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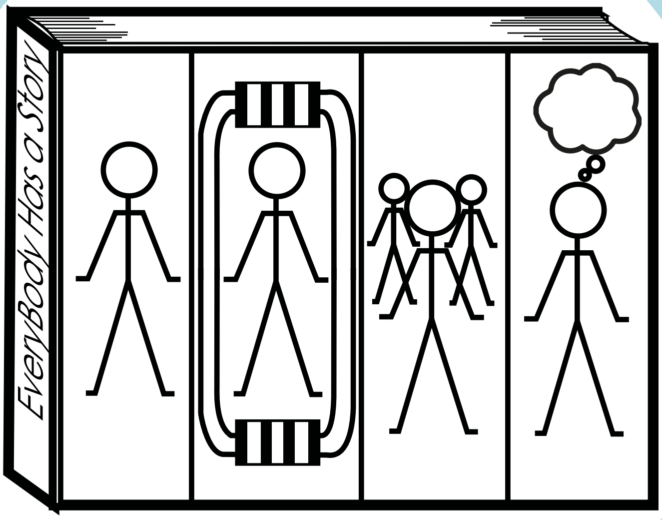
EveryBody Has a Story



Enabling Communities to meet People with Intellectual Disabilities and respond effectively to their expressed Spiritual and Religious Needs and Hopes: A Participatory Action Research Approach

‘This research paper is dedicated to the memory of Sharon, a member of our focus group who died just two months after we completed the focus group sessions’

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Executive Summary

The project entered into research partnerships with People who have Intellectual Disabilities in order to explore the role of religion and spirituality in their lives, with a view to developing effective educational materials and at the same time enabling the development of communities which can effectively meet the expressed spiritual needs of People with Intellectual Disabilities. The study provides religious and non religious communities with currently unavailable knowledge and resources relating to the meeting of the spiritual and religious needs of people with and without disabilities. The structure, content and approach of the study also has the intention of helping to develop forms of community within which People with Disabilities are acknowledged, valued and accepted in every dimension of their lives: spiritual, didactical, relational and environmental (i.e. relating to the nature of the environment provided by religious communities). A unique aspect of this study is that the insights and materials that were produced emerged directly from the experiences of and according to the wishes of People with Intellectual Disabilities who were viewed throughout as co-researchers. As well as enabling access and inclusion, the project provided theological and practical insights which will be of great benefit to religious and non religious communities alike.

The project aimed to achieve the following:

- develop new practical knowledge and understanding of the role of religion and spirituality in the lives of People with Intellectual Disabilities and how this relates to religious and non religious communities, and to use this to develop, implement and assess concrete practical strategies for enabling effective spiritual care and support;

- develop training/educational materials that will enable carers and support workers to understand, participate in recognise and help to facilitate this dimension of the experience of People with Intellectual Disabilities;

- develop a method for mobilising religious and non religious communities to cultivate strategies and ways of being that will enable the full spiritual incorporation and inclusion of People with Intellectual Disabilities;

- contribute to the body of methodological literature that seeks to discover effective ways of communicating and researching with People who have Intellectual Disabilities;

Sample size

Six groups containing 8-10 People with Intellectual Disabilities.

Geographical location

The study took place in London, Kent and surrounding areas.

Ethical Considerations

The study protocol was scrutinised and approved by the Ethics Committee at the University of Aberdeen, Aberdeen, Scotland, UK.

Findings

- Previous research evidence suggests that People with Intellectual Disabilities are often excluded from religious and spiritual activities. The research contained in this report found that they have an intuitive sense of their inner person and a powerful way of expressing this to others. It is often difficult to enter into effective relationship with People who have Intellectual Disabilities, due to language processing and psychological patterns, which can be different from mainstream society. Their lives tend to be void of the meaningful friendships that are necessary if one is to lead a full life. Our research suggests that they experience heightened loneliness, coupled with an urgency to narrate their life story, leaving them in a vulnerable, paradoxical position. The paradox is that the general ethos of the disability rights movement states strongly that they should have a valued place within society and that their stories are important and should be heard, and yet, society in general has no real desire to listen or pay attention. This has left many People with Intellectual Disabilities frustrated, with heightened feelings of rejection and difference.

- The research indicates that religious and spiritual practices, that help to generate correct attitudes and awareness of the positive contributions disabled people bring, has the capacity to provide a solution to the suggested paradoxical situation.

- People with an Intellectual Disability are not enabled by society and institutions to choose the kind of relationships, activities and people with whom they wish to relate.

- This situation occurs for two different reasons:

    1. People with Intellectual Disabilities often have differing language and cognitive skills. This can lead to barriers in communication and to

possible problems with or the discovery of different forms of communication and language.

2. People with an Intellectual Disability can therefore; enter into relationships that are based on *needs* and not on *will*. This situation creates the need for authentic friendships, whilst at the same time putting people in a vulnerable position as the drive for friendship is based on a need rather than a willful desire for relationship. This neediness could place them in a vulnerable position.

- That being so, to enter into an effective agreement and an authentic relationship, the person needs to develop new forms of communicational skills. This, coupled with empathy and a deeper understanding of the spiritual, inner self of people, will create a space for sharing life stories and a possible solution to the paradox.

- To achieve this, a change of perspective must occur: From a culture of care (caring for) to a culture of effective and authentic relationship (being with), that is based on understanding and respect for difference. It is important that differences are not deleted. What is required is ways in which such differences can be accepted and respected within the human story.

- Religion and spirituality are important aspects of such a change of culture.

- People with Intellectual Disabilities have an intuitive sense of their inner being and an urgency to narrate their life story to others. The expression of a person's inner spirit is fundamental to their psychological and spiritual wellbeing.

- It has also been evident that many People with Intellectual Disabilities experience a poverty of opportunity in finding places and people with whom they can express their spirituality, in a way that is both meaningful and authentic. One of the reasons that this poverty exists is that, whilst some people may know *how* to achieve an effective agreement and practice differentiated communication, they may not fully understand why Spirituality and Religious Practice are important for their lives.

- It appears that religious communities have the potential to be able to meet the special needs of People with Intellectual Disabilities in their particular settings and that facilitating attendance fulfils a duty of care. In turn we have found that religious communities may '*understand why'* spirituality and religion are important but may not '*know how'* to make their services accessible to People with Intellectual Disabilities.

- An outcome of our research has been the development of a practical resource/programme, which seeks to create opportunities for the development of effective agreement and authentic, hospitable relationships. This practical Journey provides space for spiritual expression, builds self esteem, tackles loneliness and fosters communities where all people belong, no matter their ability or cognitive skills. Opportunities to engage in the life stories of people with disabilities therefore, leads to a spirituality 'of being' rather than 'of mind', 'of presence' rather than 'of ability' and provides an opportunity to be attentive to the other, reciprocal in exchange and to engage in a real, authentic encounter.

Background and Overview of the Project

Recent research has indicated that spirituality is an important dimension of the lives of People with Intellectual Disabilities and one which they desire care and support providers to understand, value and take seriously (Swinton & Powrie 2004; Swinton, Mowat and Baines 2010). This research indicates that religion and spirituality form a significant dimension of the lives of People with Intellectual Disabilities and that People with Intellectual Disabilities want this aspect of their lives to be included in care and support strategies However, the research done thus far has also highlighted the difficulties encountered by many religious communities as they strive to include People with Intellectual Disabilities and to enable access to the central teachings of their traditions. To date there has been little guidance emerging from the UK as to how this might best be accomplished.

The current study is intended to contribute to a deeper understanding of the spiritual issues surrounding People with Intellectual Disabilities as they were involved with a variety of different communities and to develop a resource intended to enable communities to meet the needs that People with Intellectual Disabilities expressed. It utilised an action research method to explore the spiritual lives of People with Intellectual Disabilities with a view to developing new understandings and practical action intended to enable the process of spiritual integration and community development within religious and non-religious communities.

Research Aims

The project aimed to achieve the following:

1. To develop new practical knowledge and understanding of the role of religion and spirituality in the lives of People with Intellectual Disabilities and to explore how such knowledge affects and changes the practises of religious and non religious communities;
2. To use this knowledge and understanding to develop, implement and assess concrete practical strategies for enabling effective spiritual awareness, support and development for People with Intellectual Disabilities;
3. To challenge and facilitate religious and non religious communities to recognise and help facilitate valued spiritual roles for People with Intellectual Disabilities. In so doing, the intention was to discover ways in which *all* people can bring their gifts to their community;
4. To develop materials that will enable communities effectively to facilitate this dimension of the experience of People with Intellectual Disabilities;
5. To contribute to the body of methodological literature that seeks to discover effective ways of communicating and researching with People who have Intellectual Disabilities.

Religion and Spirituality

It is important from the outset to clarify what we mean by the key terms ‘religion’ and ‘spirituality.’ *Religion or religiousness* is defined as participation in the particular beliefs, rituals, and activities of traditional religion. It can serve as a nurturer or channel for spirituality, but is not synonymous with it. *Spirituality* is more basic than religiousness. It is a subjective experience that exists both within and outside traditional religious systems. Spirituality relates to the way in which people understand and live their lives in view of their core beliefs and values and their perception of ultimate meaning. Spirituality includes the need to find satisfactory answers to ultimate questions about the meaning of life, illness and death. It can be seen as comprising elements of meaning, purpose, and connection to a higher power or something greater than self.

The importance of both religion and spirituality is that they provide a context in which people can make sense of their lives, explain and deal positively with their experiences and find and maintain a sense of hope, inner harmony and peacefulness in the midst of the existential challenges of life. Whilst recognising the interconnectedness of spirituality and religion, the study acknowledged and worked with a conceptual distinction between religion and spirituality, whilst accepting fully the validity and positive potential of both (see appendices 8 & 9 for a deeper reflection on spirituality that emerged from the project).

Geographical location

The study took place in London, Kent and surrounding areas.

Ethical Considerations

The study was scrutinised and approved by the Ethics Committee at the University of Aberdeen. The documentation for this is found in appendix 11.

Informed Consent

There was an initial meeting to invite people to take part. All participants were assured that participation in the research was voluntary and that they could withdraw at any time and that there would be no negative consequences to them doing so. People were assured that all data would be handled confidentially and that it would not be possible to identify individuals from the results. All of this was incorporated in a standardised letter of informed consent. With regard to those who were not able to understand or process formal consent forms, information and consent forms were prepared in a differentiated format using symbols, using Makaton and Widgit symbols. Proxy consent was not used.

Design and Methodology

The study utilised a participatory action research method which located itself within the general structure and ethos of person centred approaches. As such the study sought to meet the five key features of Person Centred Planning (PCP), specifically as they related to spirituality and religion:

1. *The People with Intellectual Disabilities who participated in the project were viewed as at the centre of the research process.* Ensuring their values and rights, maintaining their independence and facilitating choice were key guiding principles.
2. *Family members, care and support workers and friends were assumed to be full partners in the research process.* Accessing and effectively facilitating these networks in the pursuit of the person's goals was seen as vital to the research process.
3. *The study focused on what is important to the people involved now and in the future.*
4. *The study made a commitment to action intended to enhance people's quality of life.*
5. *The project entailed an ongoing process of listening, learning and action aimed at enabling People with Intellectual Disabilities to get what they want out of their lives.*

In this way the project contributed to achieving the goals of the *Valuing People* document and the person-centred emphasis that are central to its recommendations (Department of Health 2001).

Practical Theology

The study was located within the discipline of Practical Theology. Practical Theology is a reflective, action oriented discipline that works at the interface between theory and practice, seeking to challenge and motivate religious communities to respond to the implications of their faith traditions and practices as they interact with wider society. We might define practical theology as: *theological reflection on the practices of the Church as they interact with the practices of the world with a view to enabling faithful practice* (Swinton and Mowat 2006). Practical theology draws on a variety of disciplines (in this case action oriented qualitative research) in order to engage in forms of theological reflection based on a cyclical/reflective movement from practice-theory-practice, with a view to developing new forms of practice that will enable religious communities to minister more faithfully. The current study used a qualitative research method within the framework and goals of Practical Theology.

Participatory Action Research

The particular mode of qualitative research used within the study was *Participatory Action Research* (PAR), which can be described as a family of research methods which simultaneously pursue action (or change) and research (or understanding) at the same time (Hudson and Bennet, 1996; Hart and Bond 1995). A key feature of action research is that it is *participatory*, i.e. it fully includes its participants, in this case People with Intellectual Disabilities. Rather than being the objects of research, participatory research encourages participants to become co-researcher with responsibility and ownership of the process and the findings.

Participatory Action Research seeks to discover new practical knowledge (i.e., knowledge which is aimed at action) that will enable and facilitate change. To enable this process of knowledge generation and change, action research uses a cyclic or spiral process which moves between action and critical reflection on that action, with a view to initiating and sustaining effective change. As the reflective cycle progresses, the method is continuously refined and data and interpretation revised and re-thought in the light of the understanding developed in the earlier cycles. In this way knowledge is assumed to be an emergent process which requires, shapes and is shaped by reflective action and which takes shape as understanding increases. It is an iterative process which converges towards a better understanding of what happens. Action Research assumes *collaboration*, *partnership* and *community*. The researcher enters into partnership with the person or people whose life experiences are being explored; ownership is shared and all parties are responsible to one another for the development and authenticity.

The action research process as it worked itself out in our study moved in a cyclical/spiral manner through four primary stages:

1. Exploration
2. Planning
3. Action
4. Reflection

Exploration

The exploration phase comprised of spending time with People with Intellectual Disabilities through the formation of focus groups designed specifically to explore issues relating to spirituality and religion. These groups were held at various locations across the London area. The focus groups were intended to be a context for the exploration of spirituality within which the team could seek out and listen carefully to the ways in which people described spirituality and the types of approach that might enable spiritual fulfilment. This enabled an in-depth exploration of the issues and provided vital baseline information upon which the remainder of the study was built.

Planning

The planning phase emerged from the provisional explorations and related to processing the information that we had gathered and beginning to work through and develop the themes and inferences with a view to enabling deeper understanding. Out of this reflection we began to examine ways in which we might develop materials to enable communities effectively to incorporate the expressed religious and spiritual needs of the people we had spent time with. Here the formal goals of the project were established and a plan for meeting these goals developed.

Action

The action phase focused on the development and provisional implementation/testing of materials designed specifically to enable communities to understand and share in the spiritual experiences of People with Intellectual Disabilities.

Reflection

The reflective phase comprised of reflection on the efficacy of the work that had been done and the accuracy of the insights that had been gathered. This reflection drew us back to stage one (i.e. as a prelude to further planning) and helped us to begin to re-assess and re-think things leading to changes in phases 2 and 3. In this way, an ongoing process of action and reflection was developed.

Exploration Stage: The context for exploring spirituality with People who have an Intellectual Disability; gaining a baseline of information for the study

After a rigorous training in qualitative research we reflected upon and interacted with the methods for conducting focus groups[1] within a social research field suggested by; Morgan, Krueger and Casey.[2] As we planned however, we realised that gathering information from People with Intellectual Disabilities within a focus group setting needed a form of interview which enabled the moderator to interact, differentiate and communicate with the person they have in front of them. The model we devised, whilst mainly based on Kruger's guidelines, was designed to meet the needs of People with Intellectual Disabilities through a differentiated structure that would enable freedom of expression and release the abilities and communication processes of People with Intellectual Disabilities.

Our process of interview was designed to provide a space for social interaction rather than one to one interaction with staff or authoritative figures. As a team we wanted to design a process which would enable the focus groups to function at a cognitive and a symbolic level and enable the research team to gather insights and information in differentiated formats.

The focus group model fitted well within the community setting in which People with Intellectual Disabilities lived and learned. In all cases this was a relevant and familiar environment. Our aim was to determine the similarities and differences within the ideas and needs of the participants.

Developing the focus group sessions

Based upon the reflections of one of our research partners[3], a man with Asperger syndrome[4], we worked with the concept that he developed as he sought to understand the difference between spirituality and religious practice. He had explained that he felt that Spirituality was: 1 *the* ***experience*** *of myself inside and life* and religious practice was: 2 *the* ***expression*** *of how we show what we experience*.

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[1] "A focus group is a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, nonthreatening environment. It is conducted with approximately seven to 10 people by a skilled interviewer. The discussion is relaxed, comfortable, and often enjoyable for participants as they share their ideas and perceptions. Group members influence each other by responding to ideas and comments and discussion." (Krueger, R. A. (1988). Focus groups: A practical guide for applied research. Newbury Park, CA: Sage Publications, p. 18)

[2] Morgan David L. (1997). *Focus Groups as Qualitative Research*. Thousand Oaks, CA: Sage Publications. Krueger Richard A., Casey Mary Anne. (2000) *Focus Groups: A Practical Guide for Applied Research*. (3rd ed.) Thousand Oaks, CA: Sage Publications.

[3] This participant was a member of the foundation community at St Joseph's Hendon and a participant of *Live Fully* and the Focus group. He proved to be a very influential force in the research process.

[4] Asperger's syndrome is a condition on the autism spectrum: a disorder affecting a person's socialisation and communication skills .

Our experience of teaching, developing and sharing the foundational course: 'Live fully' (See App. 1) was that the people with disabilities had taught us different ways of teaching and translating knowledge.

Difference had become the motivator and bench mark for transcendent knowledge (a knowledge that allows you to move forward and to go beyond what you already know), and for a mutual experience of spirituality. We therefore discerned that, if we were to create an effective model for the focus group and subsequently develop the educational material, it had to be enlightened by 'difference'. In this way we hoped that our final outcomes could authentically make a difference to the lives of people with disabilities and the way in which others interact with them.

We discerned that the following factors were vital in the development of a model for gathering information within a focus group setting. We needed to:

- Create a way to gain an insight into what People with Intellectual Disabilities know about life, spirituality and religious practice.
- Create the opportunity to learn and challenge what connections and similarities occur within the answers (as well as the differences).
- Provide opportunities for self expression and choice making.
- Note the importance of spirituality as the People with Intellectual Disabilities begin to express themselves within the human story and in turn begin to develop valuable ways for meeting their spiritual and religious needs.
- Record authentically and not in an interpretative manner.

We discussed the need to ask direct, open ended questions, about spiritual and religious experience. We decided that all groups had to be asked the same questions and that the ones we set, concerning religious practice, should not be written in a way that indoctrinates but that enables freedom of expression. We therefore ensured that the questions we prepared should be totally unbiased and not make assumptions about religious practice but allow for free expression. We then began to plan for the focus group sessions.

