as its greatest challenge. Another program identified difficulty in filling positions: the respondent indicated that finding any applicant was difficult, but that specifically trying to find qualified applicants was very difficult. Overall, eight programs identified that their greatest challenge related to staffing. This mirrors previous research on the current staffing challenges facing providers of disability services. High vacancy and turnover rates have been reported for direct support professionals, who staff residential as well as day service programs.

Challenges with staffing have been found to lead to a decrease in quality of services for people with IDD, and staffing problems are often cyclical and self-reinforcing. High DSP turnover leads to increased DSP vacancies. When there are vacancies, staff are often needed to work large amounts of overtime. Research indicates that “working large amounts of overtime makes DSPs more susceptible to exhaustion, increased mistakes, increased abuse and neglect, and decreased performance” (Hewitt et al., 2007, p.182). In addition, exhaustion leads to the phenomenon of burnout experienced by many DSPs, and burnout further leads to high turnover

rates, beginning the cycle again. From the current survey responses, there is evidence that programs are in fact stuck in different phases of this cycle. One reports issues with turnover rate, another reports issues with vacancy, and two report overburdened staff leading to “things slipping through the cracks.” With such a high proportion of programs struggling with staffing issues, it is reasonable to conclude that solutions to stop this cycle of vacancy and high turnover are paramount for the well-being of day programs in the DC, Maryland, and Virginia area.

Interestingly, however, a few programs reported not having problems attracting staff members and retaining employees. Two programs identified their employees as their greatest success: one specifically focused on their low turnover rate and one indicated the high-quality level of employees. This, along with findings that most providers would be willing to share activity information and would like to receive more information from other providers, may indicate that collaboration between programs in terms of employee incentives and training could be beneficial.

The second biggest challenge facing day programs was funding. Three programs listed funding generally as an issue, while two programs specifically referenced a lack of technology. One program reported having “not enough computers” for participants. Another observed that “[their program] could do a lot more Community Engagement with lower ratios (less than 1:3), if the funding covered more such as more vehicles/insurance/fuel.” Since it is often questioned how truly inclusive CBNW programs are, it may be that, as a society, we are not providing programs with the resources they need to actually get participants into the community consistently enough to be meaningfully integrated.

When programs were asked to identify their greatest strength, the ideological shift toward person-centered planning was evident. Seven programs referenced “person-centered” program

philosophy as their greatest strength as an organization. This was the most frequently mentioned strength. Additionally, four programs identified the level of community engagement they provide for participants as their greatest strength. Furthermore, elements of program design also reflect person-centered philosophy. The choice that participants are offered in picking activities was evident from survey responses. Some programs noted that they did not have a daily schedule of activities, because daily planning is done by individuals upon arrival. Day programs seem to be dedicated to a person-centered mission.

Dedication to person-centered planning can also be identified in the survey questions that assessed the level of agreement of providers with given statements. All programs either strongly agreed or agreed that the activities offered in their programs were age-appropriate. All programs also agreed or strongly agreed that they sought input and evaluation from participants. Similarly, all programs either strongly agreed or agreed that staff members can identify each individual by name. These responses also indicate a commitment to person-centered service delivery.

Participant engagement and activity planning are self-reported strengths for some programs and a definite challenge area for others. Four programs identified challenges in “finding age appropriate activities” for participants. However, three programs identified the variety of activities and the choice in activities as particular strengths of their respective programs. Another interesting finding is that in responses relating to listening to participants and providing age appropriate activities, all respondents either agreed or strongly agreed, with a larger proportion strongly agreeing. While respondents seemed more strongly in agreement overall for these statements, more programs agreed instead of strongly agreed about their participants' engagement. Providers did think their participants were engaged, but they seemed less confident in this response than in previous responses about participant experience. This

indicates that future research needs to be devoted to how to measure participant engagement. Training on how to observe and evaluate participants' engagement with activities may be an area of growth for programs. Additionally, more collaboration between providers about accessible, effective activities would likely be beneficial.

Day program providers have made significant gains in adopting a person-centered mission; however, future policy needs to address the vacancy-burnout-turnover cycle in staffing and allocation of funds. If more than half of programs are struggling with staffing, it seems paramount to assess policies for loan forgiveness, higher salaries, or better benefits packages for DSPs. Additionally, future research needs to address how participant engagement can be adequately measured and what programmatic design elements improve participant engagement in day service programs. Regulatory bodies need to devote time to listening and documenting the experience of providers in order to improve the quality of life for adults with IDD.

