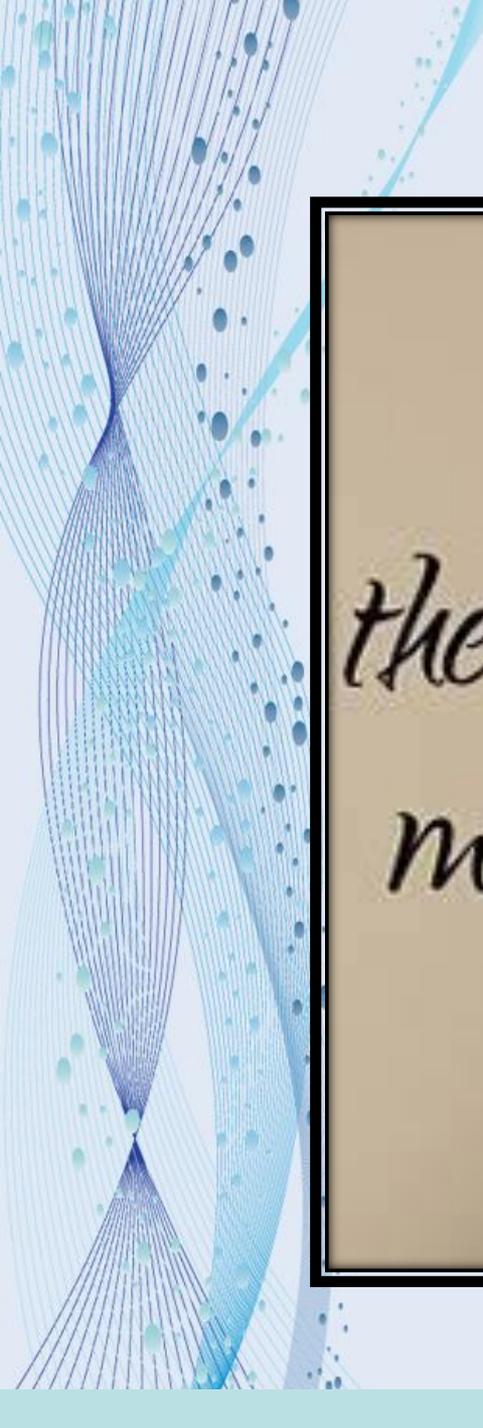


Spirituality in the Context of Non-verbal Autism

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*I swear to you,
there are divine things
more beautiful than
words can tell*

- Walt Whitman

Introduction

- Each individual with autism is unique
- WHO global stats estimate 1/160 or 1% world pop (Lai et al., 2014)
- U.S. stats approximate 1/68
- Many have exceptional gifts in visual skills, music or academia
- Approx. 60% have no intellectual impairment
- Approx. 25% are non-verbal
- Communication can be successful via assisted communication

Introduction

- The incidence and relevance of autism is increasing
- Those with most severe form a significantly under researched group
- Communication and relational barriers
- Humanness of these people must not be ignored
- Spirituality an essential element of humanness therefore worthy of exploration
- Thus.....Spirituality in the Context of Non-verbal Autism

Background



Background

- Topic birthed from my own life story
- Life brought the opportunity to ponder difficult questions
- Convinced of an intentional design rather than a random mistake
- Societal attitudes create a perspective of less than perfect – Dominant understanding (Clapton, 2008)
- Needed to expand my mind

Ponderings

- If divine inspiration does provide purpose and meaning to the life of someone living with a disability, then how does such a person experience their own connection to the Divine?
- Does the inability to express such an experience negate its existence?
- If people with profound disabilities have a unique spirituality, can the experience alone lead towards deeper divine connection?

Guiding Purpose

- Built on interwoven framework of theology and spirituality
- Life brought the opportunity to test hypothesis
- Andrew is introduced to Jesus and something changes
- Whatever happened with this young man somehow impacted me

Autism Defined

- Complex neurodevelopmental disorder
- Spectrum disorder with large variations in severity and expressions
- Increasing at an alarming rate – approximately 1% of population worldwide
- Australian statistics: 2009 – 64,400
- 2012 – 115,400 (79% increase)
- Characterised by idiopathic symptoms in skills used for socialisation and communication

Autism Defined Con't.

- One end of spectrum – Asperger Syndrome - verbally competent with social challenges
- Severe end of spectrum – Non-verbal autism - limited social engagement and little or no verbal language
- Often assumed unintelligent and unfeeling
- Extremely sensitive, higher intelligence
- Sensitivity to noise and atmospheric changes, more spiritually aware (Stillman, 2003, 2006)

Non-verbal Autism

- Absence of verbal language - Insurmountable challenges
- World revolves around language
- No language assumes no intelligence
- Largely misunderstood group
- Almost all research to date focused on innovations to develop verbal speech
- Changes slowly seen with FC/AC
- Researchers – Stillman, Grandin, Pasco, Eagle, Whittaker