We agreed that, based on the 'experience and expression' concept and by taking an initial look at the questions and the setting of themes, we would develop the session so as to enable experience and expression and also to move from the self to an outer dimension. This movement was partly suggested to the team as a result of a free interpretation of the definition of spirituality that we had initially adopted as our working model[5] (Swinton 1999). The following models were proposed:

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[5] Swinton defines spirituality in this way: "that aspect of human existence that gives it its 'humanness.' It concerns the structures of significance which give meaning and direction to a person's life and helps them deal with the vicissitudes of existence. As such it includes such vital dimensions as the quest for *meaning*, *purpose*, *self-transcending knowledge, meaningful relationships, love* and *commitment*, as well as the sense of the Holy amongst us." (Swinton, J. 1999a, "Reclaiming the Soul: A Spiritual Perspective on Forensic Nursing," in *Forensic Nursing and Multidisciplinary care of the Mentally Disordered Offender*, Robinson, D and Kettles, A eds. Jessica Kingsley, London, pp. 113-127.)

Model 1

Session 1	***Session 2***	***Session 3***	***Session 4***	***Session5***
Spirituality Experience of me and life Symbolic activity	Spirituality Expression of Me and people Questions	Religious practice Experience of me and church Symbolic activity	Religious practice Expression of Me and God Questions	Consolidate Information

Model 2

Session 1	***Session 2***	***Session 3***
Spirituality *Half session* *Symbolic activity* *Half session Table work* *Consolidate*	Religious practice *Half session* *Symbolic activity* *Half session* *Table work* *Consolidate*	Consolidate *Gather information* *Refine* *Produce final answer sheets and final statement*

Model 3: *From self to outer dimension*

Session 1	***Session 2***	***Session 3***	***Session 4***
Spirituality Ask questions and gather information in a symbolic manner A letter to world **You and world**	Spirituality Feedback Ask questions and gather information in a symbolic manner **You and others**	Religious practice Ask questions and gather information in a symbolic manner **You and your faith**	Feedback Consolidate Refine Produce final statement A letter to world **You and others in practice**

Having debated the possibilities and challenges of the three models above we decided that model three would enable us to ask the necessary questions and give participants time to recap and express their thoughts and needs. We decided that we should make a *letter to the world* as the research would have an international audience and that the letter would be a symbolic expression of the ideas and perceptions of participants, concerning their lives, spirituality and religious practice (see appendix 6). It was decided that the last session would be totally devoted to consolidating participants' ideas and at the same time provide a format for full and free expression of all the data they would provide us with. It became evident that, as such, this final session would facilitate a way of advising the research team of the 'all-things-considered' question identified by R. Kruger and M. Casey (2000 pg 45). Our aim was to discern what the participants identified as the most important message for the research outcomes (ibid pg 46).

The process we followed in ten steps; seeking out and listening carefully

Step 1: Training and reflection

After the initial training and reflection upon the process for running focus groups, we made decisions about the categories and criteria we would set for the recruitment of Focus Groups and research communities. We decided that our sample group would be People with Intellectual Disabilities; 16 years and above. Within this we made no other criteria as we felt that we needed to explore the reality of meeting the spiritual and religious needs of any person, no matter their cognitive or physical abilities. In this way we felt that the research would be able to explore what is and what is not realistically possible within communities.

We realised that, if we were to gain insights from the lives of People with Intellectual Disabilities, we would need to identify where to recruit 'rich target groups'[6] from. We tried to discern the main areas of life experience of People with Intellectual Disabilities by developing what we named 'The Cycle of Life Experience' (TCLE Please see appendix 3:) Additionally, we hoped that this would mark the main areas of transition and change within their lives.

Step 2: Choosing the focus group and research communities

We approached each community personally and explained to them what we would be doing and the reason for holding focus groups. We followed this with an email which gave a simplified abstract explaining the purpose of the research alongside its planned outcomes and benefits.

A parish community agreed to participate but after reading the abstract, withdrew due to the fact that they had too many things planned for the year. Following directives given by the team, the participants were decided upon by the community representatives, who personally invited them to take part. This was followed by a confirmation email with dates and times for the groups.

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[6] By this we intend; a target group that it is presumed will be a useful source of information.

Originally we decided to invite four communities to be focus groups but due to lack of time and large amount of data, which we felt would be produced, we reduced this to three. This gave us a sample group of twenty People with an Intellectual Disability.

Step 3: Decisions and differentiation

Our project manager, Professor John Swinton, suggested a possible questioning route[7]. From this we had a discussion about the formalizing of questions, which would better render the content accessible to People with Intellectual Disabilities. We then made the final decision concerning the model and number of sessions we would hold (see below).

Step 4: Developing of possible questioning route

Using the abstract of the research and focusing on the distinction between spirituality and religion, as stated in the project prospectus, we used the suggested questions as a guideline. We then developed two categories of focus group questions:

1. Spirituality
2. Religion

Within each category the movement was from self to outer dimension. We divided the two categories into six sections; three concerning 'Spirituality' and three 'Religion':

Spirituality

1) You and your life
2) You and the world
3) You and the holy one

Religion

1) You and God
2) You and your faith
3) You and your faith

Step 5: The questions are finalised

The team discussion produced the final questions, but the six themes were reduced to five, due to the decision to have only one question concerning the faith community. In this we hoped to focus on the individual rather than give too much emphasis to the social perspective:

Spirituality

1) You and your life
2) You and the world
3) You and the holy one

4) You and God
5) You and your faith

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[7] A questioning route is a set of questions developed for the focus groups to standardize qualitative data collection. The questioning route was developed according to Krueger & Casey (2000), and used a series of open-ended questions and pre-planned probes to enhance detail and understanding throughout the discussions. (Krueger RA, Casey MA: Focus Groups: A Practical Guide for Applied Research**.** 3rd edition. Thousand Oaks: Sage Publications; 2000).

Step 6: Refining the structure for focus group sessions

The questioning route line for questioning was divided into three sessions and the fourth session, as stated above, was designed to give participants the time and space to recap and consolidate the data from previous meetings. The sessions were divided as follows:

Session 1: You and your life + You and the world (part one)
Session 2: You and the world (part two) + You and the holy one
Session 3: You and God + You and your Faith
Session 4: Recap, Consolidation, Refining of Data

The structure of each session was proposed and discussed with the whole team. However, after we had conducted the first session in the school, the participants had expressed so much about their lives that we decided to restructure for the next focus group community; this followed the cyclical nature of action research as mentioned above, drawing upon collaboration, partnership and community. We felt that we needed to give the necessary importance to self expression, so the first session became exclusively focused on the lives of participants. This was the format that worked well and was maintained throughout our work in the subsequent communities;

Session 1	Session 2	Session 3	
You and your life	**You and your world** + **You and the holy one**	**You and God** + **You and your faith**	**Recap** + **Consolidation**

Step 7: Developing the method and differentiated resources

We decided to use the educational process, for mediating the session's content, which was developed by Cristina Gangemi in 2006 and named the 'MEET'© process (Please see appendix: 2). This process was designed for the purpose of accessing and mediating faith based issues. It was then modified in order to meet the needs of the research project and translated into a session plan for the focus group activity.

The above process provided the mediator with the same format to follow for each session and enabled all other team members to keep hold of their roles within session and make structured observations (see below Step 8).

Further team discussion included the development of differentiated resources which would render the questioning route accessible to People with an Intellectual Disability. We finalised the questions and the design of resources so as to support process. This included the letter, which took the form of a giant poster with four large circular links (appendix 6.3). We then developed question sheets to support the asking of questions (appendixes 6.1 see below Step 8).

Step 8: Applying the 'MEET' process to the focus group session

We visited the focus group venues and set the room up prior to the arrival of participants. The room was set up in the following way;

- The chairs were set out in a semi circle facing the interactive whiteboard or plain wall so that participants could see the projected questions.
- A large envelope, with an image of the world on the front, was evident throughout the session. This envelope was to hold the *letter* from participants with their answers.
- The music CD player was at the side of the moderator.
- The silent observer was sat at a table to the side of the participants.
- The moderator was facing the participants and had the projected questions behind her.
- Before the session began all the resources; question sheets and links[8] were visible on a table behind the participants.
- The resource manager, scribe, was sat at the end of the semi circle, ready to facilitate the use of resources and scribe the answers.

Using the MEET process as a session plan ©C Gangemi 2008

M: The sessions began with a piece of music being played and this was either chosen by the team or by the participants. In the first and second session at the school, the songs were linked to the message of the session[9], after which participants chose their own music. In the initial session we explained that they would be making a '*letter to the world'* and that this would form a very important message concerning the lives of People with Intellectual Disabilities. We also explained the purpose of all the resources and how they would be used. We explained that many people would receive this message and that we hoped it would make a difference to people's lives; by saying this we were presenting the purpose of the research and the aims of our visits. The sessions began by people saying something about the past week and generally setting themselves at ease.

E: This was followed by a PowerPoint presentation with pictures that helped participants focus upon the areas that the team would be asking questions about. After this the questions sheets and links were given out and explained to participants.

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[8] Each person had a laminated sheet of paper that held the question on a strip, a small mirror card and a name strip. The mirror was to support those who could not read and symbolised the giving of personal answers which was also reinforced by the use of name strips for those who could read. Metal links, in the form of a key ring, had widgit/Makaton symbols attached that visually explained the theme of the session. Each week a new and relevant link was added. This remained a keepsake for the participants and assisted them to process the themes.

[9] *Bob Marley: 'This is my message to you'* and The Beatles*: 'With a little help from my friends'*

E: The questions were then projected and asked one by one. Each participant was invited to answer and the moderator was constantly assessing their communication needs and responding accordingly. As each new question was posed, the strip with the finished question was removed from the question sheet and collected up. This symbolic action was to identify that answering *that* question was over. After this the subsequent question was given out and stuck onto the sheet. As each person and their communication system became evident, differentiated techniques for communication were applied;

An example of this is:

> *"One participant had a very challenging stutter and we had been told that it would be difficult for her to communicate verbally. Cristina noted that if she stood too far away from her she had more difficulty even vocalising a sound. Cristina then moved close up to her to see if she may be happier to vocalise but she realised that being too close caused too intimate a feeling in the participant. She then moved slightly back and suggested that she was leaving a gap for the participant to drop her voice into. This was followed by a visual movement of the hand and proved to be the stimulus for the participant to provide a whole sentence answer."*(FG 2)

And,

> *"With another participant, Cristina used the visual movement of putting the question into her hands and giving it to the participant. She then asked her to put the answer back into Cristina's hands. Again this had a positive effect and enabled vocalisation and choice making."* (FG 3)

These techniques were used for every subsequent question and within each session. Other techniques used were; Makaton signs, widgit symbol supported text, drama, choice making, rap music and composition of music. All these techniques enabled the participants to contribute their thoughts and answers.

T: Once the question time was over the resource manager would visually place the scribed answers in the large envelope and the moderator would ask: *"Have you got all of the answers on the sheet'; the answer was 'Yes, they are all here and I am putting them in the envelope".* In some cases we asked the participants to place their own answers inside the envelope themselves. The purpose of this visual and audio cue was to mediate and reinforce the idea of a letter being made and a message being given.

We thanked the participants for all that they had contributed and told them that we would reflect upon their answers during the week. We visually pointed to the letter to show them how much they had told us and how much more we knew about their lives and ideas. Throughout the whole session the silent observer completed the feedback and statistic sheets and watched the body language and response of the participants.

This same process was practiced for every session so as to build confidence and to instill continuity in practice. In the second and third session, during the **'M'** section and before we moved to the '**E'** section, we would recall and consolidate participants' answers from the previous session. We did this by;

- Placing images that represented their answers on the wall in front of them. This was accompanied by the poster (*the letter*) which was ready for them to consolidate their choices.
- We then explained the link between the image on the wall and their answers. Participants were invited to come forward and choose images that represented the most important answer they had been given and the message they would like to share with others.
- They then stuck their choices in the link on the poster.

The fourth session continued to follow the MEET process but no more questions were asked. This session was purely to refine their choices and make the final poster, indicating the most important message they wished to share.

The 'what is the most important' process[10] provided the participants with a visual representation of the personal 'pillars' in their lives; the relationships they had with themselves, with others, with the world and with religions. Additionally, it provided the team with strong themes for the analysis process.

We also used another method, alongside the poster, for expanding 'the most important message'. In two of the focus groups, with a generally, younger age group of participants, we used the medium of music. We created a tune to which the participants had to add ideas and words that corresponded to their refined choice. One student from the school even made up his own rap and created a song that totally reflected the areas he had identified as most important in the poster.

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[10] Based upon the ' all things considered' question identified by R. Kruger and M. Casey (2000 pg 45)

Planning Stage : Moving from focus groups to research communities, meeting the formal goals of the research project

Recruiting the research communities

The school, which had participated as a focus group, was also keen to participate as a research community. Therefore a different group of young adults, who were classmates of the focus group, became our first research community. At the same time, we had also recruited a parish community which would help us discover the reality of running the EHS Journey within a religious setting. Having two research communities in place, we began to search for two other communities, a secular residential home and a day centre, as set out in the criteria for recruiting research communities and in keeping with the TCLE that we had established in the exploration stage.

Having followed the same method of recruitment as we did for the focus groups, we found that we had hit a stumbling block. We approached thirty residential homes and two day centres within the South London and Kent area. Three of these were interested and we followed up the phone call with a recruitment email and the abstract. As we introduced the project we found that the mention of spirituality was generally responded to by commenting that most 'residents went to a local church' (May 2009) or 'that they were not very interested in religion' (May 2009). We therefore explained that we were not only focusing on religious practice and that our aim was to gain insights from the People with Intellectual Disabilities which would help us explore spiritual and religious needs within their life. Unfortunately, all but one community responded negatively to our request and the refusals came in the following, common, responses:

- 'The residents have too much going on';
- 'We would not be able to organize this';
- 'We do not want to pry into beliefs';'
- 'I am sorry we are not interest'.

No response at all was forthcoming from the day centres.

The one secular, residential home, that did agree to participate, did so as a result of a previous negative experience. The house manager explained that whilst being welcomed by a local religious community, the People with Intellectual Disabilities were given a cup of tea and sat in the hall, whilst the community worshiped in the church. He stated that our project may provide insights from his clients that may help him in the future.

Analysing the focus group data, enabling deeper understanding, developing materials for expressed spiritual development and religious practice needs

Having three research communities in place we moved to the analysis of focus group data[11]. a result of the analysis process some common themes emerged that gave insight into the life and experience of the People with Intellectual Disabilities who had taken part in the focus groups. These were then reflected upon and a table of themes was produced[12]. We then returned to the proposal and reflecting upon its aims, we began to identify how the themes that had emerged from the focus groups may be used within the creation of the teaching material. It became immediately apparent that a journey would achieve the purpose of assisting communities to encounter People with Intellectual Disabilities and begin to meet the needs they may express. Alongside the difficulty we were having in recruiting a fourth research community and becoming aware of the reality of having to write, prepare, produce, run and refine a four session Journey, we decided to mirror the focus groups and agreed that we would only hold the research in three communities rather than four. As we began to work with the data and reflecting on the spiritual experiences that had been expressed, we began to question the spiritual concept 'from an inner to an outer dimension' with which we had been working (see appendix 8. We began to discuss the fact that the themes and the answers that had been given did not show a linear progression from an inner to an outer dimension ending with the sense of holy amongst us. Indeed, the experience of an outer dimension always seemed to relate back to the concrete life experiences of the participant and made them think and feel differently about themselves and those around them.

This shift occurred due to many of the focus group participants commenting that answering questions and expressing on their life left them feeling different, usually in a positive sense, about themselves. These are some of the comments as expressed by the participants themselves:

- 'I like this, it makes me feel my body' (RC 2)
- 'I like this, it makes me feel confident' (RC 2)
- 'I have never done this before, it's nice' (RC 3)

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[11] The method adopted at this stage of the research is based on the *long-table approach* as described in Krueger and Casey (*Focus groups. A practical guide for applied research*, pg.132)

[12] Themes : Friendship; Love; Dislike of Injustice and violence; A sense of humanity; Enjoyment of life; Hope for the future; Self-awareness; Daily activities; Understanding and living changes; Urgency to narrate their story; Sense of Belonging; Living in the world; Freedom to express belief (Not necessarily religious);

Planning the Journey

Using the themes and the insights from the focus groups we then began to plan the Journey. The main theme that seemed to emerge as an implicit, fundamental one embracing all, be it through body language or verbal expression of participants, was ‘an urgency to narrate one’s story’. (See appendix 10)

The way in which questions were answered revealed a ‘narrative core’[13] which was to be the foundation of the Journey we were to develop. This ‘urgency’ became the building block for the Journey we had identified as our natural outcome and necessary resource.

We began planning the Journey by reflecting upon and identifying its general aims, both for participants and the communities to whom this Journey is primarily addressed. At the same time based upon what we hoped to achieve from the Journey, we identified a series of general aims for participants;

General aims for participants

The activities planned will facilitate and support participants to:

1. Express their feelings and thoughts
2. Strengthen their ability to respect and empathize
3. Develop positive and inclusive social interaction
4. Explore their own personality and being
5. Build up their confidence and self-esteem
6. Express themselves through art, music, drama
7. Explore their creative and practical skills
8. Narrate their life story if they wish
9. Create a tangible resource that will support them (as they share their story)

Our next step was to begin to identify the main areas we wanted to focus on within the four sessions of the Journey we were about to create and conduct. We all contributed to this by proposing different ideas concerning what the general purpose and title of each session would be:

1. **Session one: Me and Myself**; this session was to focus on an exploration of the self, the person and their physical features, so as to begin a journey of self-discovery where participants would have an opportunity to begin to narrate their story.

2. **Session two: Living My Life**; this session was to focus on how participants live and perceive themselves in the world. The idea was to provide a space for them

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[13] Narrative core: by this we mean that as the questions were answered the participants seemed to share so much of their life story that it ceased to be a question and answer activity but became a meeting place where they shared their story, asked us about ours and then referred their story back to other people in their lives.

to begin to express about their life and how they react and interact within the world. The title of this session was subsequently changed to ‘Living my life’, for two reasons. The first was that some of the participants, as shown in the focus groups, may have a concept of the ‘world’ as being a reality within the context of their own immediate surroundings. The second was because we felt that ‘living my life’ was more in keeping with the telling of a personal journey.

3. **Session three: My Life with Others**; this session was to focus on the social interaction of participants and their core beliefs; what gives meaning and purpose to their lives. The title of this session was subsequently changed to ‘Me and others’. This was due to the fact that, having devised a process for creating sentences, which would enable simple processing of language (ASPE), we felt that the word ‘value’ may prove to be a challenging concept for People with Intellectual Disabilities. We therefore decided that the title ‘me and others’ would encourage people to express how they interact in the world and that, as we explored their story and how they live with others, their personal values may emerge naturally.

