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Social Inclusion for People with Intellectual Disabilities

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Social Inclusion for People with Intellectual Disabilities

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Social Inclusion for People with Intellectual Disabilities

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CLINICAL SCENARIO:

The desire to be accepted by others is one of our most basic human needs; feeling excluded can lead to deterioration of physical health and well being, according to Lloyd, Tse and Deane (2006). To them, social inclusion means being able to participate in meaningful leisure, friendship and work communities. Unfortunately, there is extensive evidence of the social exclusion of people with intellectual disabilities (Abbott, McConkey, 2006). People with intellectual disabilities are being provided with more opportunities to live in the community and to take part in community activities, but this is often not effective in creating meaningful social connections with others, specifically non-disabled community members. The purpose of this CAT is to explore barriers to social inclusion for people with intellectual disabilities and the role of occupational therapy in facilitating inclusion.

FOCUSED CLINICAL QUESTION:

How can occupational therapists facilitate social inclusion for people with intellectual disabilities?

SUMMARY of Search, 'Best' Evidence' appraised, and Key Findings:

A search was performed using academic databases, which revealed moderate results for community integration and social inclusion of people with intellectual disabilities. Five articles were analyzed in this topic review. One article focused on individuals with mild to moderate intellectual disabilities perceptions of barriers to their social inclusion (Abbott, McConkey, 2006); Two articles focused on social networks and supports, one as a comparison with people with physical disabilities and the other from individual's perceptions (Lippold, Burns, 2009; Forrester-Jones, Carpenter, Coolen-Schrijner, Cambridge, Tate, Beecham, Hallam, Knapp, Wooff, 2005). A systematic review evaluated occupational therapy interventions effectiveness of facilitating community integration for people with serious mental illness (Gibson, D'Amico, Jaffe, Abesman, 2011). The fifth article reported individual's experiences living in an alternative, semi-community setting, as part of an intentional community (Randell, Cumella, 2009).

The main findings of this review indicate that people with mild to moderate intellectual disabilities are capable of providing insight of barriers to their social inclusion and potential remedies to these barriers. Individuals' social networks and supports most often consist of support staff, family and other service users with intellectual disabilities. Relationships with community members are limited and often not seen as reciprocal. These barriers to social inclusion are not shared by people with physical disabilities, suggesting that lack of appropriate intellectual skills and social stigma contribute to diminished social inclusion. However, in environments that foster social relationships between disabled and non-disabled individuals, people with intellectual disabilities are able to develop appropriate social skills and report feeling like a valuable member of their community. Occupational therapy provides interventions that facilitate community integration and normative life roles among people with serious mental illness.

CLINICAL BOTTOM LINE:

Barriers to social inclusion are similar between populations with mental illness and intellectual disabilities. This CAT presents the idea that because occupational therapy interventions facilitate community integration for people with mental illness, it may facilitate integration for people with intellectual disabilities as well.

Limitation of this CAT: This critically appraised topic has been peer-reviewed by one other 2nd year occupational therapy student at Pacific University. The search of the literature was exhaustive and the author is not an expert in the field.

SEARCH STRATEGY:**Terms used to guide Search Strategy:**

- Patient/Client Group: People with intellectual disabilities
- Intervention: occupational therapy
- Comparison: N/A
- Outcome(s): Social inclusion, community integration

Databases and sites searched	Search Terms	Limits used	# of Articles Found	# of Articles Useful
Cinahl EBSCOHost; September 2011	Community integration	Full text	446	8
	Social inclusion	2000-2011	513	9
	Developmental disability	Peer-reviewed	421	2
	Intellectual disability		983	12
	Intentional community		35	2
	Social integration		567	8
	Participation		7542	6
	Mental retardation		2669	4
	Occupational therapy		3405	2
	Occupational justice		70	0
Reference Mining from Le Boutillier, Croucher, (2010); in September 2011				4
Reference Mining from Abbott, McConkey, 2009; in September 2011				2