Non-verbal Autism

- Cause unknown
- Many hypotheses but cause basically a mystery
- Therefore, differing definitions with no one clear factual account
- Understood to mean the lack of “sufficient natural speech to meet their daily communication needs” (De Leo & Leroy 2008)
- “nonverbal intelligence and social engagement” found to be predictors of speech (Wodka, 2013)

Theology and Spirituality Defined

- Theology - The discipline supports knowledge, understanding of God
- Explores how humans may relate to this Being
- Disability Theology an emerging empirical discipline
- A different way of looking at God and humanness (Swinton, 2002)
- Opportunity for sound theological pursuit

Spirituality Defined

- A fluid process – deeply personal (McSherry, 1998; Swinton, 2002)
- Better described than defined (Adams, 2009)
- A lived reality (Chan, 1998) providing meaning and value (Muldoon & King, 1995) transformation and discovery of self (McIntosh, 1998)
- Primarily about lived human experience
- Inherently oriented towards discovery
- The place where humanity meets the Divine
- Spirituality and Theology intimately related (McIntosh, 1998)

Disability Theology

- Within Christian context a rapidly growing discipline
- Suggests implications not only for faith communities - Other organisations
- Intentional effort is required to create a meaningful space for people with different abilities to express their spirituality
- Space for unique spirituality

Disability Theology Con't.

- Statistically, people with disabilities absent from society
- Especially true of faith communities
- Modern society struggles to engage with the narrative of those with a diminished voice
- Disability Theology affirms they have a gift to give to individuals, organisations and society as a whole

Research Aims

- To come from a place of genuine enquiry
- Request to be invited into the world of the person with non-verbal autism, rather than to invite them into my world assuming it to be better

Research Questions

- 1. What are the spiritual experiences of people with non-verbal autism?
- 2. What can be learned from the spiritual experiences of people with non-verbal autism?
- 3. What are the implications of the findings of this research for faith communities and other service providers?
- 4. What should be the direction of further research on the spiritual experiences and expressions of people with non-verbal autism?

Methodology

- Starting Point – Scoping literature review
BECAUSE
 - Difficult to conduct qualitative research on people with non-verbal autism due to obvious communication barriers
 - Lack of clinical trials involving non-verbal individuals means that an alternative systematic literature based methodology such as a meta-analysis was not possible

Five Phases of Literature Searches

- Phase 1 – Theology of Disability
- Phase 2 - Theology and Spirituality
- Phase 3 - Spirituality of Disability
- Phase 4 – Alternate Literature
- Phase 5 – Social Multimedia

Phase 1–Theology of Disability

- To discover about people with non-verbal autism from a Theological viewpoint
- Current attitudes and beliefs within faith communities about disability, particularly non-verbal autism

Phase 1 - Themes

- Disability theologians and faith communities struggle with the same ethical and organisational responses concerning social attitudes of equality and inclusion:
 - Overcoming barriers to inclusion
 - Faith used as a coping mechanism
 - What the general faith community may learn from people with disability
 - The value of the dependent/interdependent relationship
 - The integration of programs designed for people with disability
 - Modified curriculum for scripture lessons

Phase 1 - Research Gaps

- Research Gaps
 - Little research exploring integration and inclusion for people with autism
 - Unique barriers for non-verbal people
 - An opportunity for autism as a specific criteria within Disability Theology
 - Limited research on unique spiritual experiences or expressions for people with disabilities, particularly autistic people
 - NO literature concerning the theology or spirituality of non-verbal people from their perspective

Phase 2 – Theology and Spirituality

- To determine difference between theology and spirituality
- To explore Theology of Spirituality
- Silence and contemplation
- Mysticism

Phase 2 - Themes

- Working definitions - theology and spirituality
- Difference between theology and spirituality
- Exploration of process and experience gained by spiritual discipline of silence and solitude
 - Silence and solitude have been used as a means to draw nearer to the Divine in history of every world religion and indigenous people group
 - Bias observed in consideration that the spiritual discipline of silence elevates one's spiritual status, however those whose life context is silent by design not choice are devalued



Phase 3 - Spirituality of Disability

- Spiritual experiences of people with disability
- Focus on autism, particularly non-verbal autism

Phase 3 -Themes

- Friendship central to spirituality
- Cognitive and developmental capability may or may not be necessary for understanding of spirituality
- Spirituality not tied to human development and can be expressed in different ways
- Autistics may express atypical spirituality
- More spiritual than religious

Phase 3 – Research Gaps

- Obvious Gaps
 - Little information available regarding role of spirituality in individuals with intellectual and/or developmental disabilities, particularly in regards to those who are non-verbal
 - Few studies investigate religious views or understandings of people with any type of intellectual or developmental disability
 - Little research investigating the range and forms of spirituality, religious or personal experiences of these groups
 - No research on spirituality of people with non-verbal autism from own viewpoint

Conclusions

- Little empirical literature exists that considers spirituality of people with intellectual/developmental disabilities, particularly people with non-verbal autism
- Prompted broadening scope of literature review
- Two additional search phases