4. **Session four: My Needs and My Hopes;** this session was to focus on the needs and hopes of participants. Our aim was to provide activities that would enable the expression of relevant choices and desires in regards to their lives. This was considered a transcending session where participants had the chance to move forward and gain spiritual awareness and confidence by sharing about their needs and hopes. The final title of this session was therefore ‘ My hopes and my needs’

The format for the EHS journey was therefore:

Session 1 : Me and My Life

Session 2 : Living my Life

Session 3 : My Life with Others

Session 4 : My Needs and My Hopes

Once the main purpose of sessions was agreed on we went back to the themes and began to wonder where they would fit in within the initial vision we had for the Journey. Our clear intention was to make sure that we were building the Journey on the foundation of the focus group and according to what emerged from the data collected; the themes were therefore arranged into four sections according to the purpose of each session and then transposed into the format of a cycle. (Please see appendix 4:)

Informed by the new understanding of spirituality, which had emerged from the focus group experience, the cycle seemed to end where it began, with a *re-turn to the self*.[14] This 'back to the self' concept was a fundamental insight and was threaded throughout the whole research process. It had an essential role in the development of the purpose and philosophy of the Journey. The radical change we experienced in the way we understood spirituality had therefore a fundamental influence in the shaping of Journey. This shift from a linear concept of spirituality to a cyclical one (see appendix 8) had a quite profound influence upon the planning of the Journey and a major influence in how we structured activities as well as the creation and development of resources.

Based upon the themes from the focus groups, and following this same cyclical format we then created a set of aims that were specific and corresponded to the purpose of each session. Due to the positive and conducive experience with the focus groups, we also decided that we would continue to use the MEET method as the format for mediating sessions.

We decided that the four sessions would be proceeded by an hour long 'getting to know each other' session. The purpose of this was to enable the participants to get to know the research team, as well as each other, become familiar with the environment and the MEET process. For us it would facilitate an encounter, and enable us to make an initial observation of their communication, cognitive and motor skills. Keeping in mind the target audience[15] for the Journey, we then reflected on a possible model. We created two possible models that we felt might work. We then listed the benefits and challenges that each model would present us. We decided on the model that seemed to be the most beneficial for us and eventually, those who would use this Journey.

At this point, having in place a series of aims, a number of themes, and strong insights from the analysis (narrative core, turn to the self, cyclical model) we began to imagine the sort of Journey we could develop. Our research had resulted in the strongest theme being an 'urgency to narrate one's story'. We had discovered that, in doing so, one began with the self and returned to the self; we therefore decided that any Journey would have to hold this at its chore. We subsequently developed a Journey that was designed to enable people with disabilities to experience their own personal story and express it to others. It was important for us that the Journey would enable communities to really *get to know* the Person with an Intellectual Disability through their story; the main purpose of this 'new encounter' was to encourage and inspire communities to make the necessary adaptations to their practices and resources so as to meet the expressed hopes and needs of People with Intellectual Disabilities. The important aim of the Journey was that it would enable a response from others so that the Person with an Intellectual Disability would be able to experience equality within communities. The

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[14] When we speak of a 'return to the self', we intend that, exploring one's life in its various dimensions, is as way of gaining new experience, self-esteem, confidence and awareness.

[15] The term 'target audience simply means; the people for whom the groups were designed and intended to facilitate.

Journey was therefore designed to provide a possible way of meeting others through the participants' own personal storytelling of their life.

We then discussed which title would better present and re-present the Journey and all agreed that it needed to reflect the main theme and outcome from the focus group (narrative core and urgency to tell one's story). We therefore simply followed the message, which had been portrayed throughout our experience of the research; that *EveryBody Has a Story and that each story is a precious opportunity and a valid way of knowing and meeting the person behind it.*

Running the Journey in the Research communities; following a cyclical process of action research

We began to run the Journey *EveryBody has a Story* in May 2009, beginning with the school, followed by the parish community and then the residential home. On the week that we were to hold the 'pre-course' session, the manager of the secular residential home, informed us that the home was closing and that the residents, after twenty years together, were going to be separated. This also had a profound effect on our planning as we realised that many 'life changing decisions are 'formed' for disabled people and that often their story becomes lost in organising and meeting needs' (Team discussion June 2009).

We also agreed, following our conversation with the house manager that 'very little is done to support transition' which is a reality that we had already encountered from focus group responses, where change and transition had seemed to be a constant issue. This discussion affirmed the way in which we had carefully but purposefully built 'change' into the Journey philosophy and its practical activities. Loosing this community left us in a difficult position as we now only had two research communities. Considering the negative response that we had experienced in recruiting communities, Cristina Gangemi approached a home that was founded by a religious group but whose clients were inter-religious. We found the home keen to participate and fortunately they responded to our invitation within a day. We booked dates, confirmed by email and carried on planning.

Action Stage : Implementing and testing the resources and process for EveryBody Has a Story© 2010; Enabling communities to understand and share in the spiritual experiences of People with Intellectual Disabilities

The Journey was then implemented within the research communities. After each session and based upon the comments and interaction of our research partners,[16] the team would reflect and refine the Journey method, content and resources.[17] . In doing this we relied heavily on the idea of moving from experience to reflection and back to experience as we tried to fully understand what was going on. As knowledge was gathered and tested, we made practical and theoretical changes and refinements, which were to enhance the experience of all involved in the Journey process and its outcomes. The outcomes below will relate the methods, theories, resources and insights gained as a result of this stage.

Reflection Stage: Reassessing insights, making Practical changes, reflecting and recording rich outcomes

In the refining of resources we consulted with two experts within the field of special education and photography: Mr. Mike Harris, a specialist communication consultant, and Andrea Capano, a photographic consultant. The resources and teaching material were prepared so as to contribute to the final outcome of the research; 'A teaching pack' and interactive DVD. Following this ongoing, dynamic process of research produced copious data. Once all the experiential work had been completed, the team began the process of recording the numerous outcomes, which had been a result of attending to and encountering the experiences and insights of our research partners; People with an Intellectual Disability. The outcomes that are to follow present the wisdom and insights of all who have been involved in this research process

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[16] People With Intellectual Disability, who were participants and co researchers :

[17] This was achieved by following the qualitative research method and through the use of feedback sheets, film, written and verbal observations.

Outcomes

Tables of outcomes

The outcomes that have emerged from this research project are numerous. For this reason they have been divided into a system of four tables, specifically designed to enable easy access to the research findings, as well as providing a simple and effective tool for consultation. Each table presents an area and corresponding outcomes, which emerged from the research journey, as shown in the index-table below;

Table of outcome	Title of outcome
▪ Outcomes intended for the people involved in the project **(PI)**	1. *Research team* 2. *Participants* 3. *Communities*
▪ Theoretical outcomes **(TO)**	4. *Shifts in concepts* 5. *Theories* 6. *Processes*
▪ Outcomes emerging from experience and insights of participants **(EP)**	7. *Focus groups; insights* 8. *EveryBody has a Story; insights*
▪ Outcomes relating to the production of resources **(PR)**	9. *Focus groups; resources* 10. *EveryBody has a Story; resources*

Outcomes for the people involved in the project; (PI Table)

This section records the main outcomes that emerged from within the life and work experience of the various people, directly involved in the project or indirectly affected by its outcomes:

1. ***Research team***: this includes the outcomes achieved by the members of the research team as a result of taking part in the project: 'How did the research activities affect us at a personal and professional level? How did they influence our practice and planning?'
2. ***Participants***: this includes the outcomes achieved by participants as a result of taking part in the project as co-researchers: 'What did the participants experience at a personal and relational level by joining in with the various activities proposed? How did they interact with the resources that were presented to them?'
3. ***Communities***: this includes the major outcomes for secular and religious communities that have emerged from the research process.

Theoretical outcomes; (TO Table)

This section records those outcomes that relate to the theoretical foundations of the study (epistemology, spirituality, philosophy, theology). By this we mean: 'the ways in which what we experienced and were told, influenced our theoretical premises and led us to new understanding and the development of new theories':

4. ***Shifts in concepts***: this includes the outcomes produced by conceptual shifts in our perspective. This led us to make major changes to the 'working concepts' and approaches that had underpinned and defined our research premises.
5. ***Theories***: this includes those 'organic thoughts' that spontaneously emerged as we listened and reflected upon the concrete life experience and witness of our co-researchers. As such these reflections became 'active theories' which reflected the interaction and dialogue which occurred during the research.
6. ***Processes****:* this includes the various processes that have been devised throughout the research. These were applied to support and consolidate the understanding and thinking of the team, as well as facilitating our practical tasks when planning activities or analysing data.

Experience and insights of participants; (EP Table)

This section records the main research outcomes which emerged directly from the shared experiences of People with Intellectual Disabilities:

7. ***Focus groups***; this includes the main insights, issues and themes which were gathered from our focused conversations with our research partners who had an Intellectual Disability.

8. ***EveryBody Has a Story (EHS)***; this includes the main insights, issues and themes gathered during the experience of writing and running the four-week Journey 'EveryBody Has a Story', which emerged from and followed the focus group experience.

Production of resources; (PR Table)

This section records the experience of creating, producing and using differentiated resources for this project. These were designed to support communication and self-expression of participants with Intellectual Disabilities:

9. ***Focus groups***: this includes the main outcomes concerning the production and use of resources within our focus group sessions.
10. ***EveryBody Has a Story (EHS)***: this section includes the main outcomes concerning the production and use of resources within the Journey sessions.

List of abbreviations used:

- FG: Focus groups
- EHS: EveryBody Has a Story
- RCN: Research Community N°
- SN: Session N°
- SI: Spiritual Identity
- LSA: Learning Support Assistant
- ASD: Autistic Spectrum Disorder

The four tables: PI, TO, EP, PR

Table PI

(People involved in the project)

1. *Research team*	2. *Participants*	3. *Communities*
a) Professional growth b) Reflective practice c) Empathic relationships	a) Focus group participants b) EHS participants	a) Knowing 'how' but not 'why'; knowing 'why' but not 'how' b) Creative change c) Outcomes for religious communities d) Outcomes for both religious and non religious communities

Table TO

(Theoretical outcomes)

4. *Shifts in concepts*	**5. *Theories***	**6. *Processes***
a) Openness to receive **b) Engage in relationship** **c) Hospitality** **d) Shift in our concept of Spirituality (appendix 8)** **e) Shift in our approach to Disability (appendix 10)** **f) Shift from medical to relational model** **g) Shift from meeting needs to listening to people's story**	**a) Narrative core** **b) Re-turn to the self** **c) Soup theory**	**a) TCLE: The Cycle of Life Experience** **b) ASPE: Aim, Structure, Process, Experience** **c) PPAC: Perceive, Pay attention, Absorb, Communicate** **d) BASE groups ('Beginning to Access Spiritual Experience')**

Table EP

(Experience and insights of participants)

7. *Focus groups*	8. *EveryBody has a Story**
• Themes; a) Friendship b) Love c) Dislike of injustice and violence d) A sense of humanity e) Understanding and living changes f) Urgency to narrate their story g) Sense of belonging • Insights; h) 'Sometimes an apple is just an apple'	a) Outcomes for reflective practice b) Empowerment c) Ownership, meaningful participation and narration of stories d) Transcendence e) Critical empathy and ex-change f) Insights from People with Intellectual Disabilities g) Specific outcomes

*** A quick reference table, which indicates how some of the outcomes from participants to the Journey link directly to other outcomes in the report, can be found at the end of this section. (p. 62)**

Table PR

(Production of resources)

9. *Focus groups*	**10. *EveryBody has a Story***
a) Images and symbols **b) Music** **c) Response of participants**	**a) The Spiritual identity book** **b) Building up relationships through use of photography** **c) Effectiveness of ‘placement’** **d) A flexible format**

The above four tables can be used as a quick reference guide to the outcomes which are thoroughly presented below:

1. *Outcomes for research team*

a) Professional growth: prior to conducting this research, the team members had a varied experience of working with People who have an Intellectual Disability; from very little to extensive. We had indeed had the experience of writing and running 'Live Fully' (appendix 1) and this helped us to imagine the sort of resources and concepts we may need to develop. Conducting the focus groups provided us with a new way of gathering information, adapting activities and resources so as to enable People with Intellectual Disabilities to express themselves and share information about their lives and values. This was confirmed by the positive responses encountered in running the Journey 'EveryBody Has a Story,' which we developed from the focus group experience. The research has had numerous outcomes, for us as a team and for our professional practice. We have:

- Gained theoretical background in how to conduct focus groups.
- Developed and refined our professional skills in assessing and responding to different communication abilities.
- Developed skills in obtaining information from participants who were deemed to have profound Intellectual Disabilities and processing difficulties.
- Developed skills in communicating at a non verbal level by using body language and gestures; with each other and with participants.
- Worked within a structure, the MEET process (appendix 2), and synchronized our practices so as to gather and assess information.
- Discovered important aspects of the lives of People with Intellectual Disabilities and gained insights into their thoughts, feelings and opinions.
- Developed varied differentiation skills.
- Developed skills in refining, analyzing and recording data.
- Acquired skills in conducting qualitative research.
- Become self critical.

b) Reflective practice: often the participants would enable us to re visit our own story and the way that we teach and communicate, therefore calling us to reflective practice**,** which became a vital element within our research practice.

c) Empathic relationships: this way of being in relationship with participants was central to our reflective practice and the way that we then encountered the people we met throughout the research. We realised that, to be open to the person we had in front of us, 'before and beyond' their ability or processing skills, we had to:

a) Empty ourselves of presuppositions in order to gather in the other.
b) Find a common language so as to communicate in such a way that life stories may be narrated.
c) Obtain an effective understanding of the other and them of you.
d) Leaving aside the need to have a 'role' to play within encounter. No loss of the self but reciprocity of being, 'gathering the other' ;

We did not experience a total loss of the self but discovered that empathy is a two way action; in an encounter with a Person who has an Intellectual Disability we discovered that ‘reciprocity of being’ is necessary. In this we intend ‘practicing the importance of perceiving the “other’s” way of being, so as to find a meditative language or form of communication. Within this there is no ‘role’ that one has to play in the exchange. The owner of the more predominant form of meditative language is not the ‘tutor’ as there needs to be recognition of both parties being active. In order to achieve a relationship therefore one needs to discover reciprocity and creative recognition of forms of communication. The challenge we encountered was to find a way by which we could enable the person with disability to form an agreement and for us to recognise their particular ‘action’ within this ‘special’ relationship.

One does not impose their ‘role or intentions’ on a person simply because it seems that they are not able to form an answer but discovers a way by which this person is able to agree or not agree with what you’re offering in that moment. This could indeed be a breath, a touch or even just a silence. Within our research journey, we were given an opportunity to enter into unique and creative relationships with each other, discovering innovative and agreeable ways of expressing the spiritual experiences that we shared as equal human beings.

2. *Outcomes for participants*

a) Outcomes for focus groups participants

I. *Personal growth*:

- Participants communicated to us that it was the first time they were enrolled to take part in a focus group. Therefore one first outcome for participants was that they experienced something new.
- Participants were given an opportunity to reflect upon their lives throughout the ‘journey’ of the focus groups. They responded ‘positively’ to the questions and were able to express their inner thoughts.
- Through the experience of listening and sharing ideas, stories, opinions, with other people they gained social skills and awareness.
- They explored some new areas and heard new words.
- Participants engaged successfully in a process of making and refining choices.

II. Relational growth:

- Participants responded with respect and recognition of the different roles people played (including the research team).
- One major outcome was the capacity most participants showed to be or remain amazed by other people’s answers. The way they interacted with each other and with the team showed a genuine interest in other people’s lives. They would listen to other people’s stories, to each other with ease and enthusiasm.

- They shared sensitive information, showing a very good ability to be empathic with what was being said by other participants. They were respectful of other people's culture and tradition.
- Some of the participants were very facilitating of others answering and supported those whose vocal skills were not very forthcoming or who found difficulty in expressing themselves.
- They did something at an individual level but within a group. They did something together and they built relational skills as a result of this.
- Participants positively engaged in a communal activity and contributed effectively towards its realization, thus showing good cooperation skills.

III. *Importance of social setting:*

Starting the research from within a comparative community setting opened the door to the research outcomes and helped us to plan for future work and promotion of resources. We were able to clearly see if the outcomes were relevant, beneficial and authentic to the experience of the lives of People with Intellectual Disabilities. The social environment enabled the flow of communication and we noticed that the participants were encouraged and prompted to respond and share more than on an individual level. This factor was reinforced by the fact that we conducted the focus groups in established communities where the focus groups were formed by people who knew each other.

b) <u>Outcomes for EHS Journey participants</u>

I. *Personal growth:*

Experience and expression; we have found that the Journey provides a place for friendships to be fostered and expressed. It also holds the potential for People with Intellectual Disabilities, religious communities, families, staff and carers to have a shared experience and discover new and creative ways of expressing all that they share. We found that the Journey enabled all involved to make comments outside those that may usually be expressed within a habitual environment. The concept of 'Experience and expression', that lead to this outcome, grew from the comments of one of the focus group participants who, having completed the activity, told us: 'ah so spirituality is what I feel inside, I experience it and when I go to church I express what I feel, ah I get it'(FG2 ; S1, Research diary CG)

- **Expressing personal opinions**; the sharing of information took place through all of the Journey activities. Participants were happy to share about their lives and also about their observations of world events and the society that surrounds them. Some participants had strong opinions about things that they see and hear and they began to discuss them with the research team.
- **Outward sign of inner awareness**; as the Journey progressed we noted that participants became more confident in expressing themselves and they all seemed to be aware of their personal appearance. They way in which they dressed seemed to take on an importance of its own and our attention would constantly be drawn

towards their physical features or new clothes or jewellery which they chose to change every session. We felt that this could be an outward sign of a heightened inner awareness.

II. Relational growth:

- **Reciprocal relationships**; as participants shared their personal stories we noted that they became increasingly interested in knowing the personal stories of the research team. This was a pattern that formed in each of the communities and the balance between facilitator and participant became an equal and reciprocal exchange of life experiences.
- **Friendship**; the Journey proved to provide an opportunity for a positive outcome both for participants, carers and staff. We noticed that they were able to gently move beyond the realms of staff/clients and service provision. Friendship was a common theme amongst the wishes made for participants in session four of the Journey. In one community, a member of staff, who had worked with participants for many years, commented that: '*You are not my clients, I think of you as friends' (RC3 S4),* This is an important outcome as the life experience of People with Intellectual Disability is that they are often surrounded by paid staff rather than friends. The process of the Journey seemed to give permission and a space for an alternative language to be expressed.
- **Getting to know one another**; as the Journey progressed we had a sense of 'getting to know' the participants and their personal story. We noticed the capacity for friendship. As the Journey drew to an end one of the participants asked if we could carry on and asked if a future session could be about 'friendship'. This suggested that, once one had shared one's story, the next step would be to think about and explore friendship. We identified the fact that the Journey could not be run as a one off activity but that it should be the beginning of a provision and adaptation of services based on an understanding of spirit, friendship and reciprocal relationships.