Limitations

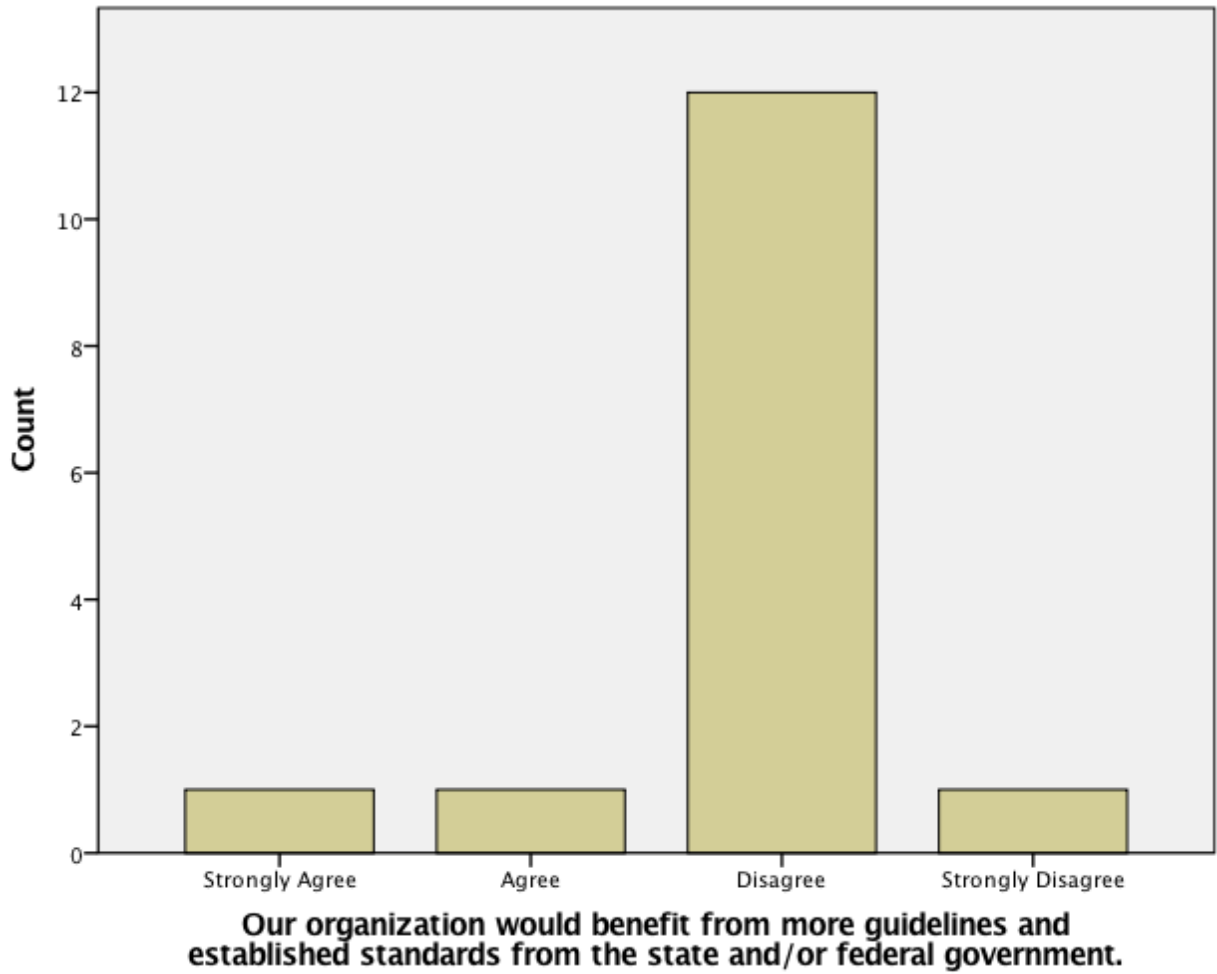
This study has a limited sample size and did not utilize random-sampling procedures. Participants in an existing coalition of day programs volunteered to participate. The findings in this study also cannot be generalized on a national level. Additionally, information on the locations, based on state, of each program was not collected. This may impact findings based on state-specific guidelines for day programming.

References

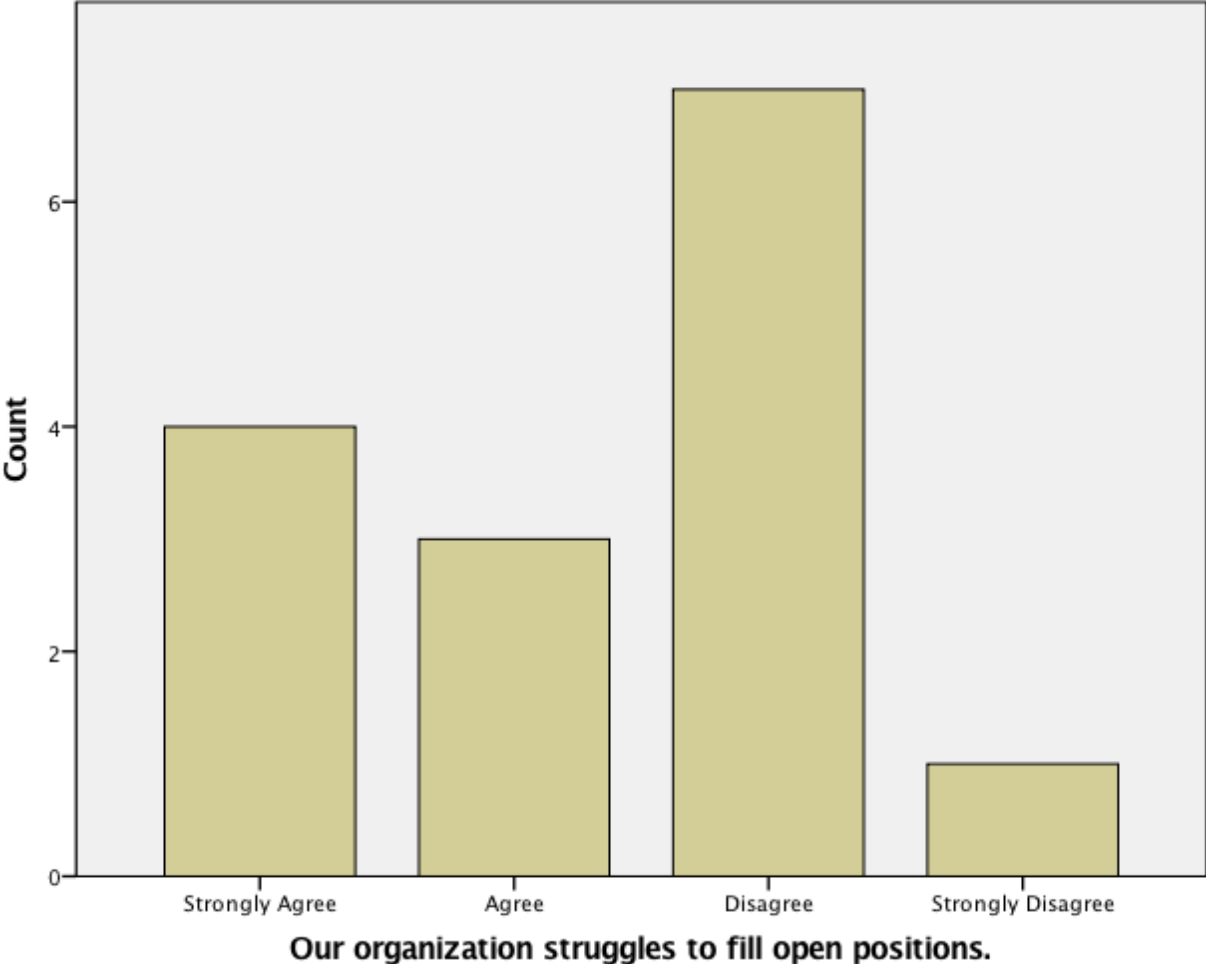
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Tables and Figures

