Listening to the Powerless: Religious Education for Adults with Severely Intellectual Disabilities

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Abstract
The fact that they cannot speak for themselves without intensive support has made individuals with severe intellectual disabilities become one the most powerless segment in a population. The status of their participation in religious educational programmes organized by local churches is sometimes ambiguous and problematic. With parental request, they could be invited to partake in religious learning activities. However, it is not easy for church educators to engage with them in meaningful ways. They could be left idle in the program for an extended period of time. Through the learning experiences of a man with SID in a Hong Kong protestant church, this paper looks to give an account of the cultural and religious forces that have marginalized this powerless group in religious education. An educational approach that combines person-centred care and communal oriented action research is recommended for church educators to identify religious needs, set learning goals, design appropriate activities and assess performance for these individuals.

Keywords: Severe intellectual disabilities, religion education, person-centred care

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It is only in the last decade that Hong Kong protestant churches have begun to pay attention to the problematic situation that the Christian message is largely inaccessible to people with learning disabilities. There are initiatives to integrate rehabilitative and social service with spiritual care in some faith based organizations (Kwan, 2009). However, lack of awareness and sensitivity to the spiritual needs of people with learning disabilities has been a major barrier to the promotion of this ministry amongst local churches (Kwan, 2009). The efficacy of evangelistic works amongst people with learning disabilities is enshrined within questions such as "whether the person concerned is capable of belief?" and "whether it is a waste of time and resources trying to get an abstract religious message across?" The more severe the learning disability that a person has, the more uncertain is her personal faith. The confidence of faith communities in delivering spiritual care decreases as the severity of learning disabilities increases. Through the religious educational experiences of a man with severe intellectual disabilities, it is the purpose of this paper to explore the cultural and religious forces that would have prevented church instructors from engaging meaningfully with individuals whose communication needs are both high and non-verbal in educational programmes. A communal oriented action research approach of spiritual care was piloted in this special religious educational case and its positive impact on instructors' practices and beliefs will be reported and discussed. Finally, implications of this study on professional training and development as well as recommendations for further research will be suggested.

Martin's story

About six years ago, Martin began to put in appearance at the bi-weekly Christian Education Programme held at the care home. The programme was organized by a protestant church with the aim to teach biblical knowledge to several church members living there. Almost aged 40, Martin had severe intellectual disabilities. He had no mastery of verbal language. He vocalized and smiled when he was in a good mood. Due to impaired development, he had a body-build and appearance of a child. Although his family practiced traditional Chinese ancestor worship, the mother supported Martin's participation in the church religious program and considered it a social activity.

Martin's participation in the church programme was a coincidence. It just happened that the programme was held in the same room where Martin and several others were staying during that time of the day. They made no indication of a wish to leave the room and naturally they became participants within the programme. From the point of view of the church instructors, Martin did not leave them with a good impression. In the interviews of September/October 2011, five instructors reported that he "disturbs others". Four of them remarked that he "is living in his own world," which means he "does not have any responses at all [e.g. eye contact and nodding]," and additionally Martin is described as "not paying attention to teaching materials," and "not listening to us [the instructors]." Pastoral responses to Martin were largely in the form of dutiful greetings and occasional behavioural management. His presence in the church group was not taken seriously by anyone. A serving team member said, "I do not take Martin as a target of instruction". His care worker did not think he would benefit from the activity as "he cannot express faith". Programme participants took the same view. A resident member commented that Martin "does not understand [instruction]".

Instructors' negative impression was in great contrast with that of Martin's carers who had daily contact with him. Martin, in fact, was rather "popular" in the care home. His care worker once commented that "he is obedient and easy going… He does not disturb others. It is as if he lives in his own world, entertaining himself, sometimes laughing without cause." The typical self-entertaining activity of Martin was unstitching garments that he wore. Though this behaviour ruined every piece of clothing he put on, his parents and care workers accepted it as his idiosyncrasy or "habit". Besides, Martin maintained good relationships with staff members and residents, and he was discreet in approaching people, though he did not always respond to strangers. He approached and played with persons who were familiar to him. Martin had enriched the social life of the people in the care home. Moreover, Martin had a keen interest in taking elevator and minibus rides. Though he did not indicate his choice verbally, he shows a preference through body language.