III. *Importance of social setting*:

- **Interaction between participants**; participants did not seem to be used to communicating with each other. We have observed that the Journey process encouraged and enabled a heightened interaction between peer participants rather than only with the mediator. The fact that the Journey takes place within a social setting rather than an individual activity has shown that this setting has immense value when sharing in the life of a Person with an Intellectual Disability.
- **Interaction between participants and the team**; in the second session of research community two, one participant asked us to write our names in his book; this was an important gesture as it showed a movement from the self to others. We reflected that this, philosophically, might be synonymous with **encounter** as this participant autonomously 'invited us in' as part of his story. *'Calling us by name, at a linguistic level, could be seen as a call for us to be present in his life at a metaphorical level'.*

- **Integrated social interaction**; a large percentage of research partners with Intellectual Disabilities categorically communicated that they want to be included in mainstream, everyday activities. When sharing about social interaction they made it very clear that they do not wish to be involved purely in Disability groups and special services; they want to be able to socialise and have access to groups that are integrated.

3. *Outcomes for communities*

a) **Knowing 'how' but not 'why'; knowing 'why' but not 'how'**: we experienced difficulty in recruiting a secular, residential home as a research community; most not wishing to participate due to a lack of time, not wanting to broach the subject of spirituality or that their residents 'already attended a local religious organisation'. One secular home informed us of the fact that 'on attending church his residents were left in a hall to drink tea whilst the community was in the church sharing worship.' We were successful in recruiting a Christian run home which was an inter-religious group. We discovered however, that whilst there was a church next door, only two participants, intermittently, attended any religious community. Religious communities seemed more enthusiastic to participate in this research however, one parent from one of the communities stated that, her son with autism, did 'not like to go to church and that she felt that no one in church really knows what to do with him'.

   Reflecting upon the above findings facilitated a major theoretical outcome for our research and the development of the Journey EHS; 'It could be that; whilst many secular organisations have skills in 'knowing how' to communicate and differentiate services for People with Intellectual Disabilities, they may not fully 'understand why' Spirituality and Religious Practice are important for their life. They may feel that religious communities are able to meet special needs within spirituality and religious practice and that facilitating attendance fulfils their duty of care. In turn we feel that the religious communities may 'understand why' spirituality and religion are important but may not 'know how' to make their services accessible to People with Intellectual Disabilities.

   This juxtaposition could result in lack of suitable provision and for the Person with Intellectual Disability to experience poverty in access to spirituality and religious practice. EveryBody Has a Story seeks to fill this gap and provide content, structure and resources, which will enable all service providers to explore and provide spiritual care for People with Intellectual Disabilities. EHS will provide the opportunity for participants with Intellectual Disabilities to make choices as to where, how and if they wish to express their spirituality. We hope this will work well alongside people of all faiths and none.

b) **Creative change**: within our research we have noted that one of the most challenging concepts for people, whether they have a Disability or not, is that of change. We would like to suggest that this 'fear of change' could exist due to the lack of knowing 'why' and 'how' change should occur. Our experience of conducting this research has given us new understanding and has led us to change our practice, suggesting that change can occur organically; this we have named ‘creative change’. We have found that change can be a positive force within a community when it’s informed by what we have defined as ‘transcending knowledge’. By this we mean: ‘a form of knowledge that takes the person beyond what they already know but in a creative and informed way’. We therefore feel that this outcome will encourage communities to gain *new knowledge* and that this knowledge in turn will bring about enthusiasm, which will be the impetus for making changes to all that they share and provide for People with Intellectual Disabilities.

c) **Outcomes for religious communities**: having explored in more detail the religious context of the lives of participants through focused questions concerning religious practice (focus groups session three), we identified an outcome which would result in a series of recommendations directed towards religious communities. These concern the environment, activities and resources deemed most appropriate for truly welcoming People with Intellectual Disabilities. The intention here is to explore ways in which a Person with an Intellectual Disability can positively engage in the life, rituals and events of the religious community that they choose to belong to:

- **People with Intellectual Disabilities need to have religious theory translated**; we found that religious theory and theological concepts may be a subject that has rarely been clearly explained in a manner that meets the varying processing skills of a Person with an Intellectual Disability. This lack of understanding emerged as we asked focus group participants what they thought the word ‘holy’ meant. Of all participants, only one person was able to give a relevant answer (focus groups session two). We also asked them what they would like their religious community to do for them and all communicated that they would like to know more about their religion. One participant explained that he would like to ‘have the Koran read to him slowly’. This will have major implications for religious communities who may need to be motivated into exploring new ways of making theological concepts accessible to People with Intellectual Disabilities.

- **Tokenism**; the data from the focus groups and research communities has suggested that religion was important to most participants though not all. However, we did not feel that most people, whilst they may attend religious communities, knew a lot about their faith and that often they had a *learnt language* surrounding their religious practice. This did not mean they did not have a sense of God and a belief in God but that their attendance could have been a sort of tokenism rather than in-depth involvement.

- **A place to belong**; the religious community provides a rich and privileged place for People with Intellectual Disabilities to belong. This can be seen clearly from The Cycle of Life Experience (appendix 3); People with Intellectual Disabilities that live in family, attend formal educational settings, live within a residential home or indeed attend a day centre may all, at some point, potentially attend a religious community. This unique setting, within the cycle, therefore becomes a place of gathering and welcome, giving the Person with an Intellectual Disability the opportunity to belong to a community that is informed and inspired, by its own theology. This, research therefore, presents the religious community with an informed opportunity to welcome and make available all that it believes and teaches.

- **A need for order**; both in the focus group and research communities, participants made it clear to us that they did not like to attend religious services that are too busy or too noisy. There was a clear message that often, quiet and orderly services were preferred over and above a busy family type service. Participants communicated the need for joyful religious practice but also a need for order so as to be able to follow what was going on. This was especially so for those participants on the autistic spectrum.

d) Outcomes for both religious and non religious communities:

- Religious and non religious communities must take time to get to know the person and their personal story. Once the way in which the individual communicates and learns is known, the community should then explore all that they provide and adapt it to meet the specific needs of the person who is part of their community. We have concluded that this must be a real commitment, one that entails 'creative change' so as to make the chosen faith, of the Person with an Intellectual Disability, something with which they can engage and learn about, in their own particular way.

- The aim of the research was to enable religious and non religious communities to meet the spiritual and religious needs, which People with Intellectual Disabilities have voiced as being theirs. We realised that we also have a special focus on enabling religious communities to do this and that, as a result of the research, religion is an important expression of a person's spirituality. Therefore, within the Journey directives we will include focused questions, aimed at motivating religious communities to ask themselves how they can begin to know and meet spiritual and religious needs and desires.

4. *Shifts in concepts*

The experience gained from conducting this research has enabled us to discern that an openness to receive information and to engage in relationship can bring about a *surprise*. The following principles, developed on the basis of our interaction with participants, witness a paradigm shift, experienced by the whole research team, in the way these issues were perceived;

a) **Openness to receive information**: we experienced a shift from a didactical approach, with specific objectives and standardized 'teaching' methods, to being open to receive the person and their particular skills, ways of communicating and interacting. This openness enabled us to truly meet the person, thus providing resources that would allow self-expression and exploration of the inner being.

b) **Engage in relationship**: the experience of interacting and sharing with our research partners, People with Intellectual Disabilities, has allowed the team to reflect on the way we approached the relationships we had formed with them. What we experienced is a shift from a staff-client approach, imbued with a cold, detached attitude of 'doing a job', to an active, engaging person-person, one based on authenticity. This made a real difference to our practice, as this attitude facilitated and reinforced a readiness to share and express with participants; we weren't yet their friends but at the same time we weren't just filling their time, or our own, we were encountering the participants and we didn't hide the enthusiasm we felt. We found that we did not put up barriers, due to our professional role. So as to be able to engage in relationship we needed to put aside the offer-request model and the functional approach that seem to be dominant within the language and fields surrounding the lives of People with Intellectual Disabilities.

c) **Hospitality**: our concept of hospitality has been deeply and radically transformed by the life experience of People with Intellectual Disabilities. One could think that to be hospitable means to have a set of 'fixed rules' that the new person we meet has to fit into; and that the simple fact of opening the door to this person implies that they 'will comply' with our norms or routine. The shift we experienced consists of an overturning of this concept: hospitality, and **hospitable relationships**, begins with the full recognition of the other person and the effort to meet their specific and unique attributes and qualities, skills and capabilities, preferences and choices. It means to embrace, by making the effort to find a key to effective communication. We noticed that any concept of, 'difference between us and them' disappeared and hospitality was a two way encounter of the other. (please see appendix 10)

d) **Shift in our concept of Spirituality**: please refer to appendix 8
e) **Shift in our approach to Disability**: please refer to appendix 10

f) **Shift from medical to relational model**: one important outcome was the shift, experienced by the team and reflected in our practice, from a medical model, centered on what the Person with an Intellectual Disability is able or not able to achieve, due to their disability, to one based on the recognition of their capabilities. We found that, in order to encounter the person, we had to put behind our preconceived ideas about People with Intellectual Disabilities, their medical condition and communication methods. Being open to the person seems to be one of the key issues raised by this research. As a team we always focused on providing effective tools for participants according to what they communicated to us; we didn't have any recipe ready, at hand, but we built the communication material in and on the basis of the interaction with them.

g) Shift from meeting needs to listening to people's story: **from a community being able to meet people's needs to enabling People with Intellectual Disabilities to tell their stories.** This has been a major outcome. The original title of the project, *'Enabling Communities to meet the Religious and Spiritual Needs as expressed by People with Intellectual Disabilities: A Participatory Action Research Approach',* seems to maintain a clear distinction between people with and without Intellectual Disabilities, a 'them and us', reinforced by this focus on someone from outside, the community, being enabled to meet the specific, differentiated needs of People with Intellectual Disabilities. What we realised is that; a fruitful change of practice for communities can only occur if sufficient space is allowed, for their members with Intellectual Disabilities, so as to release and express their needs, wishes and worries, ultimately their story. What the community is asked to do is to be open to that story and to find ways to respond to it: the focus is not on the ability to meet needs but on the readiness and openness that is needed to meet the person and subsequently their expressed wishes and needs. The title of the research has therefore been changed to *'Enabling communities to meet People with Intellectual Disabilities and respond effectively to their expressed spiritual and religious needs'.*

5. *Theories*

a) **Narrative core**: this theory was developed after the experience of the focus groups and became one of the central principles and motivators that underpinned the subsequent work of the team. What seems to be crucial, in the dialogue with a Person with an Intellectual Disability, is the need to create a space for them to express their own story rather than having it voiced by other people, who may project their own personal opinions. The ***narrative core*** is an expression that well defines 'the possibility to interact and to lay personal expressions and communications within a narrative frame', which is something that inductively emerged from the experience of participants. This was vital and enabled participants to take ownership of their story and have pride in sharing about themselves, with the team and even more significantly with other participants.

b) **Re-turn to the self**: as we analysed the focus group answers we noted a relational element that continued to arise 'spontaneously' and which became central to the research process. Further reflection led us to an understanding of spirituality whereby the spiritual side of one's life is not detached from material world and bodily experience but is inextricably connected to them. An example of this connection between the two spheres is this comment from one of the focus groups participants who, after the interviewing took place, exclaimed: 'I like this, I can feel my body'. This insightful outcome was then embedded into our research and applied to the structure that we developed for the Journey. A cyclical process, which we have named *'re-turn to the self'* (appendix 4), invited the participants to explore different aspects of their life. Once explored, we discovered that participants instinctively re-turned to their own life but with creative changes and new and transcending experience and knowledge.

c) **Soup theory**: having observed the various communication systems used by participants, we realised how often the participants had to compromise and adapt to several languages, often with significant differences from one to another (i.e. Makaton and Widgit symbols). We felt that a misuse and mix-up of symbols (similarly to an unsuccessful blend of ingredients in a soup) could often be common practice within the communication systems that are used with People who have an Intellectual Disability. We found that this could hinder processing and comprehension for people with varying learning abilities.

6. *Processes*

a) **The Cycle of Life Experience** (appendix 3): this process was devised at the time of recruiting participants for the focus groups. *'We realised that, if we were to gain insights from the lives of People with Intellectual Disabilities, we would need to identify where to recruit rich target groups from. We tried to discern the main areas of life experience of People with Intellectual Disabilities by developing what we named 'The Cycle of Life Experience' (TCLE). Additionally, we hoped that this would mark the main areas of transition and change within their lives' (Team discussion; Planning the focus groups).* As a result of creating this process, we ensured that we recruited people to participate that came from within the general life experience of a Person with an Intellectual Disability.

b) **ASPE**: this process was devised after conducting the focus groups. The team, reflecting upon the processing skills of participants, considered the structure of the questions, the language we had used and how they enabled or hindered communication with participants. We therefore created a four-step process for effective planning and asking of questions. We named this process 'ASPE', based on the initial letter of the name given to each stage of the process. The four stages can be described as follows:

A: **Aim** of the question: what is the purpose of asking this question, what does it aim to discover or reveal, what is the area of people's lives we want to explore and why?

S: **Structure** of the question: how is the syntax structured, what words are used, what are the key elements of the question, what is the level of complexity and the type of answer required?

P: **Process**: will the participants be able to process the question effectively, what will their cognitive response to the question be and what will they understand?

E: **Experience** of participants: is the question within the life experience of participants?

c) **PPAC: Perceive, Pay attention, Absorb, Communicate.** This process was part of the very philosophy of the Journey (appendix 10) and emerged as a result of the ongoing effort from the team to meet the person 'before and beyond' their Disability. Our approach to Disability has its roots in the analysis and understanding of the communication skills of People with Intellectual Disabilities. We therefore developed a process to follow when one meets a Person with an Intellectual Disability and begins to communicate with them. We named this process ‘PPAC’, based on the initial letter of the name given to each stage of the process. This process proved invaluable as we sought to achieve agreement and reciprocity of being. The four stages can be described as follows:

- ***Perceive* (Observe):** We perceived the body language and communication skills of participants. We also noted the way in which the participants related to: a) the environment b) peer participants c) the research team
- ***Pay attention* (Listen):** We paid attention to how the participants communicated with us. This occurred through sounds, words, actions, body movements, use of symbols and sign language.
- ***Absorb* (Learn from):** By gaining this new information from the person who was before us we absorbed and learnt from them and as such we moved beyond our usual cognitive skills.
- ***Communicate*:** We were, therefore, able to communicate effectively in a way that was empathetic with their ‘way of being’. As with every beginning of relationship, one has to understand and adapt their communication to have an effective exchange of feelings and thoughts.

BASE GROUPS: **Beginning to Access Spiritual Experience**. Having differentiated the theory concerning Focus Group and applied it to the task of running a series of groups, we developed different ways of interviewing People with Intellectual Disabilities. As a result of participants’ response, we developed a different type of focus group, to the ones studied in our preparatory stage. We called this a ‘BASE’ group: ‘Beginning to Access Spiritual Experience’. In fact, our focused sessions became more than just a mere collection of data, as participants opened up and expanded on the answers they gave, which resulted in them sharing much of their life story with us.

This format and its features were embedded into the specific mediating process used for the focus groups (due to the success encountered, the MEET process was then also applied to the Journey – please see appendix 2). In looking at our specially devised focus group process and all that had been shared by participants, we began to think that maybe our BASE groups could also serve as an initial way of enabling People with Intellectual Disabilities to express their inner thoughts and feelings about life and the world in which they live. In fact, the process of creating a large letter that relayed information could be one that is used for any subject that may need to be explored within the life of a Person with an Intellectual Disability. One important outcome is that this process has the capacity to release the voice of disabled people and provide them with a place to begin to express their life experience.

7. *Focus groups insights*

a) **Friendship**: when asked: 'how important is friendship in your life', participants responded with generally positive comments concerning the importance of friendship within their lives. A summary of the answers could be as follows; 'you need to be able to trust friends, a friend is someone that you can confide in and who is prepared to listen, you can tell friends things, friends keep you company and you can have fun with them, they are nice, friendship is about being supportive and offering help, caring for each other, expressing and sharing interests'. One participant in particular considered her pet to be her friend and reaffirmed this idea all the way through.[18]

b) **Love**: when asked: 'how important is love in your life', participants responded with generally positive comments concerning the importance of love within their lives. Different 'genres' of love were identified by various participants:

- *Love of friends*
- *Love of family*
- *Love for other people*
- *Boyfriends and girlfriends*

Other relevant insights depicted love as a way of *enjoying time together* and as a source (*provides*) of *a feeling of warmth*.

c) **Dislike of injustice and violence**: this was one of the most relevant themes that emerged from the focus groups. It was evident that participants did not see themselves merely as individuals, detached from other people but as persons completely aware of belonging to the human story and genuinely concerned for contemporary events (war, injustice, hunger, poverty). What emerged was a real philanthropic attitude. They seemed to fully understand their presence in the world and often showed pride in their own existence. Alongside the constancy and assertiveness with which these ideas and values were expressed, further reflection on the answers identified a 'rooted sense of respect' for others and 'wisdom concerning what it means to be human'. It was clear that the participants were suggesting 'how things should be, how people should behave'. In brief, they showed to possess a *sound* morality.

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[18] It is important to note that some of these answers were expressed to us through sign and image as well as though formal language. Where they were in a differentiated format we have translated them into written text, our interpretations were always checked with participants for accuracy.

d) **A sense of humanity**: in answering to the question: ‘what do you not like about your life’, which is supposedly a question focused on the individual, most participants redirected the focus onto a social and communitarian sphere. Evidence of this can be found in the common themes that were gathered from the answers:

- *Fighting and arguing between people*
- *Being victims of violence and aggressive behaviour*
- *Lack of respect*

The comments that were more focused on the individual also involved a communitarian dimension due to the consequences that could occur:

- *Loss of self-control* could result in an aggressive behaviour towards others;
- *Vices* (i.e. smoking or taking drugs) can lead to an unhealthy, impoverished, situation for the person who is dominated by this vice and for those who live with them.