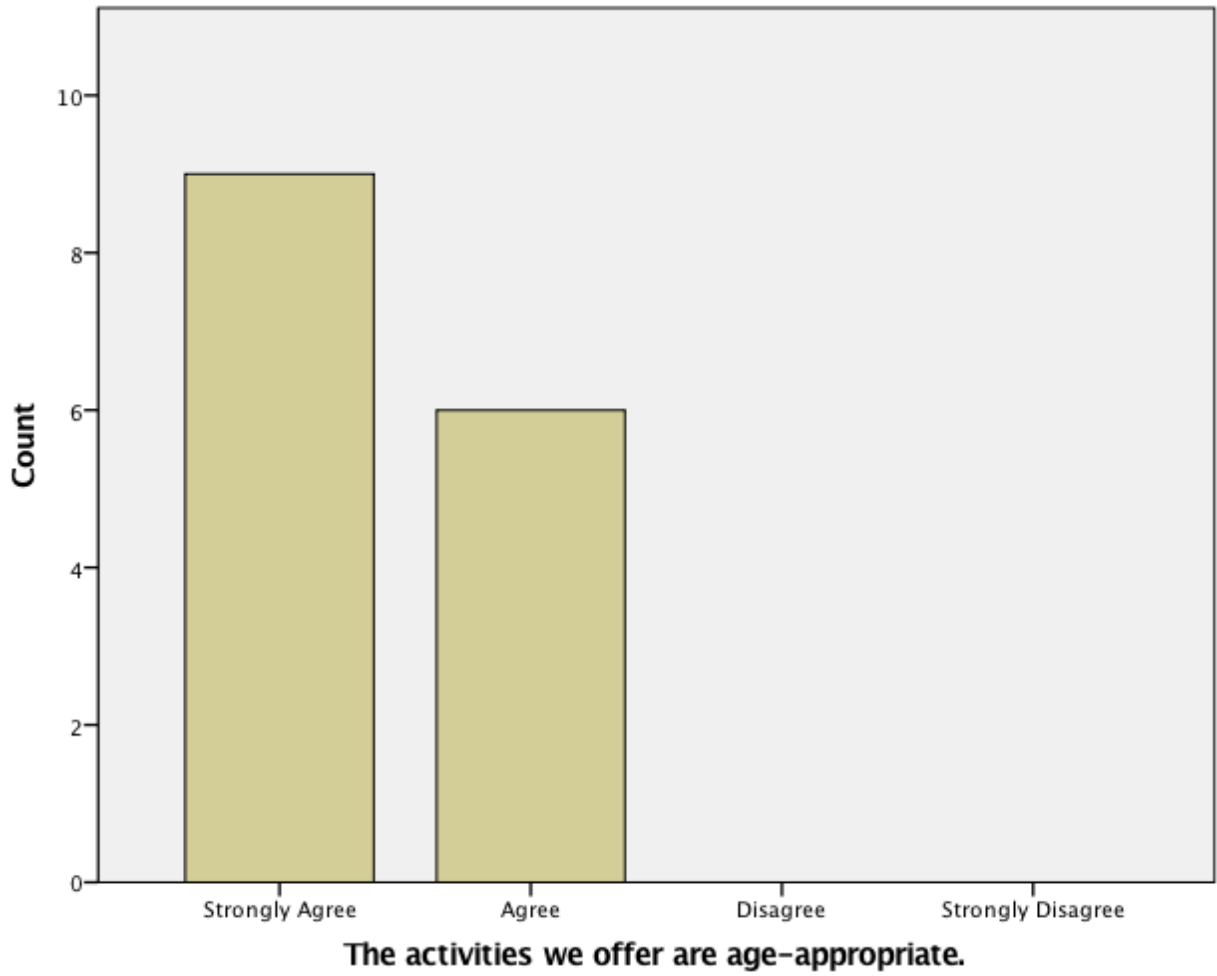
Government Involvement Response Graph



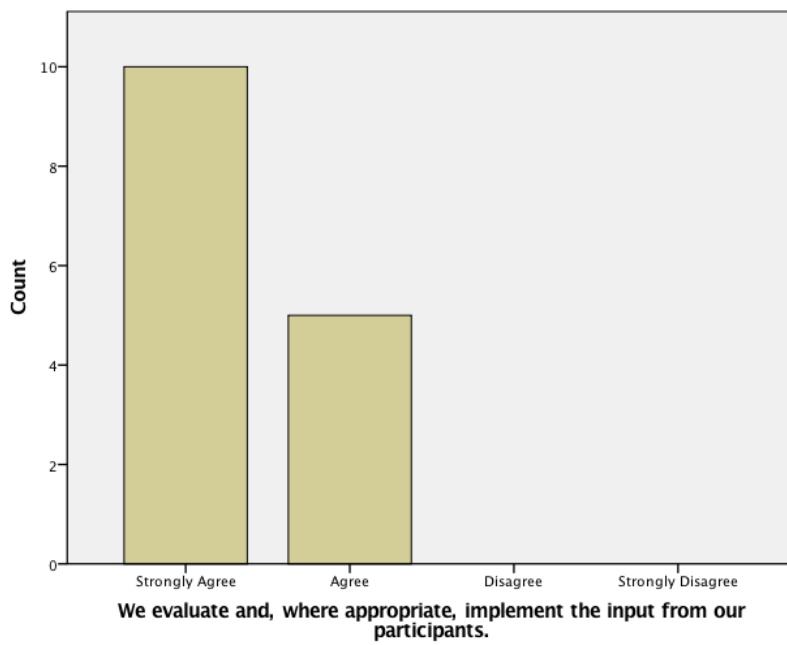
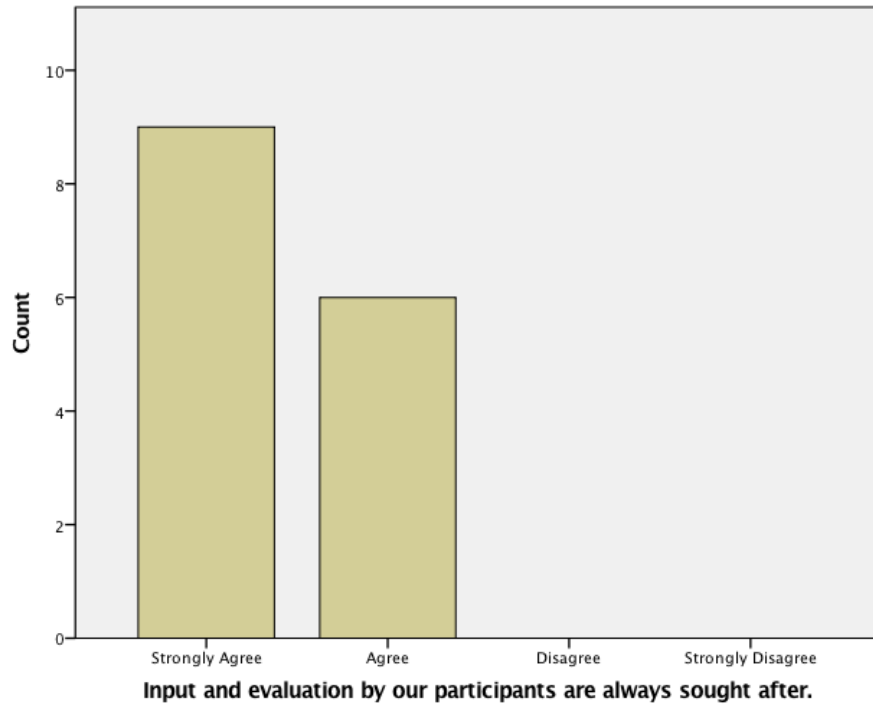