Cultural and religious marginalizing forces
Martin's case has thrown light on the fact that a church community could be both a resource and a problem for the religious education of persons with SID. Positively, their 'right' of participation in the community is recognized by instructors. Despite Martin's non-response to instruction, the serving team never considered discontinuing Martin's presence in the programme. They unanimously believed that the Gospel is for all and that Martin somehow has the entitlement to receive it. An instructor said, "God's grace is open to all. God wants all people to be saved, not wanting anyone to perish." She thought that "everyone has the right to know and worship God."

Nonetheless, the conviction of egalitarianism does not make teaching people with intellectual disabilities less problematic. Stereotypical images of SID were held by instructors. Stigmatizing tags such as "living in his own world," "not responsive to others," and "knows nothing," were uncritically adopted as references that informed the educational practice of the church. Traces of "malignant social psychology" as identified by Tom Kitwood, including labeling, ignoring and invalidation (Kitwood, 1997), were observable in the church practices. It must be clarified that what is meant by the term "malignant" refers not to the intention of the care givers but to the cultural forces that tend to suppress the true stories of people with disability (ibid.). To buffer such malignant cultural force, Swinton, Mowat and Baines suggest a communal oriented action research approach of spiritual care, which is found to be effective in generating a 'counter narrative' for persons with SID (Swinton, Mowat & Baines, 2011).

In addition, a text-based model of religious epistemology would have encouraged instructors having a low expectation on Martin's learning. 'Devotion to the Bible,' a distinctive feature of evangelical spirituality, is the main characteristic of religious care practice of Martin's church. An instructor considered it is a "must" for her to "use God's words to fulfill believers' [spiritual] needs." The other regarded "biblical teaching" is expected to be able to help care home believers "resolve daily problems." Another said "Nothing but the Bible" is considered "worth mentioning in the care home programmes." Church practitioners believed that the Spirit works in the human memory and uses fragments of Scripture to give individual Christians the assurance of divine love. However, for a person like Martin who cannot read and understand the Biblical text, it would have been nearly impossible for him to be benefited from the church teaching. Interestingly, instructors used supernaturalism to bridge the gap

between the perceived conceptual religious knowledge and the severe cognitive impairment that Martin's had. An instructor said, "Although I don't know how much he [Martin] understands my instruction, I believe that God is able to let Martin know about Him in certain ways." Embedded in the above position is a conviction that the subject could emit no observable act of acknowledging the divine reality. Having severe cognitive impairment means that either the person forms no knowledge of God, or that even if such knowledge were to be supernaturally infused, still she has no capacity to communicate their experience in intelligible ways. A logical consequence of such presumption is a kind of pedagogical inactivism. The belief in God's mysterious power is misconstrued in such a way that can lead to educational apathy towards intellectually disabled persons.

Communal oriented action research approach of religious education
In contrast to the text-based and supernatural understanding of spirituality that shaped the educational practices of Martin's instructors, emerging studies have shown that the spiritual experiences of people with profound intellectual disabilities are largely relational and communal (Swinton, 2001, 2004; Swinton, Mowat & Baines, 2011). In a study that involved the participation of several individuals with complex and profound learning disabilities (Swinton 2004), their experiences indicate that spirituality is a relational notion. Swinton says,

> Spirituality is very diverse. It is complicated and personal. Nevertheless, the participants in this study were clear that relationships with self, God and others lay at the heart of their understanding of spirituality. It would appear that spirituality is fundamentally a relational concept that may be expressed vertically towards God or horizontally towards other human beings. (p.28)

Similar findings appear in another study that focused on people with complex learning disabilities in UK (Swinton, Mowat & Baines 2011). In contrast to the conventional understanding of spirituality as a private choice or a cognitive belief, the research team concludes that it is "something that belongs to a community", as manifested in the lives of people with complex needs (ibid.). The communal nature of spirituality suggest that the starting point for any attempt to improve spiritual care is the formation of a community of care, which is structured in a way that places the individual with complex and high support needs at the centre. Placing the person at the centre means creating a space to listen to his or her voice, preference and desire rather than imposing norms upon them.

Research Method and Process
The present study is an attempt to replicate the idea of creating space of spiritual care, where the setting is Martin's church, a Chinese evangelical community in the Hong Kong SAR. The research period is consisted of 13 months, from September 2011 to October 2012. A range of data collection methods including research diary, direct observation, learning logs, interviews, focus group, and critical conversation were utilized.