Another question that clearly showed this philanthropic attitude was the following: ‘why do you think we are in this world’. Although the subject of the question is plural, we normally would expect an introspective element in the answer. Surprisingly, most of the answers were rather focused, once again, on a humanitarian dimension:

- *Stop violence*
- *Bring peace*
- *Follow religion*
- *Help other people*
- *Cooking/communal activities*
- *Belonging*

This attitude of attentiveness towards other human beings was also expressed as a will to do good for others, be it through personal commitment or the intention to financially support people in need of help. We found this particularly so when participants, in expressing their dreams for the future, answered by saying that they hoped *to do good for others* and that there would be *peace in the world.*

e) **Understanding and living changes**: this theme was one of the most important insights gathered during the focus groups and completely informed our subsequent work. As the questions progressed, we noticed that many comments spoke of a difficulty in understanding changes. As a result of this, many participants expressed the challenge in living some of the changes that may occur in their life. Further reflection on the data enabled us to identify the main areas of change that seem to surround the lives of People with Intellectual Disabilities:

- *Death, Loss*
- *Growth, Body*
- *Environment*
- *Routine, Staff*

One question in particular, ‘what makes you feel sad’, gave participants the possibility to openly manifest their concerns, thus providing the team with fundamental insights into what the challenges were within their daily existence and life story.
Within the common themes, gathered from answers to this question, four out of five included the word or the concept of ‘change’:

- *Change*
- *Losing people and pets*
- *Death*
- *Illness*

Another question which raised issues somehow related to change, was the following: ‘what would you change about your life’. Surprisingly, the responses were ‘all positives’ and the need or wish for a change was expressed with awareness of the positive outcomes that may arise from it. Looking at the common themes gathered from the answers, different types of ‘urged change’ seem to emerge:

- *Expand experience and knowledge of the world* →<u>personal growth</u>
- *Diet and more exercise* →<u>physical well-being</u>
- *Change environment* →<u>contextual well-being</u>
- *Change towards independence (job, new flat)* →<u>autonomy</u>
- *People’s behaviour* → <u>‘hope’ for a better world</u>
- *People around them* →<u>social growth</u>

There was very little inhibition from participants in stating their will of something changing in their life and all participants were able to communicate what this was, in their own way. *Change* is here seemingly perceived as ‘opportunity’ rather than ‘challenge’. The reason for this contradiction with the negative concept of change presented above could be that, in this second question, the driving force that leads to change is the Person with an Intellectual Disability rather than an external event, such as death of beloved people.

f) **Urgency to narrate their story:** reflecting on the core meaning implied in the focus groups answers, we identified this as an overall, underpinning theme, whose importance was described by the team in these words: ‘an implicit, fundamental need’. However, in order for this to be satisfied, a relational experience, as met in the shared settings of the research groups, also seemed vital. What we discovered, as sessions went by, was the basic need of participants to tell their story and have it acknowledged, respected and responded to. This theme was essential and informed the philosophy and practical outcomes of the work that followed.

g**)** **Sense of Belonging**: this theme wasn't related to any particular question we asked but, similarly to the previous theme: 'urgency to narrate their story', it was implicit in most of the answers given. Again, we were faced with a theme that is possibly one of the basic needs of humanity: the need of belonging to something, to someone, to somewhere[19].

Insight

h**) Sometimes an apple is just an apple'**: in the planning of EHS we had initially put the 'role, meaning and purpose' within its spiritual and religious realms.
However, in the light of insights from the focus groups, whilst refining the aim, we decided that 'such issues' should be removed. One insight that had a major influence in determining our decision was the answer from one of the participants to the question: 'why do you think we are in this world'. His answer, 'Because I am', amazed us all as he was considered to have a severe Intellectual Disability. We felt that he was telling us very clearly: 'Do I have to have a purpose and role to just *be* alive? I am here, that is enough! I just am' (team reflection notes Dec2009).

This reflection had a major influence in the development of our spiritual and theological writing. This thinking was subsequently reinforced, when conducting the Journey *EveryBody has a Story*, where we encountered the same meaning being answered. 'One participant gave a very deep insight in answering to the question: 'What do you like about yourself'. He said: 'Being myself'. When asked 'Why he was feeling happy', he answered 'I just am'. These comments took us back to the above outcome from the focus group and led us to understand that we should not try to seek justification for human existence but just accept people 'as they are'.

8. *EHS Journey insights*

a) **Outcomes for reflective practice**:

- **Space to express**; we realised that timing within a session is vital but that it must not come at the cost of giving up space for participants to share, process information and express themselves. We learnt this valuable lesson in the Focus Group when one participant commented that we should move 'one step at a time' (FG3 Dec 2008) .This need for the sessions to not move 'too fast' was then

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[19] **Appendix 4 shows how the themes emerged from the analysis of focus groups were embedded in the structure of the four-week Journey *Everybody has a Story*. The themes have been highlighted with different colours according to the frequency with which they occur, so as to give visual evidence of their relevance within the creation**

reconfirmed in the observations that we made of the moments when the mediator became vocal and outcome driven within the session.

- **Praise and affirmation**: this was a positive and powerful tool for encouraging self-expression and the telling of personal stories. The feeling that someone was listening with interest and giving importance to the participants facilitated heightened communication and social interaction. We noticed a continual building of self-esteem for all involved in the session, both participants and facilitators. This was especially so of a young man with autism:

*'As he arrived, we acknowledged him and showed him his book. He touched it, looked at it and continued walking. We took time and did not make him sit down but welcomed him, holding a similar ribbon to the one he liked to hold. After this, he voluntarily sat down with us in the circle. We affirmed him, thanked him and included him in all the conversations that occurred. He remained sitting with us and interacted willingly' as we continued with the session. This was a real breakthrough and his mother later confirmed it as him doing something different (*feedback from RC2 S2).

- **Structured environments**: we found that structured environments support processing of information. An environment that links in with activities provides rhythm and a sense of security for visual learners and those with differing processing skills. This, alongside specifically allocated places for activities, enabled participants to take ownership of the session. We noted that the participants who were on the autistic spectrum were more willing to join in due to 'knowing where things were'. One participant, who was on the autistic spectrum, became a little agitated when, in session three, we changed the format of the environment. He seemed more confused as the first thing he did, when he came into the hall each week, was to check the room and become re-familiarized with the chairs in a circle.

- **Differentiation to meet skills**: we found that when we tried to introduce an activity with the principle 'one size fits all' some of the participants were not able to engage fully with the activity. Differentiation to meet individual skills, rather than collective practice, definitely ensures access and allows the Person with an Intellectual Disability to interact effectively. This was especially so of the use of symbols and symbol supported texts.

b) Empowerment:

- **Enabling stories to be heard:** as a result of the focus groups we realised that People with Intellectual Disabilities had many hopes and needs for the future and that these are often unheard and unexplored. Listening to their story permitted us to reflect upon the tangible realities within their life journeys, hopes and dreams.

- **Continuity and commitment:** we realised that the Journey sets up expectations for continuous relationship building and adapted activities. Once the research sessions were over it was very difficult to explain that we would not be coming back. The Journey has the power to facilitate real change and the building of relationships. This however, requires commitment on the part of the community that runs the Journey. Follow up and development will be ***necessary*** if EHS is to reach its full potential as a positive portent for change. It has a transformative aim: to provide something that can often be denied to People with Intellectual Disabilities due to lack of understanding and effective communication. It is the first step towards and intentionally promotes 'a space to meet and make friends'.

c) Ownership, meaningful participation and narration of stories:

- **Ownership and turning point**: session three chartered a real turning point in the Journey. Participants became more active during the social break, where we found they became hosts to the team. This change was subsequently manifested in the way in which participants took ownership of their Spiritual Identity books (appendix 7) and also of the content within them. This 'change and ownership' occurred in all three communities. We noted that in session four participants were more open and shared much more information about their experiences.
- **Narrating one's story**; The SI book was a positive method of symbolizing 'ownership of one's personal story'. Whilst the activity in the final session was to encourage participants to share their story with others it was important that, through preparing for this, they took ownership of their book and of how it would be presented.
- **Encountering and sharing stories**; our research has suggested that People with Intellectual Disabilities do not have many opportunities for their life stories to be shared and voiced/expressed. Exploring future hopes and needs was the central task of session four. Guests were invited to the final section of this session and asked to express their feelings about the stories they encountered, they were also asked to make a wish for participants. The narration of stories through the presentation of the SI book became a source of affirmation for participants and a place of understanding and recognition for the visitor.

d) Transcendence:

- **Back to the Self**; the end section of the Journey is designed to facilitate a transcendent experience, where participants have the opportunity to gain *self-transcendent knowledg*e; by this we intend that 'one gains new knowledge about oneself and as such becomes more aware of whom they are'. We identified that participants practiced 'back to the self', during the final part of each session, by making comments, sharing images and making gestures, which seemed to indicate that they had gained new understanding from the session. From the amount that participants freely shared during this section, it became apparent that the issue of 'back to the self', identified as an important element within spiritual development, was indeed an outcome of the sessions. For the research team, being recipients of people's story, took the place of needing to consolidate outcomes and 'teach' something.

- **Moving beyond usual experiences**; the Journey activities enabled participants to communicate about matters that were important to them, including frustrations and opinions about world affairs. The structured activities proved to be a channel for participants to express themselves beyond their 'usual' experiences. This is especially so of session three. In this session, the participants were invited to make a letter of 'what was important to them'.

  One non verbal, Makaton signer, chose a photo of scales of justice and people signing (RC1 S3). Through a series of Makaton signs and by pointing to magazine images, he informed us that he 'did not like signing' and that he felt 'it was not fair that he was the only one that had to sign'. The whole group then had a discussion and his peers said that they would like to sign more. The LSA commented that she found it 'really interesting to hear him express his frustrations' and that they shed light on his 'aversion to some speech therapy activities'. In turn we were able to build more community signing activities into following sessions and to always convey a positive attitude about the ability to communicate through signs and symbols.

  In our Journey feedback we recorded that this session was very revealing of the participants' inner thoughts and feelings and that it enabled more of their personal story to be expressed:

'The LSA commented on how much the participants had opened up and shared information about themselves that they had not shared during their time at the school and how valuable it was for each person to have the time to express themselves.. This was affirmation of correct process and of the value of the Journey for schools and centers' (feedback from RC1 S3).

  Through the experience of EHS we noticed a *heightened openness* of the participants to find possible keys to interact directly with each other:

e) Critical empathy: Prior to A (a young man wi*th profound ASD) jo*ining the research community, his mother warned us about him not really being able to enter into activities. We thanked her for this information and remained open to how he would experience the Journey, holding an act of empathy as our key. We then noted that the way in which we remained open to him was emulated by B, a fellow participant; after two sessions B realised that A did not communicate directly with people, but that he liked to hold a ribbon. B's mother had told us that he had asked her how he should talk to A as he was not too sure.

- <u>Exchange (cntd)</u>: B went in search of a piece of ribbon and went towards A offering him the ribbon to hold, at the same time he noticed that A had a photo in his hand.

He then gave the ribbon to him and without words asked for the photo. They looked at each other and exchanged their possessions: this was done spontaneously and didn't involve mediators. This was a real moment of empathic exchange, where B sought to find a form of communication that bought about a moment of empathic encounter between the two participants, one that was not usual to their experience of sharing time with others.

f) Insights from People with Intellectual Disabilities:

- **The passing of time**; People with Intellectual Disabilities need time and space to complete activities. Time seems often to be planned for them and they are sometimes asked to complete a task within a time span that is comfortable for a person who does not have a Disability. During session two (RC2) one participant was trying to get to the end of a set task and commented: 'Time goes so fast, I have this much time (indicated a visual measure with his arms) and too much to fit into the space.' In the session feedback we noted:

'The participant's comments about time were very interesting as he was commenting on the busy nature of his life. He seemed to be tangibly showing me that he only had so much time and that he could not visually fit it all into the space. I asked him if he would like things to move slower and he said: 'Oh yes I would!! Then I could get it all done and not upset anyone' (feedback from RC2 S2/CG). This was consistent with another participant's request, in the focus groups, to move 'one step at a time'.

- **Being not doing**; as we ran the Journeys in each community, we tended to be less worried about achieving set outcomes for the session, hence began to enjoy more 'being with' participants and engaged with them, over and above the 'doing of activities'. By the time we got to the third community we were happy to 'hand over' many of the planned activities to participants:

'*Participants seemed really focused and used the resources well, in their own manner and independently. They seemed to enjoy making choices and identifying needs and hopes. The decorating of tables was done independently'* (feedback from RC3 S4/GV)

And

'It becomes ever more obvious that this Journey is not about making cognitive achievements or meeting the set aims of the session but a space to explore new ways of experiencing each other's story and expressing our own. It is a way of just being with each other within a community setting. It was a lovely way to work and freed us from the bonds of attainment and targets' (personal reflections RC3 S4 CG/MT/GV).

g) Specific outcomes:

- **Achieving *effective agreement***: as the Journey progressed we made notes of each participant's processing skills and communication preferences. We felt that this helped us get to know each participant well and was invaluable for the refining process that we undertook after each session. Observation enabled differentiation and access, removing the 'veil of the unknown' (OWL 2005). The way in which positive interaction took place, with all participants, confirmed that adaptation and effective communication can be achieved through the practice of PPAC (appendix 10). This will be an important activity for those who run the Journey, as it will enable them to build up knowledge of the person and in turn differentiate the services they provide in accordance with identified skills and needs.

- **An important place to be:** EHS provides a space for People with an Intellectual Disability to voice/express their opinions about things that matter to them and the participants felt that they had been listened to. We also noted the potential the Journey holds for building communities based on *hospitable relationships*. On the last session of all three communities one participant, who is generally non verbal and has ASD, commented: 'It is important to come here' (RC3 S4). The group dynamic of the Journey has provided a space for the participants to practice 'self-autonomy' but within a social and structured manner.

- **Freedom of self-expression**: the social break within the Journey became an extension of the planned activities in as much as it gave all involved space to interact and process information from the activities. As we all sat in a social, non cognitive setting, the participants began to communicate with one another. We noted a heightened desire to practice self-expression and to share more about their lives. In one group the participants spontaneously shared information that went beyond the activities and began to explain where they would be going on holiday. We noted that the social break became as important as the Journey activities.

- **Expressing religious beliefs**: we found that session three enabled participants to explore issues surrounding their religious beliefs: by choosing images, participants expressed their experience of faith and made needs and beliefs known. The 'what is important' activity, in this session, will enable religious communities to use resources that are relevant to their practice. Openness to surprise and the will to make changes are vital:

'Images of religious activities were chosen by most participants, could this identify that this session is the correct place to introduce religion and religious practice? Church was seen to be important for one participant, even though he shared with us that he had never been to church. Their home is right next door to a church and we wondered had he ever been invited by the local community to explore the church and feel welcomed by them' (feedback from RC3 S3).

- **Pace and choice**; initially, it seemed that a number of participants didn't seem totally comfortable with making choices. We noted that some would ask if it was 'ok' to do something of their own accord. The Journey seemed to gently encourage them to make personal choices and express themselves to a greater extent. Our feedback recorded our reflections concerning the possible reasons behind their resistance and insecurity in making choices. We wondered whether we created a space in which *they* felt they had to please *us*:

We wonder if too much is packed into the lives of people with Disabilities. Could keeping them busy and offering them 'planned choices', within activities, prevent us from just spending time with them? Is just 'being' with participants too challenging? Are we so focused on achieving our aims that we do not allow the space to let time pass by slowly, so that participants can enjoy what they are doing rather than feeling that they have to please? Could it be that they feel a need to meet expectations rather than know that we are enjoying 'being' together? This is an important note to make when pacing future sessions' (feedback and reflections RC2 S2).

- **Reciprocal hospitable relationships**: as the research progressed we noted that session four, in each community, became a place where the participants became the hosts as well as the hosted:

'The session ran overtime but this was due to all the participants patiently waiting for Molly to see their book. She was indeed the newcomer and the stranger from the local parish and yet every single person sat patiently waiting for her to visit their table. This became tangible evidence of the 'urgency to tell one's story' that we had identified in the focus groups. This was a real insight and we reflected that the person who is indeed considered 'a stranger' within society was the person to welcome and wait patiently for the stranger. The final session of EHS facilitates hospitable relationships which is a two-way experience between the visitor and the participant' (feedback from RC3 S4)

- ✓ Session four will provide religious and non religious communities with the opportunity to explore their services and identify how they can be made welcoming and hospitable. Through being guests at the last session and encountering the life stories of participants, the possible lack of welcome, identified as a possibility in the community that lived next to the church, can be avoided and communities can be known for their openness to hospitable relationships, welcome and change.

- **Changing Practice**; our experience with all of our research communities has been that the participants freely shared experience and new understanding, which enlightened our practice. Rather than us 'teaching' *them,* everyone involved in the session had an experience of new knowledge and new understanding. As a practitioner, Cristina felt that this was a freeing experience, as the process of 'doing together' became more important that having to achieve learning objectives. The Journey ceased to be a teaching activity and became an experience of mutual storytelling and encounter.

- **Self-reflection**; People with Intellectual Disabilities may need encouragement to self-reflect and to engage in activities that build self-esteem. Often, within their busy life schedule, there is little time for this to be a focused activity. EHS provided an opportunity, time and space for this to occur. Two research partners, when participating in the activity where they looked at themselves in the mirror (EHS S1), recorded what they noticed about themselves on the body board. Both commented upon the fact that they were 'handsome' and one participant proudly showed us his sunglasses. Cristina recorded in her notes for session two:

'*Once again the participants have arrived to session two and have something different about their clothes. One participant had a new shirt and a bracelet and his mum commented that he told her he had wanted to put a new shirt on. Another participant had a new T-shirt and coming towards me continued to pull at her shirt and sign 'best'. On asking if it was a top she liked she put up two thumbs and signed 'very best'. It seems that participants have wanted to make an extra effort and that they were happy to comment upon their clothes and how they felt about looking smart. All participants seemed so pleased to be back and their body language seemed more confident'* (feedback from RC2 S2).

9. ***Focus Groups Resources***

We developed and refined the resources so that the participants could absorb and respond to all that was being asked of them. This has resulted in a series of simply designed resources, which can be reproduced and which have, methodically, enabled people of varying communications skills to follow a structured, symbolic and sequential activity (appendix 6). The resources proved to be the stimuli for participants' interaction with themselves, other participants and the research team. Below follows a series of results concerning their use and effectiveness during the sessions:

- **Images and Symbols:**
- Enabled choice-making for participants and facilitated the development of refining and consolidating skills.
- Participants were able to recall and recognize visual representation of their answers from previous weeks, images proved to be an effective tool for reaffirming and consolidating their choices. We generally encountered a positive and attentive response.
- The use of images as a resource gave us a deeper awareness of the potential and risks involved in using images with People with Intellectual Disabilities.
- The risk of using images is that some of the participants were not able to link the image to their own experience. We also noted difficulties when there was no one in the picture that they recognised as part of their lived experience.

- **Music**:
- Music proved to be an effective tool for introducing a theme, consolidating information and choices, facilitating interaction and the creation of a relaxed and friendly atmosphere.