Vacancy Graph



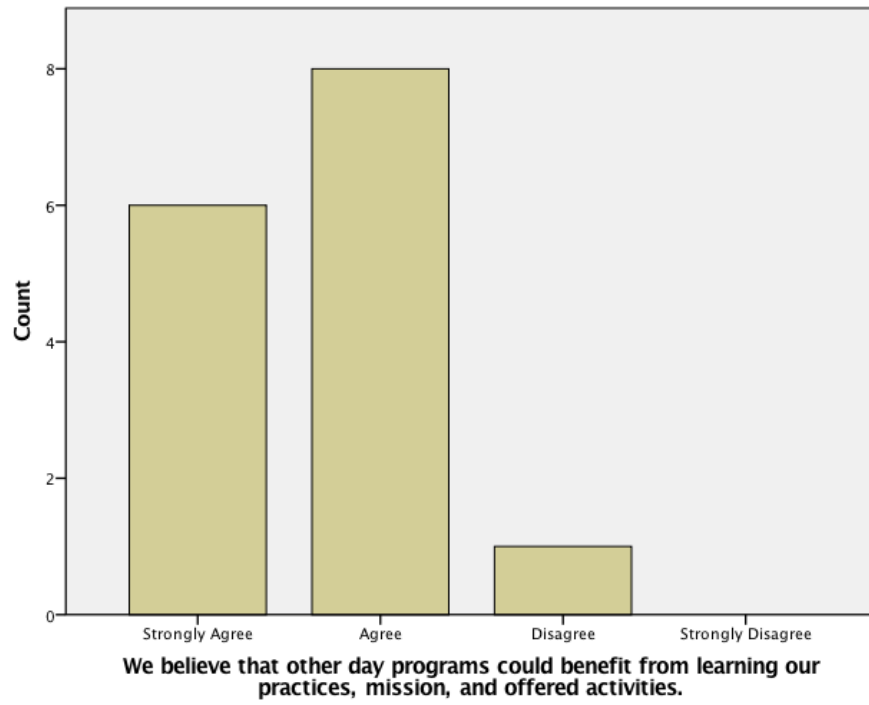
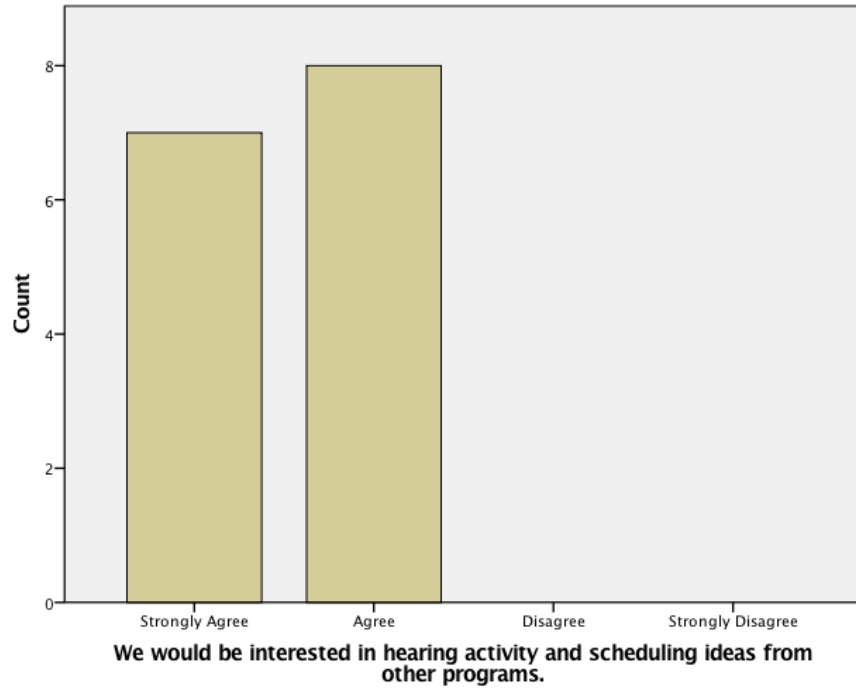
Age-Appropriate Response Graph