Combining the method of Making Action Plans (MAPS) (O'Brien, Pearpoint and Kahn, 2010) and the insider action research method, Swinton, Mowat and Baines

(2011) devise a person centered approach to spiritual care which is also a research method. The approach is consisted of six steps, as shown in Figure 1.
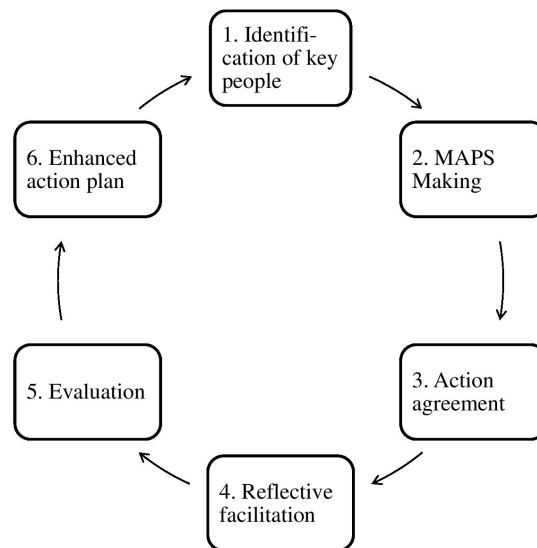

Figure 1 The six-step person centered approach to spiritual care

The <u>first step</u> of a person centered approach to spiritual care was the identification of key personnel to form a Circle-of-Support around each subject with SID. Six church instructors of Martin participated in the study and became his allies of support. The <u>second step</u> focused on working out a spiritual action plan by using the technique of MAPS. During the course of March/April 2012 a total of two MAPS making meeting sessions were held to devise spiritual profile and care plans for Martin. Each session lasted for about two hours. The framework of MAPS developed by O'Brien, Pearpoint and Kahn (2010) was adapted to the purpose of providing spiritual care in the context of a local church. In the first session, allies contributed data on the history, dreams nightmares, gifts/talents of Martin. Views collected from care home workers were reported by the researcher. In the second session the meaning of the spiritual life and the conditions necessary to facilitate the spirituality of Martin were discussed before devising an action agreement. A graphic facilitator was present in each meeting.
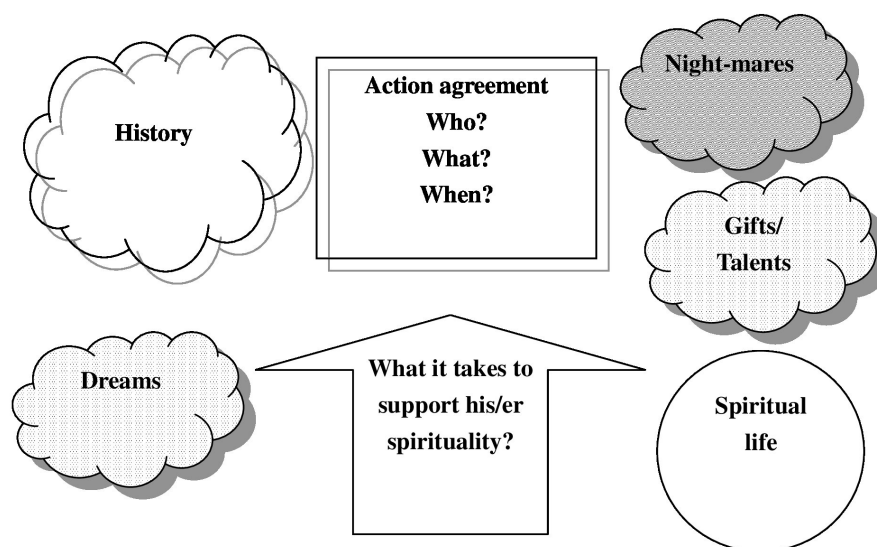
Figure 2 Major components of the MAPS.

The headings and contents of MAPS are tabulated in Table 1 in word format. Ideas emerging from the MAPS meetings were channeled and used to formulate a spiritual action plan in the third step. Overall speaking, the support team agreed to help Martin to know God through multiple sensory methods and religious symbols. They also intended to make use of his positive social impact to promote interaction and care amongst the CC1 group participants. In particular, the support team intended to involve Martin so as to enable CC1 participants to practise the biblical teaching of having "equal concern for each other" (1 Cor. 12.25).

