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School of Occupational Therapy

Creating Community: Occupational therapy's role in program development for adults with
Intellectual and/or Developmental Disabilities

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Abstract

Adults with Intellectual and/or Developmental Disabilities (I/DD) experience a variety of barriers that impact their participation in social interactions and community engagement; however, there is a distinct lack of targeted programming for this population. As adults with I/DD are beginning to live independently within their communities well into old age, it is necessary to understand the unique needs of the I/DD population and explore potential interventions to better facilitate inclusivity and independence for this population. With training in developmental stages, transitions, and activity analysis, occupational therapists can educate, train, and prepare individuals with I/DD for independently engaging in meaningful activities within their communities. This Opinions in the Profession paper aims to inform members of the occupational therapy community of the role that occupational therapists have in developing social skills programs to facilitate independence among the I/DD population and share an example of the development and implementation of one program. The Creating Community program increased knowledge, participation, skills, and confidence among individuals with I/DD and highlights a need for continued research in various service delivery methods for occupation-based group programming.

Keywords: intellectual disabilities, developmental disabilities, adults, participation, community

Creating Community: Occupational therapy's role in program development for adults with Intellectual and/or Developmental Disabilities

With the recent increase in inclusive housing developments and communities for individuals with Intellectual and/or Developmental Disabilities (I/DD), it is necessary that the individuals planning and implementing these options understand the unique needs of people with I/DD, especially as it relates to social skills. However, research focusing on adults, especially those that have transitioned to living independently and are seeking employment, meaningful relationships, and overall self-sufficiency through community integration is scarce (Marcotte et al., 2020). As adults with I/DD are beginning to live independently well into old age, it is necessary to explore these interventions to understand their needs better and promote inclusivity and independence for all individuals.

Literature review and paper position

This opinion piece is informed by the completion of the occupational therapy doctoral capstone experience with a focus on program development for the I/DD population at the community level. The purpose of implementing a social skills program with a focus on community integration was to increase the overall inclusivity of adults with I/DD within communities and increase independence as they transition to long-term independent living. A thorough review of literature was completed to understand current legislation, established practice guidelines, and research related to social skills training and programs for community-dwelling adults with I/DD. Several programs exist for school-aged individuals with I/DD; however, there is a distinct lack of targeted programming for individuals with I/DD of working

age living in noninstitutionalized housing. This paper provides one example of program development and implementation specifically for adults with I/DD.

Since the deinstitutionalization of individuals with disabilities in the 1950s and 1960s, individuals with I/DD have sought out community-based housing and living opportunities that allow for participation in meaningful activities, relationships, and ultimately self-sufficiency (Friedman, 2019). However, the majority of individuals with I/DD continue to live with their parents and rely on family members for their care (NY Alliance, 2018). As parents of individuals with I/DD age, familial stress and anxiety surrounding the topics of death of caretakers and aging in place is extremely common (NY Alliance, 2018). Families must plan for the future with limited knowledge of their options, supports, and finances, making identifying the best “fit” for the individual with I/DD a challenge (NY Alliance, 2018). Due to this lack of resources and knowledge, individuals with I/DD and their families frequently struggle to identify and secure independent housing that facilitates participation in their desired and required daily tasks (NY Alliance, 2018).

In established research, many adults with disabilities, including intellectual, chronic, and physical disabilities, that do make the transition to living independently face environmental, social, and financial barriers that prevent engagement in the activities that give them a sense of community and purpose (Angell et al., 2020). Based on interviews conducted with adults with disabilities such as I/DD, meaningful activities include giving back to their community through volunteer work, establishing friendships and romantic relationships, visiting local restaurants, sporting events, and movie theatres, attending religious services and concerts, and working (Angell et al., 2020). Overall community accessibility, including transportation, finances, and societal and individual perceptions of disability impacts community integration and participation

for individuals with disabilities despite ADA (ADA; Pub. L. 103-336) implementation (Angell et al., 2020). Individuals with I/DD and their families must consider the supports in place for community integration and accessibility when choosing a home (Friedman, 2019), as these factors impact the overall inclusivity and well-being for individuals with I/DD. For individuals with I/DD and their family members, these supports often include financial waivers and subsidies, individualized service plans, transportation, reliable staff, and planned programming and activities (Friedman, 2019).