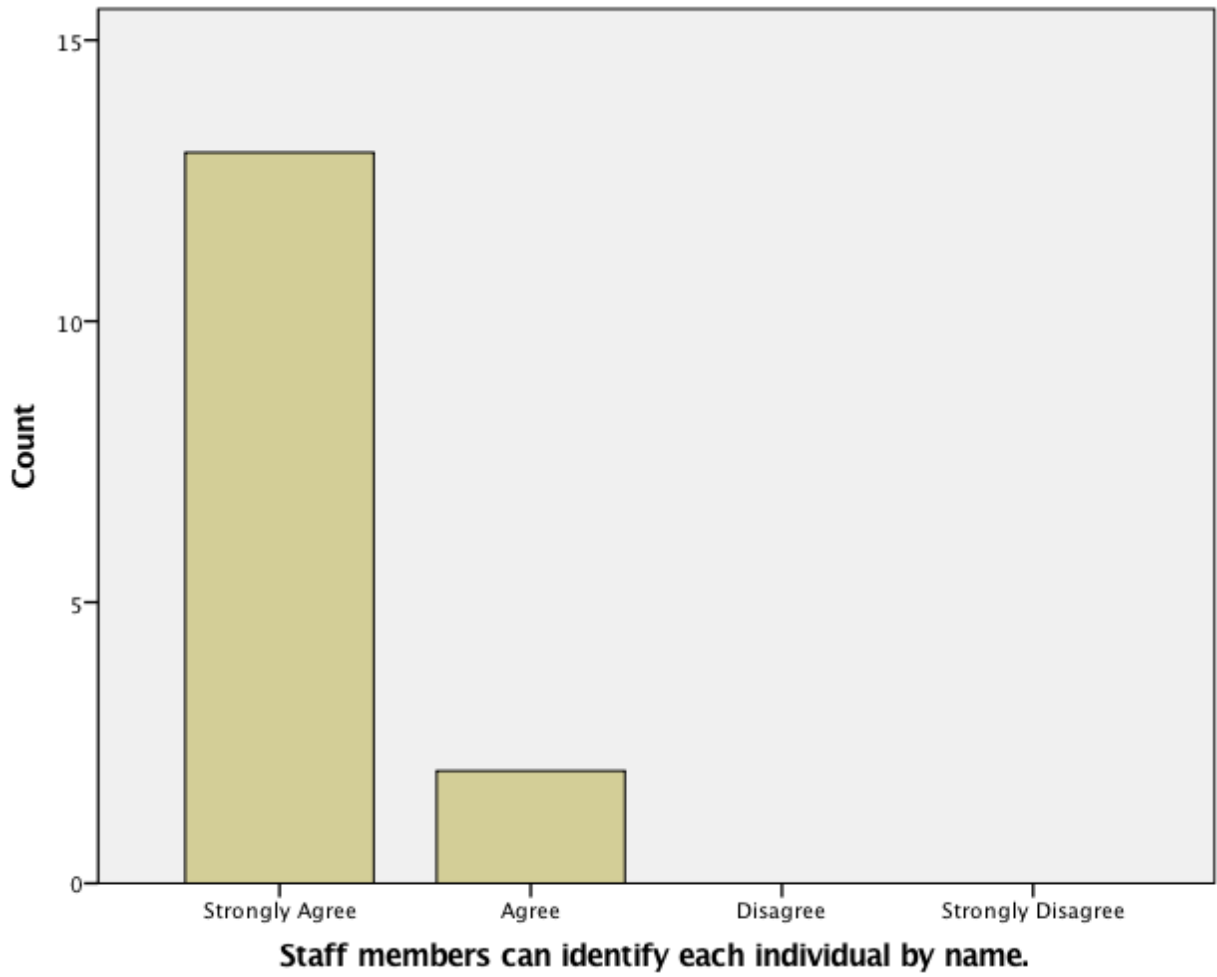
Participant Input