Table 1 Headings and contents of Martin's MAPS

Headings	Contents of Martin's MAPS
Story and talents	The group saw Martin • as a lovable, active, happy and obedient child. • has a certain degree of understanding of the living context, routine, instruction, and people. • is a popular person in the care home. • loves to play with others. • loves to move around by wheelchair and is especially fond of frequenting the lift lobby. • likes snacks. • is easy to take care of because he is in general a happy and contented person, and he is in good health. • enriches lives of other residents.

Dreams	The group saw Martin's dream as having elevator rides, an indication of his desire to explore the outside world.
Night-mares	The group saw Martin's nightmares as taking medications; being forced to do something against his will; wearing socks; and suffering from illness and pain.
Spiritual life	The group appreciated Martin's positive impact on others. They considered knowing God and believing in God are Martin's spiritual needs. The group wanted to help Martin to promote love amongst Christian residents, particularly encouraging them to practice the biblical teaching of having "equal concern for each other"
What is needed to enable Martin's spirituality?	The group needs to help Martin to be a 'goodwill ambassador'; and learn about the Christian faith.
Actions and agreements	The group agree to teach the biblical truth, 'loving one another,' with and through Martin's social impact; and help Martin to learn about the Christian faith through religious symbols and multi-sensory methods.

Reflective facilitation as the <u>fourth step</u> was about the support provided by the researcher to individual participants of the Circle of care. The <u>fifth step</u> was a gathering of participants of the circle-of-support to review the process and revisit some of the previous thoughts about the spirituality of the individual with profound learning disabilities. An enhanced spiritual action plan (<u>step six</u>) was formulated at the end of the review meeting, leading to the next cycle of action, reflection and transformation.

Findings
From April to September 2012, the support team met with Martin on eleven occasions. Eight of them were the Friday church group while the rest were individual visits. The first significant change that happened in this period was the recognition of Martin as a member of the church group by care workers, residents, and his allies. Since March 2012, Martin has been formally recognized as joining the Friday group. Whenever Martin did not attend the group, the instructor on duty would go to his room to check his condition. For the first time, he was being missed.

The second reported change was the bonding between individual allies and Martin emerged during this period. Four out of five allies reported that Martin recognizes them. Three allies expressed that Martin "accepted my care" or "accepted me" for he no longer resisted them holding his hand when praying. An ally reported an intimate encounter, "…we have eye contact for more than 10 seconds." Martin's friendly responses brought happiness and satisfaction to his allies. For the first time, at the end of September, one of the pastors addressed Martin as "a brother" and "a friend" before the congregation. She expressed her willingness to be Martin's "companion in the heavenly journey."

Lastly, there was change in the instruction methods with non-verbal elements, with the purpose of engaging Martin. Such alternative methods were not seen in the history of the group. A photo-taking activity was designed to encourage interactions between Martin and other participants. Martin was responsive to a performative approach of storytelling. He laughed heartily. Tangible objects with religious symbols were used while touching was explored as a means to communicate with Martin. However, religious symbols and objects were found to have little impact on Martin's religious learning, as he demonstrated little interest in these items. He sustained a lot more interest in people who talk to him and have physical interactions with him. Some activities (e.g. arranging Martin to sit with different participants and giving him the space to move around) were not carried out as planned due to the shortage of assistants. The level of individual attention given to Martin was much less than has been intended originally.

In addition to the above interpersonal and instructional changes, instructors acquired certain insights regarding their practices of religious education. The first insight for the allies was the awareness of the negative impact of stereotypical images of people with SID, who were often being regarded as 'incommunicable' and 'non-responsive.' In the MAPS making meeting, through listening to Martin's story, allies became aware of what had been, and still was to some extent at that time, their bias against him. A lay assistant humbly confessed, "He is not what I thought earlier on – a person who knows nothing. He thinks [his behaviour is purposive]" Other allies were surprised by Martin's positive impact on people living and working in the care home. They appreciated him as "a little angel" [a kind and lovable person] who was able to "enrich others' life." A re-description of Martin was obtained.

Secondly, the allies experienced the transformative power of listening to a person's story. The case of Martin has helped the allies to discover that "we are able to discover the bountiful life of persons [in terms of human possibilities] who are easily forgotten or ignored" if due attention is given. The following quotations show that there was a profound change of attitude towards people who appear to be less desirable.

> For individuals whom we dislike [because of their inappropriate behaviours], we are accustomed to thinking that the best we can do is to leave them alone. Yet, it is not the right pastoral attitude. Instead, we should think more about their situation. I find Martin's case helpful for me in this regard.