Occupational Therapy Theory

As part of a profession built on empowering individuals within their environments to facilitate meaningful participation in functional activities, occupational therapists have the potential to meet the long-term needs of individuals with I/DD and their families as they transition into independent living and face the challenges of community integration (AOTA, 2014). With extensive training in developmental stages and transitions, occupational therapists have the knowledge and skills to educate, train, and prepare individuals with I/DD for independently engaging in functional activity within their communities. Additionally, occupational therapists can provide consultative services to community organizations and their partners to reduce the environmental and societal barriers that individuals with I/DD face within their communities (Umeda et al., 2017). The Transactional Contextualism and Environmental Press components of the occupation-based Ecology of Human Performance (EHP) model appropriately explains how the environment affects one's occupational performance, and also conversely describes how an individual's performance affects their environment (Dunn, Brown, & McGuigan, 1994). Identifying an individual's desired or required tasks, skills, and abilities, and the environmental barriers impacting completion of function highlights this unique reaction

between person, environment, and occupation. When addressing barriers to individuals with I/DD, it is essential to focus on barriers to a successful transition from living with parents and family members to living on their own. Considering the individual's physical, cultural, social, and temporal contexts allows therapists to address barriers limiting task performance appropriately, to support individuals with I/DD by limiting Environmental Press, and to educate community partners on the unique needs of individuals with I/DD.

The EHP model can also guide intervention as therapists provide resources for meeting goals by establishing or restoring new skills through programming, adapting or modifying environments or tasks, preventing barriers, and creating new opportunities for successful occupational performance. New skills and additional knowledge allow individuals to overcome barriers limiting occupational engagement. Age-appropriate and productive goals can be set according to life stages and developmental milestones while aiding in the transition to independent living and identifying barriers to occupational engagement. Based on the nature of I/DD, individuals with I/DD are often not performing at an age-appropriate level when they transition into independent living. Still, they must learn to adapt to new environments and social situations to be self-sufficient.

Utilizing the Lifespan/Developmental frame of reference to guide occupational therapy intervention allows therapists to set reasonable goals and objectives for intervention that help meet developmental milestones and expectations (Cole & Tufano, 2008). The needs of individuals with I/DD who are looking to transition to independent living consistently include the desire to have meaningful friendships and peer support within their community and an increase in overall independence (Friedman, 2019). Occupation-based program development and

implementation can support individuals with I/DD by facilitating social interaction that develops and maintains friendships within future communities.

A Social Skills and Community Integration Intervention Group for Adults with I/DD

Participants

Program participants were adults with various intellectual and developmental disabilities who were receiving supports from a nonprofit organization in Indianapolis, Indiana that provides residential supported living to adults with I/DD through the Medicaid Home-and-Community-Based Service Waiver program (HCBS) under the Indiana Bureau of Developmental Disabilities Services (BDDS) (BDDS, 2020a; BDDS, 2020b). The social skills and community integration intervention program was developed and implemented as part of the programming available to individuals with I/DD through the nonprofit organization. The majority of individuals who participated in the program lived independently within the same apartment complex where programming was held; however, some participants were living independently or with family in the community not far from the complex. Participation in the social skills and community integration intervention program was voluntary, like all other programs offered by the nonprofit organization.

Procedure

A six-week group program was developed and conducted based on the societal needs of the I/DD population to improve and increase the social skills and community integration of adults with I/DD. The intervention group outcomes were evaluated throughout implementation and following the conclusion of week six using a pre- and post-program questionnaire and interviews. The program was then disseminated to the Executive Director and administration of the nonprofit organization so that the program could be utilized again.

Needs assessment

To fully understand the organization's programming needs and I/DD population, a thorough analysis of established programming was necessary. An informal assessment of the nonprofit organization's programming needs was conducted through facilitatory conversation and informal, face-to-face interviews with the organization's Executive Director, Community Program Director, Live in Support, and Staff Support Coordinator. Observation of the organization's current programming was also conducted, and field notes were taken throughout various programming sessions. Surveys were utilized to collect additional information about the lived experiences of the individuals with I/DD receiving supports from the nonprofit organization and the Life Skills coaches spending one-on-one time with the individuals with I/DD. Three different surveys were created and distributed: a version for individuals with I/DD living in the apartment complex, a version for individuals with I/DD living in the community and receiving supports from the nonprofit organization, and a version for the Life Skills coaches spending one-on-one time with the individuals with I/DD. These surveys were sent out via email and printed copies. Surveys were completed individually or with a Life Skills coach and were made up of 16-32 questions, with variation depending on which version of the survey was completed. Completion of surveys was voluntary. In total, 31 surveys were completed.