INCLUSION and EXCLUSION CRITERIA

- Inclusion:
 - Peer reviewed literature
 - Foreign articles in English
 - Linked full text
 - Mental Illness
 - Intellectual Disability
 - People with Physical Disability
 - Adults 18 +
- Exclusion:
 - Dated before 2000
 - Spinal Cord Injury
 - Traumatic Brain Injury
 - Children and Adolescents

RESULTS OF SEARCH

Five relevant studies were located and categorised as shown in Table 1

Table 1: Summary of Study Designs of Articles retrieved

Study Design/ Methodology of Articles Retrieved	Level	Number Located	Author (Year)
Systematic Review	I	1	Gibson, D'Amico, Jaffe, Abesman (2011)
Case-control Design	III	1	Lippold, Burns (2009)
Cross-sectional	III	1	Forrester-Jones, Carpenter, Coolen-Schrijner, Cambridge, Tate, Beecham, Hallam, Knapp, Wooff (2005)
Phenomenology	N/A	1	Abbott, McConkey (2006)
Ethnography, Grounded Theory	N/A	1	Randell, Cumella (2009)

BEST EVIDENCE

The following paper was identified as the 'best' evidence and selected for critical appraisal.

Reasons for selecting this study were:

- Relevancy to topic related to occupational therapy's contribution to the facilitation of community integration and social inclusion for people with intellectual disabilities
- Research is a Level I, systematic review, from a reputable source
- Topic was searched thoroughly

SUMMARY OF BEST EVIDENCE

Table 2: Description and appraisal of:

Gibson, R.W., D'Amico, M., Jaffe, L., Abesman, M. (2011). Occupational therapy interventions for recovery in the areas of community integration and normative life roles for adults with serious mental illness: A systematic review. *American Journal of Occupational Therapy*, 65. 247-256.

Study Design: Systematic Review of 52 studies

Objective:

To systematically investigate literature results regarding the effectiveness of occupational therapy interventions in the areas of community integration and normative life roles for people with serious mental illness, using the recovery model. Reviewed literature included interventions that were activity and occupation-based and addressed performance skills and patterns. Context, client factors, activity demands and aspects within the environment were also included.

Search Strategy:

An advisory group determined the focused question and developed a strategy to incorporate population, inclusion/exclusion criteria and intervention search terms derived from areas of occupation, within the Occupational Therapy Practice Framework.

A medical librarian with experience in evidence-based literature completed the search using a filter related to McMaster University that included: Medline, CINAHL, PsychInfo, HealthStar, Social Works Abstracts, ACP Journal Club, OTseeker, Alternative Medicine, Cochrane Central Register of Controlled Trials and Database of Systematic Reviews, and Databases of abstracts of Effects.

Selection Criteria:

To be included in the review, articles needed to: have been published in English, peer-reviewed; participants meet definition of severe mental illness, age 18-65; incorporate interventions that are within occupational therapy's scope of practice (to promote wellness, health and hope; prevent disability: and to create, modify, establish and maintain performance). The Center for Mental Health definition was used to determine serious mental illness.

The search process identified 1,064 abstracts that were reviewed by at least 3 qualified people, 101 articles were reviewed again using exclusion and inclusion criteria. Additional articles were

located from reference lists during this process. 52 articles were analysed, critically appraised, summarized into CAT format and were included in this review.

The review included:

-31 Level I studies

-13 Level II studies

-8 Level III studies

They can be viewed as Supplemental Table 1. @ www.ajot.ajotpress.net

Outcome Measures:

Evidence related to normative life roles and community integration is themed as: IADLs, including physical activity and life skills training; employment and education; social participation, including social skills training; neurocognitive training; client-centered intervention; intensity and duration; and intervention environment and context.