- Participants chose music for the start of the focus group sessions; we realised that, for those that brought music to the session, their choices reflected their characters and living environments. In this way we feel that the music choices were an extra manifestation of their inner being.
- The use of music in the final part of the last session proved to be an effective tool for participants to reaffirm their significant choices and the possibility to express their ‘important message’ in a ritual activity.
- The use of music as a resource gave us a deeper awareness of the potential and risks involved in using music with People with Intellectual Disabilities.
- When the music we used was too fast and too complicated in texture it caused confusion and resulted in the participants ‘turning off’. This outcome was then reconfirmed in the Journey, where we noticed that for some participants, trying to make sense of words and music became a blockage to understanding. Thus some of the songs that we had chosen became negative resources.

c) **Response of participants**: All participants accepted and responded effectively to a different way of using the resources proposed by the team, thus showing good adaptation skills. We feel that they:

- Initially participants seemed confused if the images or symbols used were not totally familiar to them, but were able to adapt once they were explained.
- Following the cyclical process of reflection and refinements we found that the recommendations that we were given by our research partners improved and rendered our final set of resources accessible to all. Each participant was able to use and understand the resources we brought.
- Approached a different way of communicating their thoughts.
- Were able to use the resources to support choice-making.
- Were able to interact effectively with the multi-modal approach we employed (spoken language, images, music, symbols).
- Became more confident in using the resources as sessions progressed.

10. *EHS Journey Resources*

The materials for the Journey have been developed in direct negotiation with the participants. We continually reminded them that, as research partners, their advice and critique were very important for the outcomes of this research. As such, the resources have emerged inductively, rather than ‘being enforced from above’.

a) **The Spiritual identity book** (appendix 7): this resource, which recorded the exploration and spiritual journey of participants throughout the Journey, was vital and became a source of self-reflection, social interaction and positive, effective communication:

'One participant shared a lot and whilst being a very shy person she was able to use the SI book to relate information about people in her life, which filled three pages. Giada was amazed at all she shared and they had a very intimate conversation. Giada commented that she felt that she knew her more and that they had similarities. Filling in the pages of the SI book, helped this person express her own feelings and identify people who were important to her. At the same time it allowed Giada do the same' (feedback from RC1 S3).

The spiritual identity book also enabled a non verbal person to communicate with a verbal participant who was on the autistic spectrum. Watching the non verbal exchange of information through a resource, that did not require too much social interaction, was a powerful experience and reinforced the potential of the Journey to facilitate hospitable, empathic and achievable relationships:

'It was amazing to watch the participant as he sat in front of the other. As they turned the book, not a word was exchanged. Their body language met and their facial expressions demonstrated a deep understanding of needs, be it of the person whose story was being shared and of the guest who was observing and acknowledging the visual account of a person's life' (feedback from RC1 S4).

b) Building up relationships through use of photography: the combination of the use of photographs within structured activities proved to be a positive form of exchanging information for people with autism. This was especially so when the photos were from the life experience of participants. We noticed that it encouraged voluntary interaction and communication with others:

'Today photographs were used to communicate and one participant, who has ASD, chose to bring in some of his personal photos. He then shared and showed them to peers. This was an amazing moment of interaction between a person with severe autism and a fellow participant without ASD. The man with autism also explained, through answering open-ended questions, where he was, what he was doing and who was in the photo' (feedback from RC2 S3).

c) Effectiveness of 'placement': we found that using placement during activities assisted processing of information, over and above using passive observation skills. By **placement** we intend; A tangible method of **combining the following components** to support cognition; visual resources, physical spaces, audio guidance, movement and symbolic placement which connects to a given activity.

d) We noticed this in session two, when we changed one of the activities from 'watching' a power point of images, to 'choosing from and placing' images on a wall

'In research communities one and two, we showed the participants a series of images that sought to represent daily activities. The participants were invited to watch and identify with the images shown on a power point. As the images appeared on the wall,

they seemed to drift and not take any notice' (feedback from RC2 S2). *'In the third community we did not use the power point but invited participants to* ***look*** *at large photos on a table and to* ***choose*** *a daily activity that was familiar to them. After choosing, they were invited to* ***place*** *their image on a ribbon that was on the wall in front of them. This worked very well and all the participants were engaged and made comments about their choice. They became familiar with the process of placement and the second half of the activity flowed'* (RC3 S2).

e) **A flexible format**: the Journey is extremely flexible and can be run within a variety of time scales. For two of the groups we ran the Journey over a four week period and for the last community we ran the Journey over two weeks, holding two sessions per week. We did not note any negative outcomes from either model. We also feel that the Journey would be effective if each session was run over a whole day rather than a two-hour span, which was the practice of the research program. A whole day session would enable 'being before doing' and allow participants more time to reflect, express themselves, explore and consolidate information, but more importantly to socialise. We feel that it would solve the concern, expressed within the outcomes, of the need to give more time for activities.

   It would also give communities the opportunity to get to know participants and enjoy heightened social interaction by sharing a lunchtime meal. Nevertheless, this would have major implications for the staffing of the Journey.

Conclusions

The findings of our research have shown that spirituality in both its religious and non-religious forms is significant for People with Intellectual Disabilities. Whilst religion was an important aspect of some people's lives, it was clear that spirituality in its broader forms was important for all of our participants. People need such things as love, relationships, meaning and purpose. In a world that clearly tends to devalue people with disabilities, to recognise and help to bring to fruition such aspects of people's lives is fundamentally important. The key lies in whether those around them are prepared to take time, listen and understand what spirituality means *for this person*. The report has outlined the feelings and opinions of People with Intellectual Disabilities around the issue of spirituality and the conclusions we have reached are firmly rooted within their experiences. We hope that by providing a forum where their voices and insights can be expressed, received and understood, we have enabled people to take another step along the road towards spiritual and religious empowerment. The approach that has been developed is intended to allow communities to be places of inclusion where *all* voices are heard and understood; disabled *and* non-disabled.

It is our hope that what has been developed has the flexibility to accommodate the needs of People with Intellectual Disabilities who belong to a broad range of religious traditions. For religious communities we have tried to provide a body of knowledge and a framework which can be applied to a broad range of traditions. The findings presented here will mean different things to different traditions and the ways in which the insights are applied will take different forms across the traditions. It is also our hope that the findings presented here will be flexible enough to accommodate to the needs of those with no interest in religion but who see the importance of spirituality for the well-being of themselves and others. The insights and frameworks presented in this report will enable the key issue that revolve around spirituality to be recognised, understood and worked through in important and creative ways.

We are the stories that we tell and that others tell about us. We only really know who we are and perhaps more importantly *why* we are who we are, as we tell our own stories and listen to the stories that others tell about us. Most importantly, we can only really tell our stories well if people are prepared to listen and receive them. The model presented in this report is intended to help people to be better listeners to the stories that People with Intellectual Disabilities tell. This report provides a way of attending to and telling stories. We hope that the reader finds in it the resources to be present and respond to the stories that People with Intellectual Disabilities are telling and perhaps more importantly, to allow their own stories to be told differently by those people whose story is rarely heard, but which has the potential to transform all of our worlds.

Appendices

Appendix 1: The Live Fully Journey

Background to the Journey:

In 2006, having explored the definition of Spirituality (J. Swinton 1999) [20], suggested by Prof. John Swinton, Matteo Tobanelli and I, Cristina Gangemi, began to ask what were the possibilities and opportunities for People with Intellectual Disabilities to really explore, at a cognitive and emotional level, questions such as ‘ Who am I and why am I alive? ‘. We therefore reflected upon our practical work and created a Journey which would address the subject matter within the Swinton definition and attempt to provide a process by which opportunities to explore and develop personhood and spirituality could occur for People who have Intellectual Disabilities. This resulted in the Journey: Live Fully!!

Location for pilot Journey and students attending:

St Joseph’s Pastoral centre, in Hendon, West London is a multicultural, interreligious day centre for People with Intellectual Disabilities. The centre is partially funded by the Roman Catholic Archdiocese of Westminster. The students are generally mature adults. Four people attended our Journey in spiritual development, three men and one woman. They were all middle aged. One student was Hindu, the other three were Christian. Three students knew each other from previous Journeys at St Joseph’s and one was new to the centre but was a friend of one of the participants.

Purpose of the Journey:

The Journey is designed to provide an opportunity, over a period of thirteen weeks, for People with Intellectual Disabilities to explore and make sense of; their self, their life, their purpose within the world, as well as an exploration of where a ‘sense of holiness’ exists within this milieu of life experience. We designed the sessions in such a way that they would encourage self-autonomy, the development of self-esteem and confidence in self-expression. The Journey is divided into six, two week sessions that unpack and develop the following questions:

- Who am I?
- Why am I alive?
- What can I do?
- Who do I share my life with?

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[20] Swinton 1999b *A space to listen, meeting the spiritual needs of People with an Intellectual Disability*

- Where can I find love?
- Where can I find God?

We also wanted to explore if it would be possible to encourage spiritual development through the creation and practical implementation of a program of education that was differentiated, person centred and derived from Prof. John Swinton’s definition of spirituality. One of the main aims was to allow the gifts of each individual to surface and to enable them to explore all that they have to offer.

Appendix 2: MEET process - ©C Gangemi 2008

I. **Meet**: Gather the participants and welcome them, encourage them to communicate about their lives: who they have met and shared time with. Play some soft music which enables them to relax and reflect.

II. **Explain**: Explain the activity that they will engage in (use of differentiated resources, language and process patterns).

III. **Explore**: Engage participants in differentiated activity and mediate questions using the question sheets (appendix 6: 1) and PowerPoint presentation. Ask participants to explore their thoughts, opinions and answer questions. Use differentiated formats and resources to mediate learning and obtain answers. Encourage participants to express themselves.

IV. **Transcend**: Re-gather group, show them the answers they have given that have been written on answer sheets. Use tangible, visual, evidence to show the way in which they have shared information about themselves and how this has helped the research team to know them at a deeper level. Listen to the music again and ask them how it felt to share their ideas. Invite a participant to physically place the answers in the large envelope (appendix 6: 2) and explain that this will be added to the letter that will mediate their message to the world. Encourage them to take ownership of how they have transcended themselves and have shared this transcendence with fellow participants, the team and the audience of the research.

Appendix 3: The Cycle of Life Experience

The focus group (age 16 and above) and research community participants should be chosen from the main areas of the life of People with Intellectual Disabilities, which are generally;

Faith Community

The religious community provides a unique setting within the cycle as it has the possibility of gathering people from any of the areas, of life experience, within this cycle

It could be a;
1) Place for social interaction
2) Opportunity for spiritual expression
3) Community setting
4) Place to develop friendships

We have named this the rich target audience.

SCHOOL (age 16-18)

Participants here may;
1) Live within a family setting before, during and after formal education
2) Attend religious communities
3) Be multi-faith
4) Be Non- religious

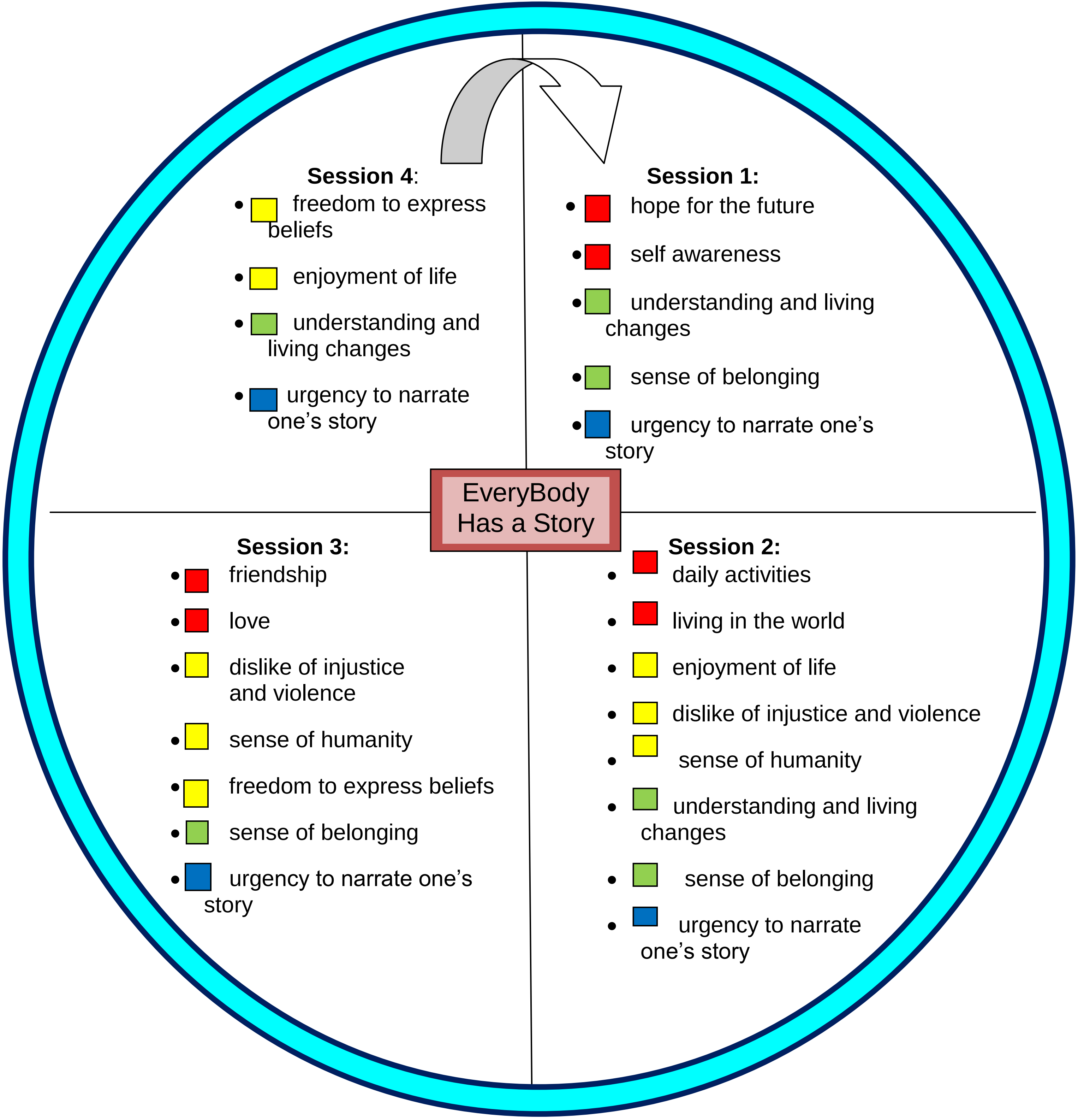
Residential home

1) Post family experience
2) Living context
3) Post formal education
Participants here may be;
4) Living in a community setting
5) Multi-religious
6) Developing personal and independent skills

Day centre or work

Rich resource for collecting data, the day centre provides;
1) A place for social interaction
2) A intellectual environment
3) An opportunity to gain new experiences
4) A place to make friends
5) A place to develop interests

Appendix 4: The *Re-turn to the Self* diagram



EveryBody Has a Story

Session 1:

- 🟥 hope for the future
- 🟥 self awareness
- 🟩 understanding and living changes
- 🟩 sense of belonging
- 🟦 urgency to narrate one’s story

Session 2:

- 🟥 daily activities
- 🟥 living in the world
- 🟨 enjoyment of life
- 🟨 dislike of injustice and violence
- 🟨 sense of humanity
- 🟩 understanding and living changes
- 🟩 sense of belonging
- 🟦 urgency to narrate one’s story

Session 3:

- 🟥 friendship
- 🟥 love
- 🟨 dislike of injustice and violence
- 🟨 sense of humanity
- 🟨 freedom to express beliefs
- 🟩 sense of belonging
- 🟦 urgency to narrate one’s story

Session 4:

- 🟨 freedom to express beliefs
- 🟨 enjoyment of life
- 🟩 understanding and living changes
- 🟦 urgency to narrate one’s story

The above diagram shows how the themes emerged from the analysis of focus groups were embedded in the structure of the four-week Journey *EveryBody has a Story*. As you can see from the diagram, the themes have been highlighted with different colours according to the frequency with which they occur. This is to give visual evidence of their relevance within the creation of the Journey. The colours have been assigned as follows;

- 🟥 **Red**: theme occurs once
- 🟨 **Yellow**: theme occurs twice
- 🟩 **Green**: theme occurs three times
- 🟦 **Blue**: theme occurs in all sessions

Appendix 5: Format used in conducting our BASE groups

Letter to the world: The letter is made up of two components; a giant envelope and a large poster with four empty circles. The letter is designed to be a visual aid to support understanding and record ideas. The letter represents the sharing of information with others. The outcomes recorded on the letter have the function of building up confidence in the participants and making them aware that they contribute to the building up of a message in their own unique and valuable way.

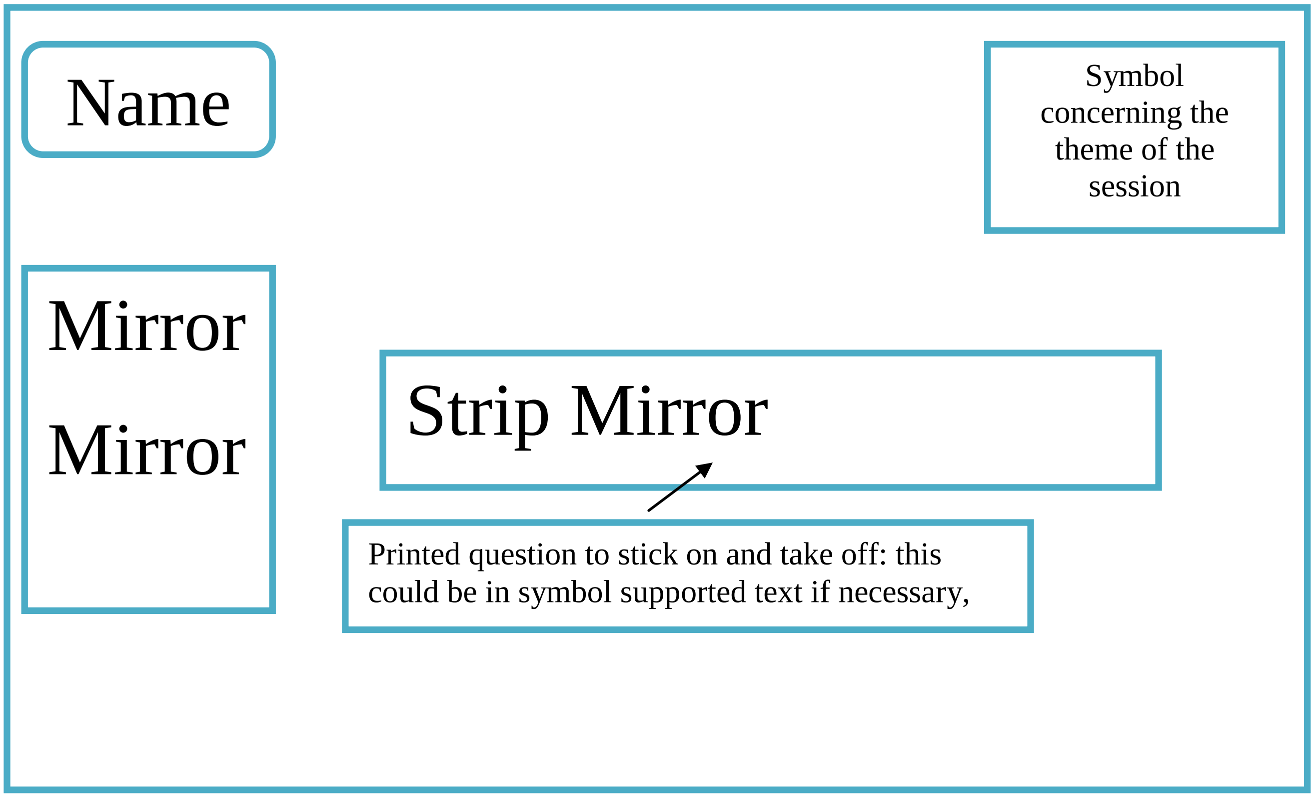
Symbolic placement: This process is used to help participants recall and consolidate answers given in previous sessions, by inviting them to choose images representing their answers to the questions. These are then physically placed inside empty circles on the poster. Each circle on the poster represents a genre of questions that are asked.