Thematic Analysis

Data collected through conversations, interviews, observations, and surveys were analyzed to determine the overall needs of the organization and the I/DD population, which guided the development and implementation of the group program. Specifically, thematic analysis was completed to understand the community participation and integration experiences

of individuals with I/DD receiving support from the nonprofit organization. Survey questions and responses from people receiving support from the nonprofit organization analyzed included:

1. How often do you go out into the community (e.g., appointments, shopping, restaurants)?
2. What do you like about going out into the community?
3. What is hard about going out into the community?

Survey questions and responses from the life skills coaches providing support to adults with I/DD included:

1. In your opinion, what are the biggest barriers to independence that the people you support experience?
2. What are the biggest barriers within the community that the people you support experience?
3. How often do you go out into the community with the people that you support?

The thematic analysis process followed Vaismoradi et al.'s (2016) method for theme construction beginning with a thorough review of data and identification of keywords, followed by creating codes and categories, and concluding with identification of the overall themes within the data (Vaismoradi et al., 2016). After reviewing and analyzing the data collected, the following themes and subthemes were identified: Desire to be in community with others, limited communication and social skills, decreased confidence in social situations, decreased initiation of social interactions, lack of access to the community, limited opportunity for community outings, and lack of knowledge of community resources. Four program objectives were set based on the results of the needs assessment and thematic analysis. Program objectives included:

1. By April 2021, group members will demonstrate increased knowledge of resources available for accessing the community by identifying at least 1 way to interact within the Indianapolis community.
2. By April 2021, group members will demonstrate increased participation by identifying at least 1 way to maintain friendships.
3. By April 2021, group members will demonstrate increased social skills by identifying at least 1 way to initiate a social interaction or community outing.
4. By April 2021, group members will report increased confidence in their social interaction skills.

Program Implementation

A six-week group program, titled Creating Community, was developed and implemented based on the societal needs of the I/DD population following Cole's (2018) Seven Steps for Group Leadership (Cole, 2018). Cole's (2018) method for leading an occupation-based group facilitates group participation through occupational engagement and reflection (Cole, 2018). Cole's (2018) seven steps include an introduction, activity, sharing, processing, generalizing, application, and summary (Cole, 2018), and were utilized throughout the six-week social group for individuals with I/DD to engage participants in activities and discussion that facilitate the growth of social skills and knowledge necessary for successful and confident community integration. Group sessions took place once a week for six weeks and were held using video conferencing technology. Each session lasted approximately 60 minutes. Sessions were planned and led based on the needs assessment outcomes and identified themes. Sessions are outlined in Table 1.

Table 1
Creating Community Interventions

Session	Occupation-based Program Objectives	Intervention	Rationale
Session 1: Meet & Greet	Objectives 1-4	The first session served as an introduction to the social group. The focus of this session was to introduce the purpose of the group program, establish group expectations, explain the goals of the program, and build rapport between the group leader and participants. Group members assisted in establishing group expectations, guidelines, and goals.	Overall community accessibility, including transportation, finances, and societal and individual perceptions of disability impacts community integration and participation for individuals with disabilities despite ADA implementation (Angell et al., 2020). With this knowledge, individuals who are planning and facilitating independence-related training and activity can address the barriers to these meaningful activities to support individuals with I/DD and increase their overall participation and confidence related to community integration and social interaction.
Session 2: Defining Community	Objectives 2 and 4	Session educated group members on the different types of community and the benefits of being in community with others. The purpose of this session was to explore the communities that group members are a part of and discuss opportunities to expand these groups. Group members spent time discussing what types of environments they like to be a part of, how they can create these types of environments with other people, and then as a group defined community.	By introducing individuals with intellectual and developmental disabilities to the many concepts of community, including physical spaces, relationships, and virtual connections, we can create a sense of belonging, empower individuals to increase participation in the communities they are currently a part of, and facilitate the creation of new communities (Wigfield et al., 2020).
Session3: Interests & Community Activities	Objectives 1, 2, and 4	Session addressed interests and how group members participate in community activities that interest them. Group members spent time	By discussing interests, hobbies, and favorite activities in a group setting, individuals with intellectual and developmental disabilities can discover shared