The above response indicates that it is easy to ignore and forget some persons by keeping one's personal distance. Learning to listen to a person's story and giving individuals due attention is conducive to the creation of a space for spiritual care, and it helps reinvigorate commitment and interest towards these seemingly insignificant human persons.

Discussion
Martin's case enabled instructors to see the inadequacy of previous instructional practices that are mainly conceptual and textual. Many participants, like Martin, were being ignored in the past because the instructor's attention was directed to members with higher learning abilities. This mode of instruction leaves no space for getting to

know individual participants, particularly those with high communication needs like Martin.

New educational practices that are person-centred and communal are emerging. The shift from an instructional to a person-centred approach to religious education has prompted co-workers to develop new expectations regarding the organization of the educational ministry. In the planning of future religious education, it is relationship building, not knowledge transmission, has come to the foreground. There has been a growing awareness of friendship as a foundation for people to experience God and to grow in faith. An instructor's reflection is illuminating.

> Perhaps it is the impact of MAPS that I am now more patient with and gentle to members who I regarded as difficult in the past.…[In the face of daily hardship], the notion of God appears to be abstract for them. As a pastor, I represent God as I stay close to them.

The quotation spelt out a significant correspondence between an interpersonal relationship and a divine-human relationship in spiritual care. In fact, practitioners' awareness of the limitation of a cognitive and textual understanding of faith and the discovery of the communal nature of faith are affirmed in theologies of disabilities. Objections against a hyper-cognitive and an individualistic understanding of faith are not uncommon. Theologians writing about the experience of persons with severe and profound intellectual disabilities criticize the fact that such an understanding of faith is a product of an "enlightenment pathological account of revelation" (Demmons, 2008, p. 9) or "ableist assumptions" (Yong, 2011, p. 170). The propositional view of faith is incomplete for the reason that there exist other legitimate modes of knowing that are non-cognitive and non-rational. David A. Pailin and Tracy A. Demmons refer to Michael Polanyi's tacit dimension of knowledge to show that understanding is not restricted to what people can conceptually express (Pailin, 1992; Demmons, 2008). By making reference to Howard Gardner's theory of multiple intelligence, Brett Webb-Mitchell (2003) reminds us that "we need to take into consideration *all* of the ways people learn." (p.18). In a similar manner, Amos Yong (2011) points out that people with SID engage the world through affective, embodied and relational forms of knowing, rather than following the propositionalist scheme. He calls for the development of an understanding of faith that is grounded on the experiences of people of different intellectual abilities.

Several theologians have offered their insights into the notion of friendship and of reciprocity in human love relationship as possible means of replacing words through which grace is mediated. For instance, Pailin (1992) thinks that faith is "an existential commitment to the reality of the divine" and is to be understood as a "personal reality." (p. 126). Thus, faith is "far more like a deep friendship" than an intellectual assent (p.127). John Swinton (1997) suggests that "faith and spirituality are not intellectual concepts but relational realities" (p. 21). He considers that the double love command has shown that to love God and to love humans are inseparable acts and in fact "interpenetrate each other" because these two aspects of love acts are done "in and through the work of the Spirit." Hence, "in a very real way God is present and at work within our temporal relationships." Awareness of the transcendent love of God for people with profound disabilities is "mediated through, and experienced in, temporal love, offered in loving relationships" (p. 24).

An important contribution made by the above relational model of faith is that it offers an alternative interpretation of faith that is not exclusively dependent on the power of human cognition. Emphasizing the relational and communal aspects, it has the potential to generate educational practice that is appropriate to the life experience of individuals with severe cognitive impairment.

Conclusion and implications
The case of Martin throws light on the cultural and religious forces that would have been marginalizing individuals with cognitive impairment in church religious educational programmes. It also shows the power and effect of listening to and telling counter-stories within a circle of support in resisting such destructive forces. To improve the quality of religious education for this group, appropriate professional training and development, for example person-centred approach of spiritual care, is helpful. A broadening understanding of religious epistemology and learning is also recommended. In addition, this pilot study indicates the need of further cross disciplinary studies on the spirituality of people with severe learning disabilities. Apart from using qualitative research methods (e.g. the method of communal oriented action research approach of spiritual care) to understand the diverse and complex phenomenon of spirituality, doctrinal and biblical studies in light of the spiritual experiences of this group are essential for the development of a sound theoretical foundation of education that is able to guide and inform appropriate educational or spiritual care practices.

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