Consolidation: When working with people who have varying processing skills, the retaining of information can be challenging. Therefore, visual aids and the practice of making ideas known through symbolic placement is a powerful way to support cognitive skills and assist in the processing and retaining of information. Once choices have been made, questions answered and representative images chosen, they need in some way to be placed within a framework that will visually help consolidate the cognitive process that has been made. As the participants made and refined choices, they were invited to physically pick up images and *place* them inside the relevant circle of the large poster.

The most important message: The poster design held a final circle which was named 'the most important' circle. Participants were invited to look at the images that had been placed in the other circles on the poster (representing their refined answers from previous sessions) and to remove the image that was the most important to them (appendix 6: 3). By placing and then permanently sticking their choices (representative images) in the 'most important' circle, participants were discerning what they wanted to share with others and what was important to their lives. In the very last session the letter was looked at by the whole group who, the mediator took the letter down from the wall and folded it up. The letter was then placed inside the giant envelope and the group was told that the message they had created would be shared with other people in the world (please see appendix 6.2 below).

Appendix 6: Resources used for the focus groups

1. The question sheets



Name

Symbol concerning the theme of the session

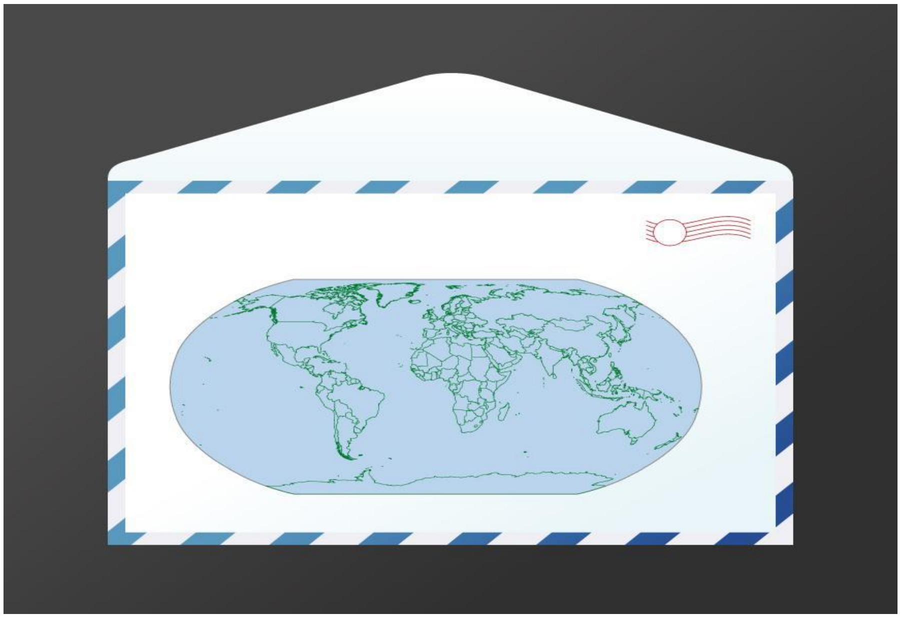
Mirror

Mirror

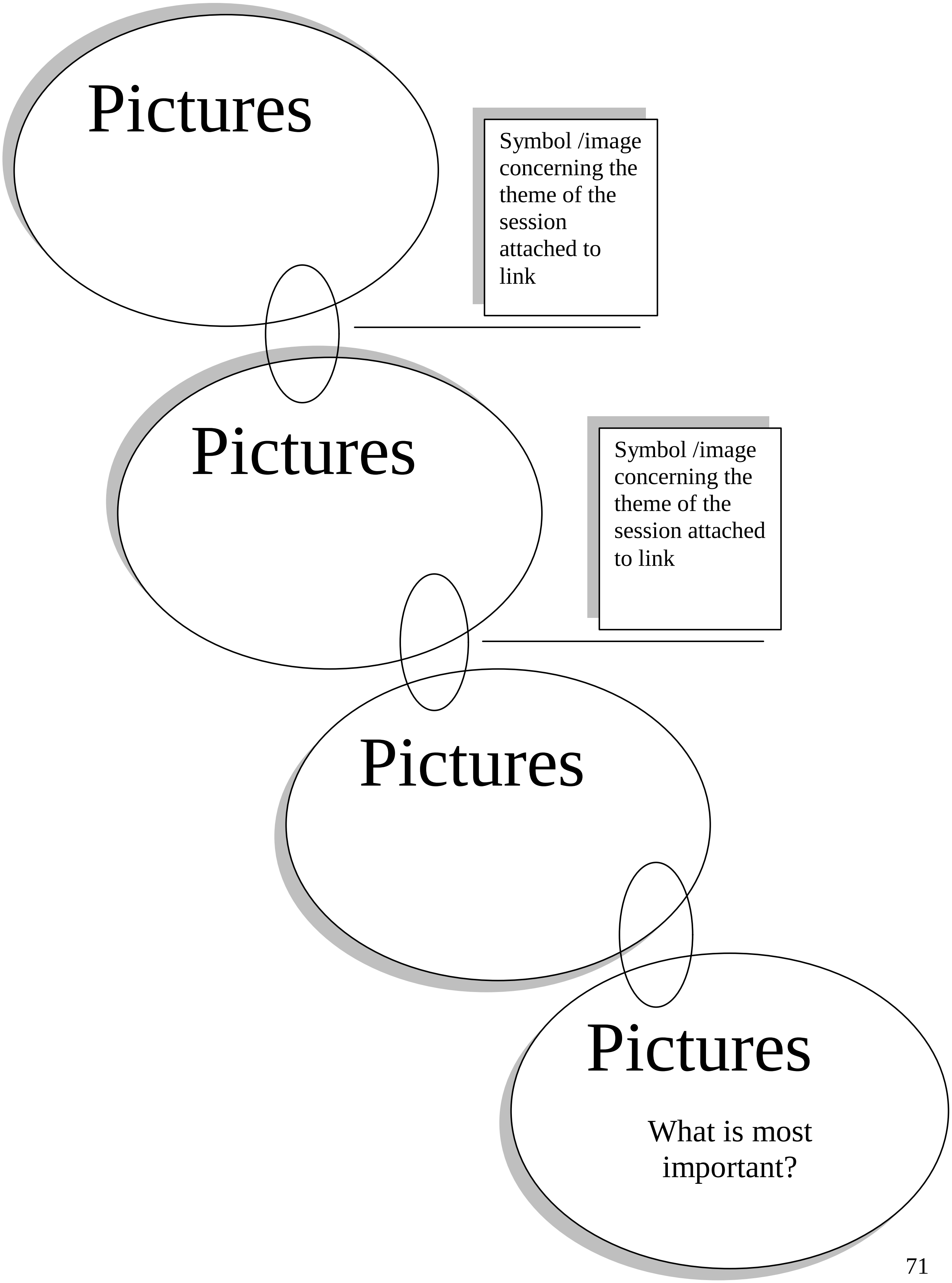
Strip Mirror

Printed question to stick on and take off: this could be in symbol supported text if necessary,

2. The giant envelope



3. The poster



Pictures

Symbol /image concerning the theme of the session attached to link

Pictures

Symbol /image concerning the theme of the session attached to link

Pictures

Pictures

What is most important?

Appendix 7: The Spiritual Identity book

The spiritual identity book is the personal story book that is created by participants throughout the duration of the Journey: EveryBody Has a Story. The book works in total synchronicity with the Journey schedule, which is used at the start of each session.

In this book, the pages have been carefully constructed, according to the focus of each session. Each activity is designed to have a visual or written outcome, which can be recorded or stuck on each page. These outcomes relate the personal choices, opinions, thoughts and feelings of each participant as they engage in the Journey activities.

Thus, the book serves as a form of communication between their personal story and those who have the opportunity and gift of sharing this book with them. It is in itself a form of relating and narrating a personal story, which goes beyond words.

Appendix 8: A relational approach to Spirituality

1. Our initial working definition

The working definition that has guided our research prior to this project refers to the work conducted by Prof. John Swinton within spirituality and Disability. Below is his definition of spirituality;

> '…**that aspect of human existence that gives it its 'humanness.' It concerns the structures of significance which give meaning and direction to a person's life and helps them deal with the vicissitudes of existence. As such it includes such vital dimensions as the quest for meaning, purpose, self-transcending knowledge, meaningful relationships, love and commitment, as well as the sense of the Holy amongst us.'**[21]

According to the above definition spirituality includes several dimensions within one's life. This comprehensive description of what could be regarded as spiritual has made an invaluable contribution to the research process, in two senses:

1. On a theoretical level this definition has informed and guided our approach to spirituality; it has also had a major influence on some of the decisions made within the research.
2. On a practical level it has proved to hold the capacity to 'bring about change and offer concepts that work in practice'. This was evident on two occasions, the development of the course *Live Fully* (appendix 1) and the planning of questions for the focus groups:

- The Journey was structured into six sessions according to the dimensions identified in the second part of the definition above. These concepts were then reformulated into six questions each of which constituted the main theme of each session.
- Similarly, when planning the focus groups, the interview questions were chosen according to a dynamic from inner self to outer dimension (empirical world and transcendent realms). In other words we interpreted the order in which these 'spiritual dimensions' are offered in the definition as an implicit progression from the self to something *completely other*.

However, reflecting carefully on some of the answers and insights shared by participants during the focus groups, we gradually began to challenge this definition. Below are some of the questions that arose within the team which concern how this definition was 'within or outside' what we were being told by participants with Intellectual Disabilities:

- What are the 'vital dimensions' expressed by participants with an Intellectual Disability and do they correspond to those suggested in the definition?

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[21] Swinton 1999 *A space to listen, meeting the spiritual needs of People with an Intellectual Disability*

- Was the language used in our conversations with participants compatible with the language used in the definition?
- Was the spiritual experience shared co-incident with the proposed dimensions? Were the participants focused on reaching something or did they express something quite different but still within the realm of spirituality?
- Was there a connection between these spheres and how did they combine within the understanding of spirituality, which we had discovered within the original definition?
- Was the initial working model still able to have the central function, which it had held at the start of the research?

2. The challenges within the initial model

The reflections that followed clarified the need of developing a definition of spirituality which was more rooted in the experience of People with Intellectual Disabilities and informed by what they had told us to be important to their lives. It is important here to make a necessary distinction:

I. The **concept of spirituality:** according to the evidence collected during the focus groups, this was quite a problematic concept and one that was often challenging for participants.
II. The **definition of spirituality:** we were looking at, was a definition that would be informed by what we interpreted as being relevant to the lives of People with Intellectual Disabilities.

What was not clear, within the definition, initially embraced, was 'how these spiritual dimensions relate to each other and exist within one's life and spiritual being'. The problem was therefore the urgency to find a definition that would have gathered all these 'separate' dimensions into a whole existence.

Another aspect of the definition that we began to challenge was the focus on the *quest*. In fact, what the research has discovered is that people who have cognitive difficulties (and are apparently 'not able' to verbalize, elaborate or express a quest within their life) seemed to hold a strong spirituality. They also had a deep sense of their own existence and the world in which they live.

The quest implies a free will and the ability to reason thus identifying what the object of the quest is (the ability to make judgments so as to define the object). This model of spirituality seems to lie within an individualistic assumption and frame: that a person 'has to do something' in order to actualize their spirituality. The risk we recognized in this is the possibility of creating a **hierarchy of abilities**.[22]

'Within a model of spirituality, which was to serve and enhance the experience of People with Intellectual Disabilities, the introduction of rational skills challenged us. The centrality of rationality within the original definition, moved us towards a definition

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[22] Master's Thesis, *Those who have been called*, C. Gangemi 2006

more in keeping with the experience we had gained from our research partners; participants with Intellectual Disabilities'.

3. A grounded model of spirituality

As the research progressed, our understanding of spirituality gradually changed and we were led to embrace a definition that was no longer coincident with the original starting point. This new definition, however, is contextual to the research team and the People with Intellectual Disabilities who contributed to the project as co-researchers: it is not aimed at describing what spirituality is and there is no intention to claim any core meaning to it. The model developed, is rather aimed at providing 'grounded meaning' to the concept of spirituality. We interpreted the *experience and expression*[23] of People with Intellectual Disabilities by focusing on the need to stay within the 'words and concepts' that emerged in the dialogue with them. At all times we sought to use a 'similar' language.

This model seems to have relationship at its core. The relational element arose 'spontaneously' during the analysis of the focus groups answers and in the underpinning theme 'urgency to narrate their story'. Further reflection led us to an understanding of spirituality whereby the spiritual side of one's life is not detached from material world and bodily experience but inextricably connected to them. This connection became apparent to us as, having completed a focus group session, one participant exclaimed 'I like this, I can feel my body'.

This relational model also seems to be embedded in a cyclical process. This was confirmed throughout the research in the way we structured and developed the Journey *EveryBody Has a Story*; within the Journey participants were asked to explore different aspects of their life and through the various activities to relate these dimensions back to themselves and their lives.

4. The centrality of being in relation

The challenge we have ahead of us is to define spirituality, not in any core meaning but according to what has emerged from our conversations with People with Intellectual Disabilities:

a) According to the dialogue established with the definition of spirituality we had initially embraced and based upon the perception and awareness we had gained from being with our research partners, the newly discovered model suggested that; 'quest' is not key to one's spirituality, it rather seems to constitute a source of further enrichment to one's life. Spirituality does not seem to be fully compatible with a *search for answers and meaning*.

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[23] 'Experience and expression' is the explanation of a participant from the focus groups. He explained how he understood spirituality, 'I experience myself inside and express it many ways, including religion and going to church.' Team Notes, 2009

b) According to the experience gained from conducting this research and on the basis of what People with Intellectual Disabilities have told us;
    I. Spirituality is not about finding space for the individual to deal with the ups and downs of life.
    II. It is not about finding a method of letting one's spirit communicate with one's self (It is not about 'me', what many participants with an Intellectual Disability have told us is that; 'I and my spirit exist also for others').

All these reflections are leading us toward; a spirituality 'of being' rather than 'of mind', 'of presence' rather than 'of ability'. We might define spirituality as **being present and attentive to the other, reciprocal exchange and real, authentic encounter**.

This new definition of spirituality relies totally on one's own capacity to be truly human, and on the recognition that the story that is uniquely ours is not just for our own possession, but also for the *radically other*. The spirituality we suggest is a 'sense of life' that is present before any intellectual effort to discover or uncover meanings. Spirituality, in its original and more basic reality, is *presence*. It is a dialogue, being in relationship with meaningful dimensions without any word being spoken, before any rationalisation, of what is being experienced by the person, takes place. By 'meaningful dimensions' we do not intend what is objectively observable, quantifiable or definable, but a subjective experience of encounter with *something other,* which is meaningful and enriching of a person's life. The **relational and cyclical core** of this new model of spirituality becomes real and tangible in the presence and physical narration of *meaning*: unsaid and not explicable in human terms, but at the same time source of dialogue.

Appendix 9: The concepts of Spirituality and Holiness

Reflecting on the focus group answers, concerning spirituality and holiness, the team identified and isolated those comments that seem to have relevant implications for the philosophical and theological framework. In doing this, the contribution of all participants has been taken into account; this is reflected in the outcomes presented below;

Aims of reflection:

I. To gain insights into the general experience and thoughts of participants.
II. To seek to interpret answers and comments within a philosophical, epistemological and theological context.

Response to the word *Spirituality*

Only three people out of twenty had any sense of what the word 'spirituality' meant. The responses were vague and it seemed a difficult concept for participants to grasp. Only one participant was able to express ideas, having already undertaken some work on spirituality, hence his comment that 'experience and expression' were a way of defining the relationship between 'spirituality' (considered as the 'experience of God, felt within the self') and 'religion' (considered as the 'expression of a belief in God').

Attempt to define Spirituality

Firstly, it is important to note that the question 'what do you think spirituality is', wasn't part of the questioning route. This was a probing, transitional question, strategically woven into the sessions, so as to explore participants' understanding of the word and concept of 'spirituality';

- **Insight one: 'Our life and the world'**; one participant understood the goal of the focus group sessions well and her responses reflected all that we had been doing in the first and second session. Rather than claiming that her answers were totally 'her own thoughts', we needed to be aware that, as a participant within a process, they may have reflected her observations of our comments, as we spoke of spirituality.
- **Insight two: 'a bonfire'**; another participant seemed to have a cognitive response to the question by looking at the image shown in our power point presentation, which related to the word 'spirituality'. This seemed to have an immediate relationship with his answer and we reflected upon the influence that images may have on cognitive processing.

Attempt to locate Spirituality

- **Insight: 'in your mind';** one participant commented on spirituality and said it was a 'real thing that exists'. She did not give a definition of 'spirituality' but assigned a bodily place to it. Pointing to her brain, she commented that it is 'in your mind'. We wondered if this would have been something that she may have heard and if it was indeed a learnt word. We then asked ourselves: 'was the concept too difficult for her to process or did she have a concept of her spirit linked to her thoughts?' She did not say it was something that you feel and she did not link this directly with feelings or experience. It was not connected to an emotion but to a reality shared by all human beings.

Response to the word 'Holy'

In the third session of the focus groups we asked the participants the following question: 'Do you think there is something Holy amongst us'; the answers were numerous and varied from one group to another;

I. **For the first group**: a Secondary School for Pupils who have Severe Intellectual Difficulties (non-religious and inter-religious);

- The moderator linked the word 'holiness' to a concept of 'something bigger'. It became obvious that this approach was mistaken as it guided rather than enabled participants' answers to be freed (answers included physical entities such as 'moon, sun, sky, stars, clouds'). The answers that came from this group were generally connected to nature or to something that is not tangible. It seemed that, for participants holiness was something that you could not have a physical relationship with. *Holiness* could have been something that they had an experience of but at a distance, it was not something they were readily able to communicate.