		discussing how they could create community with people who share the same interests as them, how they could start conversations with people based on interests, and how they can advocate for participating in activities that are meaningful to them in the future.	interests with others and consider how they might initiate conversations or plans with those who share the same interests. Because this population has decreased social circles and social connections, it is important to organize social groups that are based on interests to facilitate social participation and occupational engagement (Johnson et al., 2019).
Session 4: Planning an Outing	Objectives 1-4	Session educated group members on the steps necessary for planning a meeting with friends and a community outing. Group members spent time identifying the information necessary for planning when making various plans, learned where to access this information, and practiced initiating social interactions through role-play scenarios.	To facilitate community participation and integration, we must first consider community mobility and challenges that adults with intellectual and developmental disabilities face due to executive functioning and working memory deficits. Planning, preparation, and practice can help individuals with disabilities feel more confident in their ability to participate in community activities and more motivated to engage within their communities (Kersten et al., 2020).
Session 5: Virtual Community	Objectives 1, 2 and 4	Session focused on exploring Zoom alternatives for creating virtual community as following the email invites, meeting IDs, and passcodes can be a difficult process. Group members were introduced to the concept of virtual community and challenged to identify the benefits of virtual community as well as ways that they can create virtual community in the future.	Because barriers to using social media commonly experienced by adults with intellectual and developmental disabilities include, but are not limited to, safety concerns, difficulties caused by literacy and communication skills, understanding cyber-language, following cyber-etiquette, and accessibility, intervention should address internet safety education, specifically on the topics of etiquette, appropriate posting, profile security settings, and being assertive. By addressing the barriers related to technology use

Session 6: Staying in Touch	Objectives 1-4	The final session served as a conclusion of the program. The focus of this session was to re-visit the overall goals of the group and summarize the skills learned throughout the program. Additional resources for community integration were provided based on the outcomes of the previous sessions, as the development of the social skills and knowledge necessary for successful community participation is an ongoing process.	and social networking, we can combat the social isolation and loneliness typically experienced by this population and limit the risk of individuals being bullied, exploited, and sexually harassed online when they seek or create virtual community (Caton & Chapman, 2016; Sallafranque-St-Louis, & Normand, 2017). Social skills should be taught and practiced in a group setting and activities should give individuals the opportunities to use strategies for initiating and sustaining social interactions with others AOTA, 2017). By following these guidelines, adults with I/DD can continue to develop and refine their social skills, which can then increase social interaction and participation and decrease social isolation.
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Program Evaluation

The social group program was evaluated using pre- and post- program questionnaires and interviews to measure the effectiveness of the six-week intervention to meet the overall goals of the program. The pretest-posttest design has been used in the past to measure change overtime within a variety of populations and settings and is recognized as an appropriate method for the program evaluation portion of the program development process (Taylor, 2017). Additionally, interviews and other in-person outcomes measures give a voice to individuals participating who are often left out of the data collection process due to their disability, empowering them to participate in programs (Scaffa et al., 2010). The pre-and-post-program questionnaire was

administered following the first and final sessions of the program to evaluate the knowledge, participation, skill, and confidence of participants. The questionnaire consisted of six open-ended and multiple-choice questions and was administered to eight participants following Session 1 and seven participants following Session 6. Questionnaires were administered in-person and over the phone to accommodate for the cognitive deficits of participants.

Dissemination

Following the conclusion of the six-week social group, the program was disseminated to the Executive Director and members of administration at the nonprofit organization where the program was implemented. Dissemination included a thorough review of the data collected during the initial needs assessment, a review of the program goals and objectives, a review of program interventions, a review of the program evaluation data, and a review of additional resources. The Executive Director was given curriculum and materials for an additional four weeks of the program. Curriculum resources included session outlines following Cole's (2018) Seven Steps for Group Leadership and Writing a Group Protocol (Cole, 2018). Curriculum and resources were based on the skills developed in the first six weeks of the social group program and the additional interests and needs of the group members. An empty outline of Cole's steps and protocol were also provided so that the Program Director could create additional sessions as the program continued.

Results

Following the final program session, individuals who attended three or more sessions completed the post-program questionnaire to measure the effectiveness of the six-week intervention. There is a difference of one individual between pre-and-post- program

questionnaire data. Complete results from the pre-and-post-program questionnaire are reported in

Table 2.