Main Findings:

There is positive evidence of the effectiveness of occupational therapy intervention in areas of community integration and normative life roles for recovery for people with serious mental illness. Results indicated moderate effectiveness for improvement in performance in areas of IADLs and life skills. Evidence for neurocognitive training indicated moderate success when paired with skills training for IADLs, work and social participation. Social skills training results indicate moderate to strong evidence of effectiveness. Results indicated positive evidence for increased treatment duration and intensity. There was also positive indication for client-centered intervention. However, available literature evidence was limited in these areas.

Original Authors' Conclusions:

The authors discuss the lack of evidence directly related to occupational therapy interventions and improved recovery for this population. There is substantial evidence for the effectiveness of these interventions to improve performance in components of recovery, specifically community integration and achievement of normative life roles for people with severe mental illness. The authors believe that current findings are the best available evidence for client-centered, individual intervention planning and program development for people with serious mental illness. This information may be useful to occupational therapists independently or in interdisciplinary program development. The findings are also important inclusions to discussions by occupational therapists to many audiences, including families, care providers, government agencies and third-party payers, regarding current best practice of the profession in psychiatric care.

Further research is needed regarding the use of the recovery model to assess behavioral changes. Well-designed research that uses widely approved assessment tools and captures long term information about client-centered and occupation based interventions would provide greater strength for its use in practice.

The authors feel that it is important for the most current evidence-based information regarding mental health to be incorporated into academic curricula and that students be taught the skill of distinguishing thorough evidence and limited evidence. By developing evidence-based mental

health practices within educational programs the number and quality of people interested in this area will increase.

Critical Appraisal

Validity:

Question is clear and focused:

The review is looking for the effectiveness of interventions within occupational therapy's scope of practice, intended to modify, create, establish, and maintain performance; prevent disability; and promote health, wellness and hope in the context of a recovery model in the area of community integration and normative life roles for adults with serious mental illness (Gibson et al., 2011)." This question defines the population and clarifies occupational therapy's scope of practice. Interventions included were also clearly defined.

Criteria Selection:

The review clearly identified inclusion and exclusion criteria. The definition for "serious mental illness" was agreed upon and followed by reviewers. A comprehensive list of search terms was provided in the review.

Literature Search Method:

The method of searching was specified, including information for filter used, databases searched, and by whom.

Quality of Identified Studies:

Included studies are identified and evaluated for quality. The review includes an online Supplemental Table 1. @ www.ajot.ajotpress.net. Authors, study purpose, design method, level, number of participants, outcome measures, results and limitations summaries are provided.

Degree of Agreement:

Initially, abstracts were evaluated by at least 3 independent reviewers; they were then assigned to individual reviewers. Information was summarized, synthesized and submitted to consultants for the project and AOTA staff for further review.

Interpretation of Results

Consistency:

Most articles reported positive results for outcome measures to varying degrees. A few showed no clinical difference. Limitations were reported as small sample sizes and level of participant drop out.

Results:

A sensitivity analysis was not carried out for this review.

Summary/Conclusion:

The provided information has been determined by the author of this Critically Appraised Topic to be of high quality. A wide sample of participants was selected, providing no reason to suspect different results based on specific characteristics.

Are my patients similar to participants of the study?

My conclusions are that people with mental illness have similar experiences to people with intellectual disabilities related to barriers to inclusion in the community. Both populations report a lack of friendships outside of service agencies, relationships that are not reciprocal, and inability to feel accepted as they are.

Feasibility of intervention:

Interventions, such as social skills training and client-centered, are in occupational therapy's scope of practice and may be implemented in a variety of settings using different methods to meet the needs of clients and practitioners within treatment environments. Interventions within the community may establish better rapport between individuals with ID and community members.

Costs/Benefits:

Though not addressed directly, risks are limited because they are already determined to be effective interventions within the scope of practice for occupational therapy. The potential benefits are increased self-esteem and sense of value to individuals with ID, decreased dependence on government services and support staff, and more diverse and open communities.

