

## **The experience of spiritual participation among people with intellectual disabilities in an evangelical church in Hong Kong**

There has been much controversy over whether or not people with intellectual disabilities (ID) have spiritual needs or how their spirituality should be addressed. An article by Shea (2019) indicated a common belief in Hong Kong that acquiring certain religious knowledge with an appropriate intellectual ability is a prerequisite of personal salvation. The public question is whether or not people with ID can fully understand the concept of faith, thus their spirituality is always neglected. I am an occupational therapist in Hong Kong and an occupational therapy master's student in the US. I am also a Christian, and I value spirituality. Spirituality has been highly associated with my well-being as it allows me to interpret the meaning of life and health. As Moltmann et al. (1983) described, "Health is not a condition of my body; it is the power of my soul to cope with the varying condition of that body." Due to my professional interest in working with people with ID and my value in spirituality, I want to investigate the importance of spirituality among participants with ID and their experiences. I reflected on society's neglect of their spiritual needs and applied the concept of occupational justice.

Occupational therapy means the therapeutic use of everyday life occupations, such as feeding, dressing, driving, employment pursuit, play participation, leisure participation, etc., with persons, groups, or populations to enhance or enable participation. Occupational therapists use our knowledge of the transactional relationship among the client, the client's engagement in valuable occupations, and the context to design occupation-based treatment (American Occupational Therapy Association, 2020). For instance, a person who has an amputation might participate in occupational therapy with self-care activities, to maintain the person's meaningful role in taking care of themselves. We value occupational justice, which recognizes occupational rights to inclusive participation in everyday occupations for all persons in society, regardless of age, ability, gender, social class, or other differences (American Occupational Therapy Association, 2020; Nilsson & Townsend, 2010, p. 58). Engaging in spiritual activities and expression is an important occupation that gives meaning and purpose to life (American Occupational Therapy Association, 2020). Spirituality is "a deep experience of meaning brought about by engaging in occupations that involve the enacting of personal values and beliefs, reflection and intention within a supportive contextual environment" (Billock, 2005, p. 887). The existing barriers to spiritual participation potentially compromise occupational justice among people with ID. In this article, I will briefly explore and discuss the experience of spiritual participation among people with ID in an evangelical church that pioneered the facilitation of spiritual participation among people with intellectual disabilities in Hong Kong. For research I conducted interviews in this church with an participant with intellectual disabilities, the participant's caregiver, a volunteer and two pastors. Interviewees from this church are identified by pseudonyms. I also interviewed Professor Sarah Shea, who engaged in research

relating to practical theology, theologies of disabilities, and ministering to the marginalized at Hong Kong Baptist Theological Seminary.

After the interviews, I identified the following themes relating to spiritual participation among people with ID.

### **Participants' individualized needs and gifts in spiritual participation**

David, a volunteer who helped organized and hold group activities for participants with intellectual disabilities in church, mentioned that some organizations and faith communities in Hong Kong provide limited opportunities for spiritual participation among people with ID due to their poor comprehensive and expressive skills. David identified, however, that despite participants' generally decreased language skills, they enjoy singing gospel songs, watching dramas of Bible stories, and dancing in the church. He described participants' eagerness to go to church by their actual verbalizing, "I want to go to church." Anna, a participant with severe ID, also expressed in her interview her wish to bring me to her church. She joyfully shared with me about her friends at church. Betty, Anna's sister as well as her caregiver, shared that spirituality helped Anna further understand life and death. "It is inevitable to face life and death. Our mother passed away in 2014. Knowing that our mother is in paradise is a huge comfort to my sister. She would know that one day, our friends and I will be in paradise, too. Other rehabilitative groups are good, but they can't provide such comfort." The desire and need of people with ID to participate in church was vividly revealed, despite the differences in cognitive abilities. This also implies their occupational right to participation in spiritual and religious activities without the prerequisite of a particular cognitive level.