Search Phases 4 & 5

- Amazon and Google books
- YouTube
- Online blogs
- Facebook
- Websites

Phase 4 - Alternate Literature

Search of Google Books, Amazon

- Genres included: Biographies and autobiographies of people with non-verbal autism
- Literature written by professionals in the field
- Over 20 autobiographies authored or co-authored by people with non-verbal autism – A small number discuss spirituality
- Many written via assisted communication – Controversial
- These works essential contribution to research therefore identified as distinct category of literature
- ‘Non-verbal Narratives’

Phase 5 - Social Multimedia

- Wider scope of 'Non-verbal Narratives' to locate relevant social multimedia sites to find sites specific to non-verbal individuals
- Web pages, blogs, YouTube, and Facebook sites
- 43 blogs & 16 Facebook pages written/co-authored by people with non-verbal autism
- 7 YouTube videos relevant to topic
- 3 websites relevant to topic
- Identified as a subcategory within the 'Non-verbal Narrative' genre
- 'Internet and Social Media Narrative'

‘Non-verbal Narrative’

- Many young – Children, adolescents
- Authored/co-authored with family member/carer
- Use assisted communication or typing
- Many have significant health problems
- Many taught RPM (Soma)
- Several have had media attention

Justification of ‘Non-verbal Narrative’

- Vital to research because:
 - No available academic literature on topic
 - Such a unique topic that this omission rarely even acknowledged
 - Liu and colleagues (2014) concluded in their study on spiritual experiences of individuals with intellectual disabilities that “creative approaches are needed to discern the perspectives and practices of individuals who cannot speak, but still have something important to say about this area of their lives” (p.400)

Justification Con't.

- Only in recent years that the personal journeys of non-verbal individuals have been documented through assisted communication
- Term 'Non-verbal Narrative' intended to characterise and make alive unique life stories
- Assist to normalise their experience
- Intended to introduce an alternative understanding of difference rather than a negative or deficit approach
- Data 'pure' as it has not been contaminated by societal and religious norms



Emerging Themes from the ‘Non-verbal Narrative’ Literature

Theme 1 - Love

- Predominant theme
- God is love
- Pass on God's message of love to wider society
- People should love each other
- Love is always the answer
- Ability to communicate – Can now share God's message

<https://www.youtube.com/watch?v=inRak4jGgmE>



Theme 2 - Intelligent

- Need to be recognised and treated as intelligent
- Importance of education
- Self-teach – many read at an early age
- Many gifted

Theme 3 - Life Purpose

- Have message for the world
- There is a purpose for being created with disability – Made perfectly
- Life purpose –
 - Educate people about people with non-verbal autism, tell world they are intelligent
 - God's message of love
 - Disability advocate
- Ability to communicate – 'Liberation from a cage'. Can now fulfil life purpose (Sydney, Max, Bella and Brayden)

Theme 4 - Relationship

- Relationship vital
- Family and friends important
- Refer to self as 'we' – Relationship with wider community of people with non-verbal autism
- Relationship with God

Theme 5 - Unique Spirituality

- Spirituality important
- Parents report people with non-verbal autism have spirituality more mature than their own – Irrespective of exposure to religion
- Parents report their spirituality is beyond understanding
- Have knowledge/experience of spirituality pre their ability to communicate – Irrespective of exposure to religion
- Have always known God
- Possible to communicate with God without speech

Research Gaps

- People with non-verbal autism represent a very under-researched group
- No information on their spirituality from their own perspective
- Academic literature only provides gaps for future research
- Must use what literature is available – ‘Non-verbal Narrative’

Implications

- Life experience of non-verbal autistics unexplored – Ability of service providers to understand or advocate appropriately
- Implications for many organisations, service providers, and other community groups as well as faith communities
- Spirituality fundamental to holistic health care and services
- Education, nursing, social work, disability carer roles
- Autonomy, informed consent, socialisation, lifestyle choices, development of personalised communication devices, creative expression, societal acceptance
- Faith communities – Inclusion, enrichment of faith communities

Continuing Research

- Valuable because it will work towards bridging the gap between general society and people without verbal language
- Will expand on the collective understanding of purpose and meaning for people without language
- It is underpinned by academic as well as personal data
- It will have implications for many organisations, service providers, and other community groups as well as faith communities
- May provide a platform for further research opportunities

Next Steps

- Narrative, multi-method (Bricolage) approach
- In-depth exploration of 'Non-verbal Narrative' literature
- Interview data via assisted communication – To identify themes not documented in literature

Interviews

- Unique – never been done
- 15 males and females with non-verbal autism
- QLD literary group
- One-on-one interviews via assisted communication
- Transcription and analysis of data
- Focus group
- Follow up interviews

Emerging Conclusions

- People with non-verbal autism appear to have unique and superior giftedness irrespective of exposure to formal religion
- Unique spiritual insights
- Predominant themes – Love, intelligence
- Want to share insights with world
- Blogs/Facebook richest source of information

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