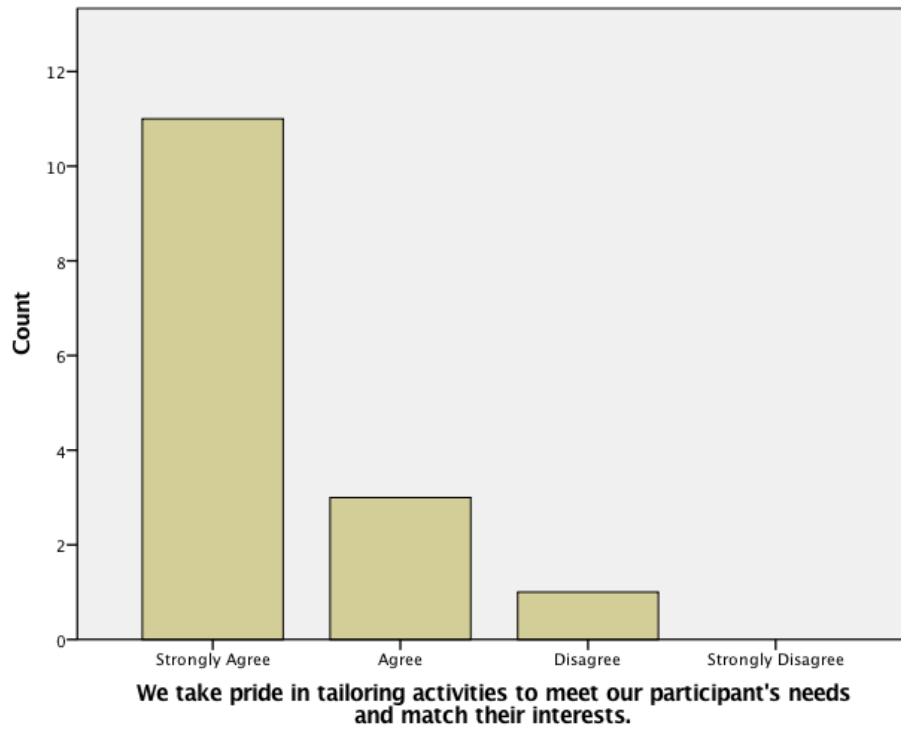
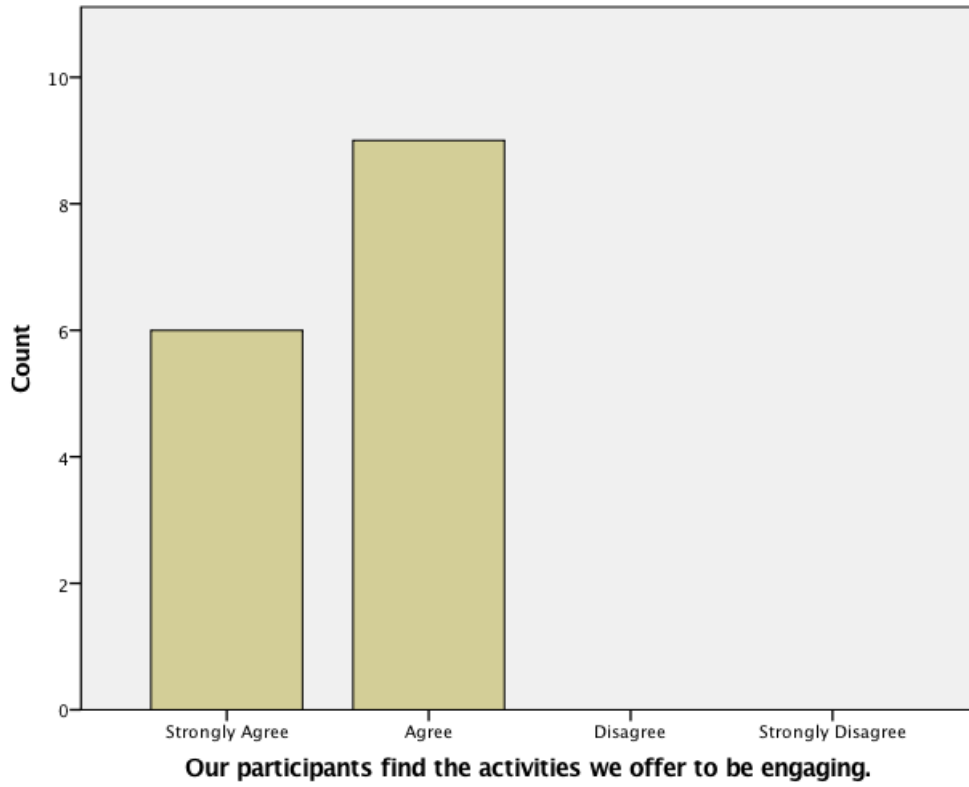
Collaboration