Betty further expressed that Art, such as coloring pictures from scripture, dancing, and singing, would be an effective medium to convey spiritual messages to participants with ID. Pastors from the church explained that the delivery of the scripture message to people with ID could involve various sensory experiences instead of utilizing materials meant for children. For instance, they would light a candle in the darkness, or ask participants to touch and hold a cross. These sensory and Art experiences could further facilitate participants' reflection and understanding of their own spirituality. Betty shared how her sister, Anna, who has severe ID, lived in an isolated hospital room due to swine flu in 2009—throughout the ordeal, Anna held the cross to stay calm because she thought Jesus was staying with her.

To facilitate the best spiritual participation among participants with ID, one should not only focus on the participants' cognitive level; the experience should be "the integration of mind and heart, belief, and experience" (Shea, 2019). This requires a thorough understanding of a participant's individual life story. Staff members at Betty's church explored each participant's personal history, dreams, nightmares, gifts and talents (Shea, 2019). The team at church evaluated an individual's life stories to facilitate tailor-made activities for spiritual participation. This also allows them to be more sensitive to participants' individual needs, such as their confusion about life and death, or fear about loneliness.

## **Participants' need for a true social connection with other members at church**

In the interviews, the volunteer, caregiver, pastors and Professor Shea all indicated a lack of true social connection among people with ID and other members of evangelical churches. A pastor mentioned that the "social poverty" among people with ID is caused by "typical people" in church. David, the volunteer, indicated that many people have the misconception that

people with ID have poor hygiene, and many people become volunteers because "they want to feel better", setting up volunteers to feel superior to those who are served. The pastor indicated another misconception that only professionals should interact with people with ID; however, she disagreed and suggested that everyone can be friends with this population. Betty, the caregiver, shared that although sometimes people in churches were friendly and tried to interact with her sister who has ID, the conversation usually could not last long. "They did not know what to say," Betty said.

As I interviewed Anna, Betty's sister who has severe ID, I noticed the difficulties in building a true social connection. Despite the social stigma, I understand that social interaction with this population might require some skills and knowledge. I interviewed the participant online, which increased the difficulties. However, as I talked joyfully and interviewed in simple sentences, the client gradually became attentive and active. She prayed for me and expressed that she wanted to bring me to church.

People's lack of understanding of this population inevitably becomes the barrier to building a genuine social connection. However, volunteer David suggested that although he did not participate in much training, he established friendships with this population by interacting frequently with them and treating them with empathy and as true friends. A pastor mentioned that sometimes "typical" people focus too much on structured social norms and skills but neglected natural interactions such as facial expressions, touches, and gestures. The pastor suggested that the first step to building a social relationship is to treat this population as regular friends. Betty also expressed how she and Anna value home visits and telephone calls from people in the church. She said, "the intensity is different, the interaction is many times more than that in the previous church, they created many memories."

Professor Shea shared with me another story: "A participant with intellectual disabilities in our church faced discrimination when he was young. His relatives had always given red envelopes, important gifts from adults to children which symbolizes blessings, to his sisters, but not to him. One day, he met a student volunteer from a mainstream school. The student asked his mother to give this participant a red envelope. When the participant received the red envelope, he was so glad, and his mother was so grateful that they kept this gift for more than 40 years." A small act which shows our empathy and friendship can heal people's soul. We can establish genuine social connections in simple ways, which effectively facilitate people to engage in a more meaningful life.

## **Inspiration to other participants' broadened understanding of life**

David the volunteer, pastors and Professor Shea also shared that their own participation in spiritual activities with people with intellectual disabilities has allowed them to reflect on their lives. David shared that interacting with participants with ID inspired him to be joyful and thankful about simple things in life. A pastor in the church also expressed that participating in spiritual activities with this population allowed her to understand more about humanity—our emotions

and feelings. “There should not be too much disguise about our emotions, and we should embrace our feelings,” she said.