Table 2

Creating Community Pre-and-Post-Program Questionnaire Results

Question	Occupation-based Program Objective Association	Pre-Program Questionnaire	Post-Program Questionnaire
Tell me what ways you use to connect with your friends, family, and other people. (open-ended)	Objective 1: Knowledge of ways to interact or connect with others to be a community.	100% of individuals identified at least one way to interact within the Indianapolis area.	100% of individuals identified at least one way to interact within the Indianapolis area.
	Connection methods identified included using the phone, social media, Zoom, in-person conversations, and making plans with others.	57% of individuals identified more than one way to interact within the Indianapolis area.	71% of individuals identified more than one way to interact within the Indianapolis area.
In the last six weeks, how often have you connected with other people? (open-ended)	Objective 2: Participation and social interactions.	50% of individuals reported connecting with others at least a few times a week in the last six weeks. Only three individuals reported connecting with others every day.	100% of individuals reported connecting with others at least a few times a week in the last six weeks. Five individuals reported connecting with others every day.
Tell me what you know about how to make plans with a friend. (open-ended)	Objective 3: Making plans with friends.	88% of individuals identified at least one way to make plans with a friend.	100% of individuals identified at least one way to make plans with a friend.
		25% of individuals identified more than one way to make plans with a friend.	57% of individuals identified more than one way to make plans with a friend.
Tell me what you know about how to plan a community outing. (open-ended)	Objective 3: Planning an outing.	88% of individuals identified at least one way to plan a community outing.	100% of individuals identified at least one way to plan a community outing.

		13% of individuals identified more than one way to plan a community outing.	86% of individuals identified more than one way to plan a community outing.
How confident do you feel in your ability to connect with other people? (multiple choice)	Objective 4: Confidence in ability to connect with others.	50% of individuals reported feeling confident in their ability to connect with others.	71% of individuals reported feeling confident in their ability to connect with others.
How confident do you feel in your ability to plan and go on a community outing? (multiple choice)	Objective 4: Confidence in ability to plan and go on a community outing.	50% of individuals reported feeling confident in their ability to plan and go on a community outing. No one reported feeling confident in their ability to do so without the help of a life skills coach.	86% of individuals reported feeling confident in their ability to plan and go on a community outing. Three individuals shared experiences of planning and going on community outings with friends since the beginning of the Creating Community program.

Conclusion and Implications for Practice

The purpose of this Opinion in the Professions paper is to inform individuals developing programs and providing services for adults with I/DD of the role of occupational therapy in facilitating independence and provide one example of program development and implementation for adults with I/DD. A social skills program focusing on community integration was developed and implemented by an occupational therapy doctoral capstone student to increase the overall inclusivity of adults with I/DD living independently. As a result of program interventions, group members recognized more than one way to connect with others and initiated more social interactions with their peers. Group members also identified additional steps to take when making plans with friends, such as talking about their schedules and availability and were able to follow up with important questions to clarify their friends' availability when practicing and

applying these skills. Lastly, group members identified additional steps necessary for planning community outings such as arranging transportation and managing their money to cover the cost of their leisure activities. The overall confidence levels for making plans with friends and planning outings in the community of group members increased throughout the program as well.

To continue to increase knowledge, participation, skills, and confidence for independently initiating and participating in social and community activities, occupation-based interventions for adults with I/DD should consider the use of technology to support this population. This is especially relevant as this population continues to age in place. Occupational therapists can support adults with I/DD across the lifespan by introducing adaptive technology to modify daily routines, provide visual supports, and provide remote services. Although the Creating Community program did not directly address assistive technology, group members did explore using technology as a way to expand their social circles and increase social participation. Most group members were familiar with using technology to connect with others, however, they struggled with accessing and navigating virtual community and required step-by-step instructions for completing these tasks. Because of this, additional education and practice are necessary, and as society continues to rely more on technology for participation in communication and other everyday occupations, such as work and leisure activities, occupational therapists should work with adults with I/DD so that they can be independent in these tasks and live fulfilling lives. Along these same lines, future programming for adults with I/DD should focus on developing working memory and executive processing skills with individuals as these deficits present as some of the greatest barriers to independence among this population. Implementation of the Creating Community program led to identifying these needs; however, continued research

related to facilitating social and community autonomy is necessary to fully understand the best-practice methods when teaching these skills.

There is limited literature that details the benefits of occupational therapy-based social skills training for adults with disabilities. The American Occupational Therapy Association (AOTA) outlines opportunities for occupational therapy intervention and research when working with individuals with disabilities such as ASD (AOTA, 2017). A 2017 article, AOTA (2017) acknowledges group-based social skills training programs as an intervention strategy with strong research-supported evidence for improving social skills in individuals with ASD. AOTA included activity-based interventions, computer-based interventions, and focused interest interventions in the same article as intervention strategies requiring additional research in the future (AOTA, 2017). Although evidence is limited, positive outcomes in peer-led social skills intervention groups have been reported by occupational therapists when working with adolescents with ASD. When using these strategies, Tomchek et al. (2017) identified positive outcomes in initiating social interactions, social responsiveness, communication, and engagement in social interactions (Tomchek et al., 2017), and occupational therapists participated in facilitating discussion, giving feedback and prompts, and offering redirection if needed.

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