Name Response Graph



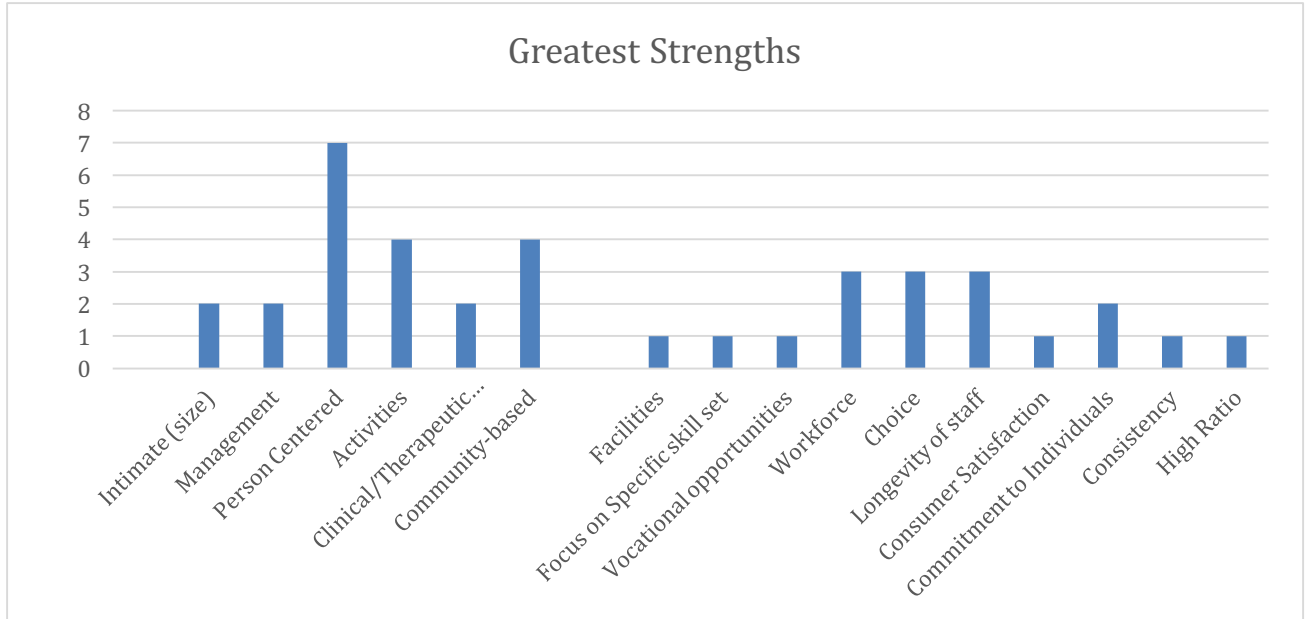
Engagement Response



Greatest Strength: Responses and Coded Category

Original Response	Coded Category
Management is constantly coming up with new ideas to help provide services that are person centered.	Management, person centered
We offer a wide variety of onsite and community activities, including volunteering and offer access to onsite Nursing, therapies, and behavioral supports. We have a large cadre of volunteers and activities	variety of activities, clinical/therapeutic services, volunteers
Focus on specific skill set, vocational opportunities, passionate and skilled work force, beautiful and program owned building/gallery/studio space, community based programming	community based, focus on specific skill set, vocational opportunities, workforce, facilities/resources
Our greatest strength is ensuring choice and freedom of movement. We value our dedication to being person centered.	choice and freedom of movement, person-centered
Person centered.	Person centered.
Our individuals/families state they are satisfied with the services provided, mission and values of the organization. Clinical therapeutic services offered on site Expressive therapies offer on and off site Staff compassion towards individuals served Families seek our program for their individual due to the variety of activities and services provided Longevity of many staff	consumer satisfaction, therapeutic/clinical services, variety, longevity of staff
-person centered philosophy -self-guided schedules -new opportunities -higher than typical staffing ratios -behavioral focus to support individuals with significant behavioral challenges	person centered, choice, high ratios, new opportunities, behavioral focus
Our day program is small and intimate, allowing for close and person active engagement. In addition, we love to celebrate the gifts and talents of our participants. The tone of our program is very festive and jovial.	intimate, recognizing gifts and talents

Person Centered service delivery. Dedicated staff. Very low staff turnover. Excellent management for the program	person centered, dedicated staff, low turnover, management
small numbers and community based	intimate, community based
* We offer services that help our individuals to reach their goals socially, academically, and physically. * We stand on the premise of Choice and Community Integration *Our activities are meaningful * We have an amazing team * We are great will developing and maintaining relationships/partnerships in the community. * Several staff members are degree holders	choice, activities, workforce, community partnerships
Community Engagement activities are stimulating, interesting and truly teach individuals to independently engage with others. Volunteerism with others from the community. Person-centered, age appropriate, respect all individuals and treat them as adults. Staff longevity lends to consistency in service delivery with more effective outcomes.	activities, volunteerism, person centered, age appropriate, staff longevity, consistency
Our commitment to our individuals.	commitment to individuals
Community engagement activities, on site programming, person centered plans	person centered, community engagement