The pastor also shared that participating in spiritual activities with this population allows her to reflect on the hierarchy among different people. She stated her belief that God loves every human and that every human has the right to participate in meaningful activities. She upheld the value that volunteering should involve empathy instead of sympathy. She believes that participation in spiritual activity should be a meaningful occupation that all people mutually support and encourage each other in as friends. In Shea’s (2019) article, a researcher also shared that a participant with ID reminded them of neighborly love. There was a time when the researcher was teaching a participant with ID about how to pray. The participant, however, could not focus well because he heard another participant screaming. The researcher was initially annoyed by the participant's insufficient attention but then reflected that he was trying to address his neighbor's emotions and needs, which the researcher felt guilty of ignoring. Professor Shea further shared we can always learn from one another despite cognitive differences.

## **How the general public can address spiritual participation among people with intellectual disabilities**

David, the volunteer, stated in the interview that “society, even Christians, don't have an adequate understanding about people with ID.” A pastor suggested that not only professionals, but the general public should interact with this population and provide caring to them. He also suggested that the concept of occupational justice probably does not merely focus on participating in a particular occupation but also emphasizes the meaningful interaction among different people within that context. As David expressed, “interacting more with this population has improved my communication skills and my empathy toward them as well as toward others.” The other pastor suggested that only true friendships with trust would facilitate the best engagement in meaningful occupations and promote the best quality of life. She hoped that the general public would take initiatives to reduce the social stigma, interact with this population and treat this population as true friends.

On the other hand, people in churches can also develop a more thorough understanding of this population with ID. David expressed, "Sometimes churches don't accept this population because they believe this population can't understand the concept of faith." However,

according to the interviews, participants with ID vividly showed their desire and need for spiritual participation. Shea's (2019) article also suggested that thoroughly understanding a participant's life story is crucial in facilitating the person's spiritual life. However, individualized attention might not always be feasible among staffs at church (Shea, 2019). Therefore, Professor Shea shared that caring for people might not merely be the staff's responsibility. All members in churches should care about one another and listen to each other's life stories. Shea's (2019) article also mentioned that there should not be a triage of Sunday classes but should facilitate mutual interaction among all participants to build a true friendship.

### **Implications for OT practice**

Occupational therapists can educate the general public about learning about and caring for people with ID and help promote the public's empathy towards this population. Betty, the caregiver suggested that instead of providing in-person workshops, occupational therapists can spread the knowledge, concepts of empathy, and occupational justice via social media, such as posting videos, posters, and articles on social platforms.

Occupational therapists can also facilitate spiritual participation among people with ID via the direct provision of therapy or indirectly via consultative roles. We value individual beliefs, goals and needs. In addressing spirituality, occupational therapists can utilize appropriate art or sensory approaches according to participants' strengths and interests to facilitate their understanding of religious materials and enrich their spiritual experience. Other therapeutic means can include addressing participants' proper positioning for communion and worship, and providing environmental modification and adaptation for churches to facilitate participants' spiritual participation.

Professor Shea has further shared in the interview that she highly appreciated the concept of occupational justice, an unfamiliar term for her. It was thus suggested that occupational therapists and occupational therapy students could develop a more thorough understanding of occupational science and occupational justice. The study of occupational science would help us further reflect on the meaning of occupations and clients' perceived meaningful life, which fundamentally enhances our quality of therapy. Professor Shea and I discussed that undoubtedly it might take a long time to promote the concept of occupational justice and the involvement of OT in community practice as there are barriers such as the lack of understanding of occupational therapy among the general public, inadequate rehabilitative resources, and the low occupational therapist to patient ratio. However, she added that it would still be meaningful if we start to acknowledge and reflect on this concept. "There should be someone who takes action first before the idea can be widely spread. This article might be one of the first steps." Thus, we envision that the idea of occupational justice and the essential role of occupational therapists would be widely promoted someday, not only in the rehabilitative field but also in community settings.

## Reference

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