Table 3: Characteristics of included studies

	Lippold, Burns (2009)	Forrester-Jones, <i>et al.</i> (2005)	Abbott, McConkey (2006)	Randell, Cumella (2009)
Purpose of Study	To investigate the social supports and networks accessible to people with Intellectual Disability (ID) compared with people with Physical Disability and the general	Description of size and types of social supports by people with intellectual disabilities (ID) and a comparison of social networks in different community living settings	To gain insight from people with intellectual disabilities (ID) in supported living arrangements about their perception of social inclusion barriers and	How people with intellectual disabilities (ID) view their experiences in an intentional community living setting and their idea of "community".

	population. It is hypothesized that people with ID would result with lower levels of social integration, less social support and more restricted social networks than people with physical disabilities.		possible solutions to these barriers.	
Participants	Two groups consisting of people with ID, with assistance of their caregivers, and people with PD. Both groups were from day centers in the same geographic area. Participants were between the ages of 18-60.	The sample for this research was obtained from a resettlement project, <i>Care in the Community</i> that had occurred 12 years earlier. 117 males and 96 females agreed to participate. Most had mild to moderate ID, some with behavior difficulties. 36% lived in small group homes, 27% lived in residential nursing homes, 22% in supported accommodations and 15% in hostels.	23 male and 45 female participants, age 21-82, self-selected to attend one of six focus groups, from invitations sent to the 16 service providers involved. 55% lived in supported living schemes, 36% lived in group homes and 9% lived in residential homes.	10 male and 5 female participants, ages 38-78, whom had lived at Botton Village for 5 to 50 years. Individuals gave reasons for moving to intentional community such as: increased independence, geographic location, conclusion of formal education, and diminished home environment.
Outcome Measures and Information gathering process	Study measured life experiences, social networks and social supports using the following assessments: Social Support Self Report, Circle Task, Functional Support Inventory,	Social Network Guide maps the structural, interactional and functional components of people's networks. Social network members are identified using a "wheel of life".	Information was gathered using a focus group methodology. The same protocol was followed for all 6 groups. Sessions took 4-5 hours with breaks. Process began with icebreakers,	Research was described as from both an ethnographic and grounded theory approach. Information was gathered using a simple, open-ended interview. Questions related

	<p>Life Experiences Checklist. Information was gathered by interview at the day centers, and then Assessments were administered to participants. The LEC was completed for participants with intellectual disabilities by an informed caregiver.</p>	<p>Specific support provided by each network member was recorded under Support Behavior: personal, domestic, material help, decision making, confiding, company, invisible and critical comments; and Interactional Behavior: reciprocity, frequency of interaction, duration and closeness.</p>	<p>then “social inclusion” was introduced using photographs and conversation. A standardized method of presenting this topic was not mentioned. Participants moved into small groups to discuss experiences and asked questions about their lives. Information was transcribed and later</p>	<p>to participants’ home environment, friends, hobbies, work, religious beliefs, and views of Botton Village. Before the interview, pilot questions were presented initially to determine appropriate communication style and were not included in data. Interviews were audio recorded and took 90 minutes. Participants chose the time and setting of interview to ensure feelings of confidentiality.</p>
Findings	<p>People with ID were shown to have significantly more diverse life experiences more often than people with physical disabilities and the general population. In spite of this, their number of relationships was significantly lower than people with physical disabilities and the general population. Findings suggest that people with ID</p>	<p>Generally speaking, results indicate smaller and denser social networks than other studies. This may suggest segregated social groupings, lack of privacy and potential for exploitation. Network members were most often other service users, staff and family. This study found opportunities for community integration and</p>	<p>Four main themes were identified: Talking to people, being accepted, using community facilities, and opportunities. Barriers and solutions were compiled into sub themes: personal abilities and skills, staff and management, the community, and home scheme. The study concluded that people with ID were capable of</p>	<p>Results of the study confirm previous findings that people living in intentional communities experience higher quality of life and degree of satisfaction, explained by: lack of subordination of residents to staff, friendships between people with ID, meaningful employment and a sense of</p>