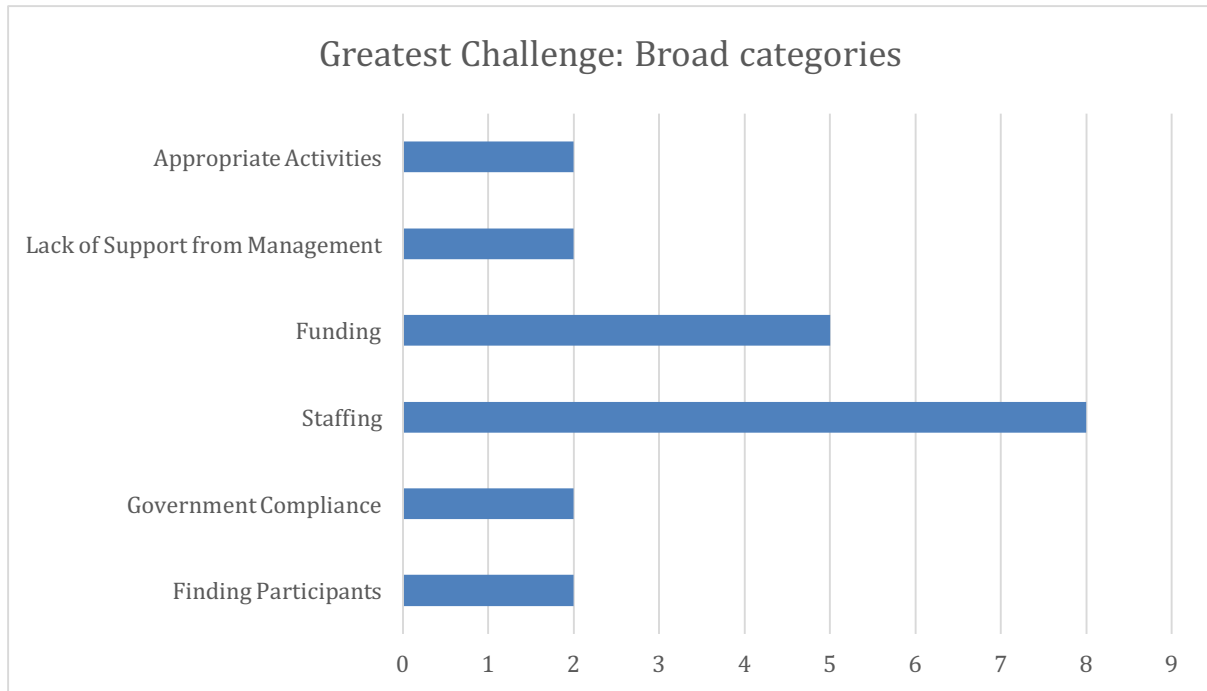


Greatest Challenge

Original Response	Coded Response
Not enough management to meet the needs of the individuals/staff. Due to this is can become quite difficult to juggle so many balls and frequently things aren't done to a perfect standard or get lost somewhere along the way due to the heavy responsibilities	Management, overburdened staff
Funding and Staffing	Funding, staffing
Having a steady stream of members that engage in the targeted vocational work and skill development that we offer. Each staff person wears many hats/shoulders a lot of varied and essential tasks. Stability of sales opportunities for members.	finding participants, overburdened staff
Our greatest challenge is identifying local cost effective, age appropriate community activities in our area.	activities
Over regulation and underfunding.	overregulation, funding
Receiving applicants as well as qualified applicants for the vacant direct care positions Keeping up with the daily requirements set forth by governing bodies	staffing, government regulation
Staffing	staffing
The high performing employees want higher pay	staff salary
Lack of support from upper management in listening to our needs (technology, logistics, how the program actually operates). Lack of field-based technology for a program that is a community-based program and we are in the community 6 hours per day.	lack of support from management, lacking technology
replacing participants as they retire (or age out). No funding available	finding participants, funding
Rate of pay has always been the program's challenge. Not enough computers	staff salary

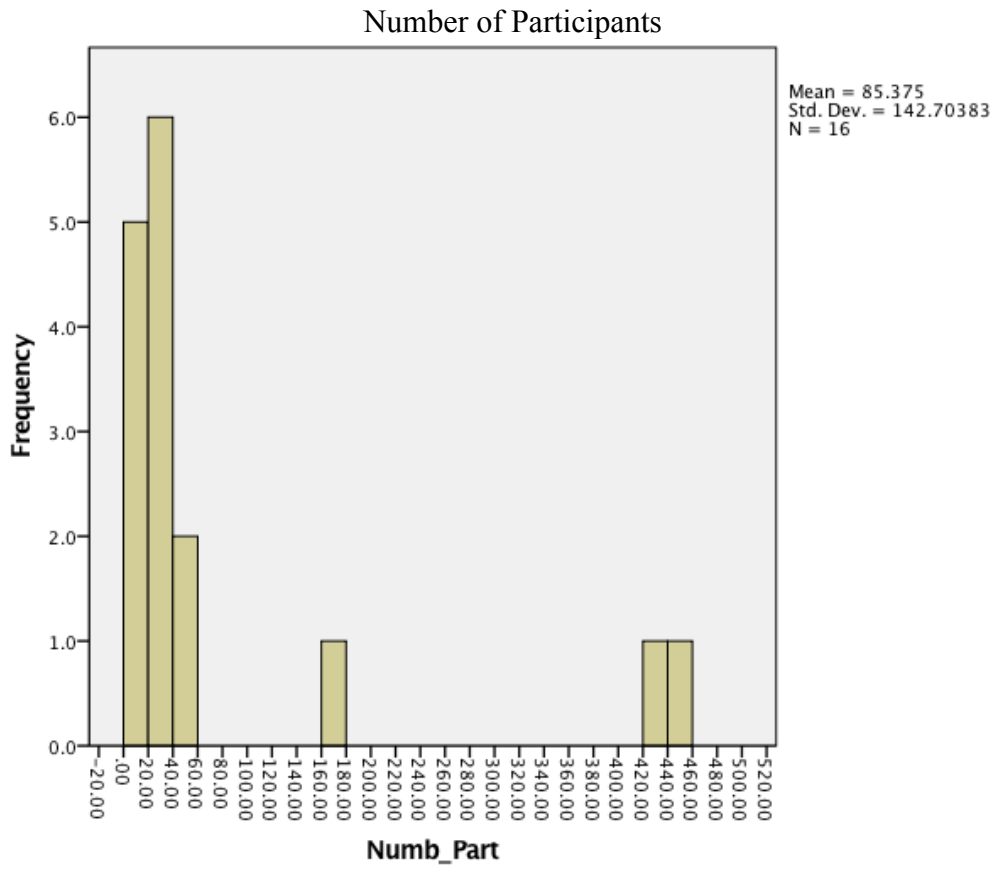
We could do a lot more Community Engagement with lower ratios (less than 1:3), if the funding covered more such as more vehicles/insurance/fuel.	more technology, high ratios
Funding by far is the biggest challenge to our programs.	funding
Retaining employees	Retaining employees





“Select all Challenges that Apply” Results

Challenge	# of Programs that identified this challenge
Hiring enough staff members	5 (33%)
Retaining Staff Members for more than 2 years	9 (60%)
Funding	8 (53%)
Government Compliance	5 (33%)
Finding Age Appropriate Activities	4 (27%)
None of the above	0



Reportable Incidents