	<p>have denser networks, more limited community experiences and inefficient opportunities to make friendship connections compared with others in society. This study also suggests that development of social relationships is affected by type of disability, being more difficult for people with ID than people with PD. This may be due to deficits in learning skills for forming and maintaining friendships. This study also suggests that societal stigma plays a role in the isolation of people with ID, due to a lack of genuine openness to reciprocal friendships.</p>	<p>employment to be lacking for people with ID.</p> <p>Less than half of participants answered all questions related to supports provided by social relationships, this limits reliability of some finding.</p>	<p>self reporting barriers to their social inclusion and ways to improve them. Thus, they provide important contributions to facilitate changes in service planning. Participants reported their desire to change relationships with staff from a care giving to a more supportive role. They also voiced a need to reassess safety supports, so they do not overburden opportunities for social inclusion.</p>	<p>community. Participants reported valuing relationships with co-workers and family group, feeling positive about their employment opportunities, being active in community and individual leisure activities, a strong sense of security, but also feeling a lack of privacy at times.</p>
Origin of Article	England, UK	England, UK	Ireland, UK	England, UK

IMPLICATIONS FOR PRACTICE, EDUCATION and FUTURE RESEARCH

Abbott and McConkey (2006), demonstrated through their study that people with intellectual disabilities are able to identify barriers to their social inclusion and feasible solutions. This ability needs to be acknowledged within the professional community, including occupational therapy, so that their contribution may be utilized for service planning on individual, organizational and population levels.

It has been determined that people with intellectual disabilities have smaller networks of social support from the community and rely heavily on staff members, family members and other individuals with intellectual disabilities for relationships. The study by Forrester et al. (2006) highlights that 12 years of living and receiving care within a community setting does not generally result in social inclusion for people with intellectual disabilities. This emphasizes the importance of meaningful social and employment activities that provide the opportunity for community integration. Facilitating friendships should be incorporated into individualized plans in collaboration with developing new community connections.

Occupational therapists have the opportunity to facilitate individual's achievement of the knowledge and skills necessary to being active participants within their community, such as social competency, communication, money skills and navigation in the environment. This may be accomplished through education for individuals as well as education for support staff in teaching these skills. Studies have shown that the competency in these skills can have a positive impact on social inclusion (McConkey et al. 2006).

Some barriers expressed by people with intellectual disabilities that were reported by Abbott and McConkey (2006) included a desire for staff to assume a more supportive role than carer role, especially in regard to assessment of client safety. These well meaning precautions have the potential to act as a barrier to access to community participation and social inclusion. Study participants also identified the need for community members to establish welcoming attitudes towards people with disabilities, to facilitate community participation by all; bullying should not be tolerated by anyone within a community.

Positive attitudes improve with increased contact; therefore it may be beneficial for occupational therapists to provide opportunities for meaningful contact to be established during community activities.

The contrast between the organization and functions of an intentional community compared with common residential and supported living care was highlighted by Randell and Cumella (2009) as a reason why people with intellectual disabilities have different experiences of community integration. In residential and supported living care, staff duties are generally to provide specific duties for a set amount of time, during business hours. Providers receive limited government and private funding for completing these duties. As government funding decreases for these programs, staff members are less able to be reimbursed for the services they provide to clients. Also, because many agencies are non-profit, their ability to provide competitive wages to staff is limited, making it difficult to retain quality staff members. In contrast, intentional communities provide a system that places value on strong relationships and shared effort for work and living tasks. Community members' basic needs are cared for equally in reciprocal fashion and care is provided when need and opportunity arise rather than during business hours. This community provides structure, support and sense of purpose to individuals participating within it. It may be possible to integrate some elements of the intentional community into service planning to facilitate greater social inclusion for individuals with intellectual disabilities in other settings.

Further research is necessary to determine the effects of occupational therapy interventions on social inclusion for people with intellectual disabilities. Research is also needed to further examine the elements within a community environment that facilitate community inclusion for people with intellectual disabilities.

Strategies need to be determined for providing training resources to staff and clients that are client-centered.

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