II. **For the second group**: a residential home with religious connections;

- In this group most people gave general and collective comments which identified 'Holiness' with religion and religious practice. In particular they linked it to activities where people 'take part', for example: 'helping people, praying for people'. For this group people provided the source for holiness. They also seemed able to process the word at a linguistic level and to connect it with a process of a memory of particular events or objects in their lives ('holy communion, the holy mass, sacred heart, statues of saints, Our Lady, religious objects from within certain religious traditions'.

  We thought that that they may also link the word 'holiness' to language and concepts that they had heard and learnt. This, we reflected, may have resulted from familiar and significant events in their lives and that of those who surround them.

- Some individuals were able to articulate their thinking on a more personal level. For one participant 'holiness' was not an object or a word but *something* that helped her to think about something. This was something quite different to the answers from her fellow participants, with whom she lived. She did not say 'God' or 'Holy' but she did comment that holy objects helped her to think about things, especially her prayer book.

  Giada commented that 'Holy' did not seem to be something that was tangible and that the participants seemed to understand that holiness is not something given to them, like a cup, but that it is accessible and present through rituals and symbols. This would be in keeping with their response to symbolic languages and intellectual.

Cristina reflected that a Person with an Intellectual Disability is often described as not being able to 'understand' and that often this is the cause of them being excluded from activities and religious practices. The experience of the focus groups, however, has suggested that People with an Intellectual Disability have a heightened capacity to follow symbolism and ritual and to transcend within them. It is too often the case that we mistake religious practice with a capacity to be able to follow academic reading patterns and complicated intellectual concepts.
It is almost as if the academic world has hijacked the world of faith and religious practice. The opportunity to share faith with People who have an Intellectual Disability provides religious communities with a chance to remember and return to their symbolic roots, thus finding a way of sharing rich traditions and theology with all. In today's practices there seems to be too much emphasis on intellectual ability and not enough on spiritual transcendence.

III. **For the third group**: a day centre (inter-religious);

▪ This group provided us with a varied set of data to reflect upon. The cognitive and physical abilities within the group were diverse, from profound to mild. The responses to the questions on spirituality and holiness were all individual answers from several participants;

a) We were informed that one particular participant, would probably not be able to respond to questions as he only ever said a set series of sentences to anyone. However, he was indeed one of the participants that contributed some of the most in-depth insights. When asked his concept of holiness and having given him time and space to answer, he stood up, without being prompted and instinctively went to the wall and pointed to a picture and word that said 'US'. His answer could have indicated that he saw no detachment or distance between 'us and holiness'. As with the second group his response was rooted in symbols. We felt that this participant gave us the most comprehensive, universal answer.

b) Another participant, a young woman, said that she had no idea at all what it was and it seemed far away. For her it was not a tangible reality.

c) Another participant seemed to find it difficult to articulate his thoughts. He suggested that spirituality was not something you could touch ('we can't see the spirit but we can see the spirit') but that 'heaven can be holy'. He saw holiness as being related to religious belief, and identified the Holy with God ('only one holy person and he's God').

d) We asked the same question to two female participants who were deemed to be the less able in expression and verbal ability. Both gave an answer that was not connected to religious practice but that were quite profound;

One participant explained that ‘people are special’. Another, a young woman with Down syndrome, who is usually non verbal due to a speech stutter, indicated a desire to speak. Realising that she needed space and time to project her voice, Cristina created a visual and imaginary space for her to’ drop her voice into’. Feeling less pressure to project her voice and also having time given for her to be listened to, she began to speak. After the session we discovered that this was unprecedented in social gatherings. Her answer to the question about holiness gently proclaimed ‘It is as if people are beautiful’. Both answers were directly linked to humanity and to the answer given by the participant who chose ‘us’. The answers were not related to God but to human nature. These were profound answers from those who were presumed to be the least able within the group.

At a visual level the answers that included a qualification of holiness as ‘beauty’ and ‘special’, were similar and seem to suggest that all people can be holy. Holiness is therefore, in this context, a transformative facilitator of human beauty: it transforms people.

Appendix 10: A shift in approaching Disability.
A philosophical reflection

Presupposition about disability:

At the beginning of our research journey we reflected upon our individual and collective understanding of Disability. This led us to suggest that people with Disabilities were: 'people with different physical and intellectual needs who are generally rejected by society for their difference, they stand at the bottom of society'. Thus, we had defined people with Disabilities according to their ability to interact within the world. What we hoped our research may achieve, was to suggest a way of providing 'full integration of people with Disability' through suggesting a way in which society could have the possibility to understand and interact successfully with people who have a Disability. At the start of the research, for us, Disability was a definition, a noun to categorize a particular 'kind of person' and a way to define a category within the human race that needed to be protected and respected.

The realty of 'protection':

As a philosophy student who was fairly new to research and to the field of Disability, Giada felt that society seemed to have created a marginalised group of people whom they have labelled as disabled. People with Intellectual Disabilities are vulnerable, in as much as they are open to discrimination and marginalisation. Due to this, they seem to have become a minority group. Also, due to the vulnerable reality of their lives and their marginalised state, they are people that society needs to protect.

When we speak of the need to 'protect and respect', however, we intend that it is not given within a culture of care, but within a culture of recognition and respect. That people with Disabilities need care of varied sorts, is an undeniable truth. Nonetheless, protection and the giving of care must be given with total 'respect' for freedom of choice, and the meeting of needs. By this we intend that; people with Disabilities must be recognised as equal human beings. For example, the Disability Discrimination Act *protects* the rights of disabled people but at the same time it promotes *respectful* living.

How can this be achieved?

As a result of this reflection *our approach to* Disability therefore seemed to occur in four steps, which we have named PPAC. Our emerging new approach to Disability, resulting from the focus group experience, thus seems to have its roots in the analysis and understanding of the communication skills of the people with whom we were interacting or who were choosing to interact with us;

Perceive (Observe): We perceived the body language and communication skills of participants. We also noted the way in which the participants related to: a) the environment b) peer participants c) research team

Pay attention (Listen): We paid attention to how the participants communicated with us. This occurred through sounds, words, actions, body movements, use of symbols and sign language.
Absorb (Learn from): By gaining this new information from the person that was before us we absorbed and learnt from them and as such we moved beyond our usual cognitive skills.
Communicate: We were, therefore, able to communicate effectively in a way that was empathetic with their 'way of being'. As every beginning of relationship, one has to understand and adapt their communication to have an effective exchange of feelings and thoughts.

When sharing with People who have an Intellectual Disability the challenge is bigger and one needs to find strategies which will allow personal, cultural backgrounds and personal, specific intellectual skills to stand apart.
In relational philosophy, the individual has to gather the 'radically other'[24] to oneself so as to be hospitable. To arrive at this practice of hospitality, one has to adapt personal skills and intellectual expertise to the ability and needs of the person with whom they are relating.
It seemed to us that this became entirely and effectively possible through the practice of; Perceiving, observing, paying attention, listening, absorbing, learning and communicating (PPAC), as doing this enabled a successful exchange with the people we had before us.

We found that, once PPAC was applied as a process, we began to interact *empathizing with* the 'other' person's way of communication and this allowed them to *teach us* how to communicate *with* them. This led us to think of our actions as empathic.

An exploration of Empathy:

Contemporary philosophers such as Simon Weil[25] and Hanna Arendt seemed to be a natural voice within the research. Their work on the 'gathering of the other' and on different definitions of empathy seemed to have a natural draw for all team members. Another philosopher, whose writing held great relevance for our research experience, was Edith Stein, whose work 'On the problem of Empathy' held a very important parallel

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[24] By citing the term 'radically other', we have drawn upon modern philosophers such as Simon Weil, Adriana Cavarero, Jacques Derrida and Michael Foucault. We suggest that the 'radically other' relates to a person who is distant from my personal life experience. The radically other could be a stranger, a person with a different culture or ability.

[25] Simone Weil is a modern philosopher whose work spoke directly into our experience. Giada explained that within her mystical experience of God she re-defined the concept of empathy. According to her work in "Waiting for God" and 'Love of God", she suggests that, in order to have a relationship with God, we have to create an empty space to gather the radically other. This concept was thus transposed into the relational model within the human story and as such became a language that we were able to relate to and which powerfully described our experiences.

with the insights that were bearing forth as we shared time with our research partners[26].

As we observed and absorbed the experiences and communication skills of participants, we revisited our initial definition of Disability and wondered if society had miss-told the story of Disability. Our experience of gathering the radically other and finding a way to enter into empathic, hospitable relationships with them seemed to stir, within us, an urgent need to re-narrate this story and give it as a gift that had the potential to create a paradigm shift in the concept of what it means to be human. The story of Disability, for us, was far from negative or about people who were 'not able'. We encountered a story of people with an incredible potential to communicate and teach, to relate and to be hospitable, to us as 'radically others'.

As a result of running the focus groups, writing and developing the Journey 'EveryBody Has a Story', we began to develop a new philosophy of approach and this guided us throughout the duration of the research and into the spiritual and theological reflections that have followed. The main influences in our thinking have been;

- 'Who I am' comes from one's own personal story. When we tell our own personal story, the 'other' absorbs what we share in the stories that we re-tell about ourselves and somehow give us back a different vision of our own self. I offer my own story which relates to 'Who I am' and I do this in my own way. The radically other, through the telling of their own story and personal perceptions of how they encounter who I am, gives me back my story but from a different prospective. This is given, as if it is a gift.

- Society has told the story of people with Disability in an incorrect and negative way: it seems to have perceived them as a problem to be solved and sorted out. This is a negative addition to their story which could result in them having a vision of their relationship with the world that is vulnerable and void of value. This could possibly be an abuse the 'being' of the Person with an Intellectual Disability whereby they are placed in the vulnerable context of a negative narrative. This addition is therefore 'not' gift.

- Non stereotypical forms of uniqueness of the person and their lived relationships: an example of relational story-telling that is *gift*.

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[26] In her doctoral thesis '*On the problem of empathy',* Stein explores the issue of 'empathy'. As with Weil, her writings spoke directly into the outcomes of the focus group and Journey *EveryBody has a story*. For Stein empathy does not entail a loss or projection of the self. Instead, she suggests that whilst maintaining a personal identity, individuals are often able to share in what the 'other feels' due to having had similar experiences and emotions. Stein believes that this commonality with the 'other' brings life to one's own experience and as such, from the 'I' and the 'you' arises the 'we', which she claims is the subject of a higher level (On the problem of empathy, p. 17-18, 1921).

At the start of our research we interviewed a woman, married to a man who is profoundly, physically and mentally disabled; she is his primary carer. Many perceive him to have an experience of humanity that is troublesome and burdened. It is often told that his existence places an unnecessary amount of work and effort onto his wife, thus adding a 'negative' to her own story and human, everyday reality. The human story that we were told, however, presents a very different prospective. The uniqueness of the person who is deemed to be disabled, due to illness, is presented through her own personal view point and speaks powerfully of the presence of her husband in her life. For us, their relationship is based upon a form of non verbal communication and through the lived experience of togetherness.

She is able to interpret his needs and to enter into effective agreement with him, learning his way of communicating and observing his way of being. The interview records her commenting: 'I do not see him as a negative presence but as the person that I love'. For her the very pattern of his breathing becomes a form of communication and presence (interview 2009).

- As we have now suggested, the relational nature of the *self* is sometimes made visible through the way in which another encounters you. From within that relationship additions can be made to the telling of your story, thus adding to your own understanding and experience of the self: this could, however, also be open to a misuse of power whereby one *tells* you *what* your story is, rather than make an addition to it that is given as a gift.

- During a conversation with Matteo and Cristina, Giada commented on the input of non verbal members of the focus group and research communities. She mentioned how they made powerful contributions to the telling of stories. Giada commented that she had begun to discover that all people are able to communicate in some unique way. This connected directly to our reflection on spirituality as presence (see appendix 8, p. 64). The nature of humanity enables a dialogue that moves beyond the stereotypical formats of communication, which generally seem to be based upon grammatical structures, sounds, syntax and semantics (Language). Humans, we have discovered, have the capacity to *present* their existence and an ability to relate to each other in non stereotypical ways. We have witnessed that, whilst our research partners had limits, as we all do due to our human nature, which included their capacity, or incapacity to relate to other people and to enter into reciprocal relationship, some also held a unique capacity to engage in relationship that went beyond language. We have discovered that, reciprocity of being can be implicit in any relationship between humans, what is not granted for many individuals, whether disabled or not, is a 'factual reciprocity': cultural, social, economical, sexual, reciprocity of choice and expression.

Philosophical principles in achieving effective, hospitable relationships

Having reflected upon the outcomes from the focus groups and research communities we would like to suggest that;

α) Agreement-Relationship

To have a relationship it is indispensable to have an *agreement* [27] before this relationship occurs.

β) Possibility-Impossibility

To have an agreement with People with Intellectual Disabilities could seem almost impossible but at the same time could become *too possible* because of issues of loneliness.

To enter into agreement with a Person with an Intellectual Disability could seem impossible; this could be due to barriers of communication and to a possible inability to empathise or discover different forms of communication and language. However, what makes a relationship possible is an openness that People with Intellectual Disabilities seem to show, due to a potential feeling of loneliness and a lack of opportunity to interact; this could create a *neediness,* within the person to obtain agreement with others outside of their usual environment.

An example of this was found in research community three, where participants waited patiently to welcome a visitor they did not know and showed her their Spiritual identity[28] *books (Giada's observation notes RSC3 session 4*.)

We noted that a need for friendship can create an open space (gap) within the Person with an Intellectual Disability, which could urge them to invite a stranger in without first reaching an effective agreement. This openness, if misjudged and misused, could create, however, an environment in which an exchange can occur easily but where the person is left vulnerable and unprotected against possible negative attitudes of others. It could be that their story is told *to* them out of a lack of understanding, damaging their story rather than *adding* to it as gift. This analysis leads us to underline the fact that, in the life of People with an Intellectual Disability, there is a Paradox which we have named; 'The paradox of effective agreement'.

γ) Effective relationship through Hospitality; a possible solution

It's therefore important to find a way to communicate with People who have an Intellectual Disability, so as to obtain an effective agreement, one which *facilitates* life choice for each person. In an authentic way, based on empathy and hospitality, a solution to the paradox could be found by balancing what is possible and impossible within the life of a Person with an Intellectual Disability.

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[27] By agreement we intend the consent of both parties.

[28] The spiritual identity book is the personal story book that is created by participants throughout the duration of the Journey: EveryBody Has a Story. In this book participants, having engaged in symbolic and creative activities, record their thoughts, choices and opinions. Thus, the book becomes a form of communication between their personal story and those who have the opportunity and gift of sharing this book with them. It is in itself a form of relating and narrating which goes beyond words.

This can occur through ‘encounter’ and through ‘intellectual’[29] new forms of communication that may need to go beyond words and formal language. There also needs to be a paradigm shift in our philosophical and anthropological understanding of what it means to be a member of the human community, where all are accepted in difference. Hospitality therefore, becomes a vital dimension within effective agreements and relationships with others.

Once again, as the dimension of hospitality arose in the research, we reflected upon some modern philosophers.

Jacques Derrida is one such philosopher who has approached the issue of hospitality. His exploration has its roots in the crucial issue which faced western society; that of migration. His goal was to understand and accept differences without judgements and presumption, without imposing one’s-own values and cultural statements on people. According to Derrida:

> ‘Pure or unconditioned hospitality does not consist in such an invitation; "I invite you, I welcome you into my home, on the condition that you adapt to the laws and norms of my territory, according to my language, tradition, memory, and so on". Pure and unconditional hospitality, hospitality itself, opens or is, in advance, open to someone who is neither expected nor invited, to whomever arrives as an absolutely foreign visitor, as a new arrival, not identifiable and unforeseeable, in short, wholly other"[30].

In our opinion, Derrida’s concept of hospitality is too wide, it seems unrealistic and in some ways his ‘unconditional hospitality’ could prove to create yet another vulnerable situation. In the light of this paper, we observe how easily, even within ‘unconditional hospitality’, the ‘paradox of effective agreement’ could occur and how the need for protection with respect must come into play. It is vital that the person with Disability is supported to be aware of what she is encountering.

Within the context of our research, the ‘wholly other’ that Derrida speaks of, could indeed be a person with completely different languages skills, a person that, when encountered, leaves one disarmed and amazed. Therefore, within this philosophical argument, we would suggest that, after the first encounter you have with the person who is ‘wholly other’, the next step is to find a common language which enables an effective exchange with them and begins to build relationship. A verbal language, within this context, is thus not necessary. We suggest that one should let the person that is before them be the ‘teacher’, in their personal form of communication, and vice-versa. The research team agreed that it is fundamental that a safe and respectful concept of hospitality is based on an effective agreement from both parties.

We applied this concept of hospitality to the way in which we interacted with our research partners with Intellectual Disabilities. We absorbed their communication skills and tried to replicate them in our attempts to achieve effective and meaningful

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[29] From the People with Intellectual Disabilities with whom you enter into agreement.

[30] (Philosophy in a Time of Terror, edited by Giovanna Borradori, p. 17-19, 2003)

communication (PPAC). People with Intellectual Disabilities, in turn, welcomed us through a ‘language of hospitality’, by gathering us into their environment and allowing us the possibility of getting to know them individually. For us, as a result of the research journey and outcomes, hospitality is a gift that needs reciprocity, an agreement and respect of spaces, choices and intimacy.

The question that therefore remains to be answered is; “Does society offer an un-hospitable hospitality, based on a need for conformity, or does it offer hospitality as a respectful gift?”

Here, we would like to suggest a possible answer to this complex paradox. As human beings we are born relational; an example of this could be the need of a foetus for its mother’s womb. Within relationships there should exist freedom of choice and balance of power, this should also be so in the relationships that People with Intellectual Disabilities have within the human community at large or with those directly involved in their lives. After the established agreement, identified in this paper, relationship can occur. We are all human beings, exposed to the world in our vulnerability and potential. As we see from the example of the foetus and the mother, our first need is to be protected and subsequently to be related to another; these are ‘conditions of each other’. Relatedness provides the possibility of being in contact with others, and through this one can gain a deeper understanding of their own self. From a relationship that is based on mutual respect, understanding and empathy, friendship can also occur.

So as to have a deeper understanding of *our self,* we can relate to people’s stories, as well as our own: the story of our childhood, the story of our dreams, and the story of our days. We found that the ‘exchange of stories’ is a very effective way for people with an Intellectual Disability to arrive at a deeper understanding of themselves. It also provides them with a possibility to communicate, interact with people inside and outside their immediate environment. However, the opportunity to share their story is often denied to them and more often than not their story is ‘told and decided upon’ by others. Every story is as unique as every person is. Each single story in relation with another story can be the basis for a strong and deep understanding, a way to empathize and build up friendships.

From the experience of our research journey we, therefore, intend empathy to take on the following meaning;

> “A way in which one finds a space to gather another person and all that is part of who they are, into themselves. This is done, not through losing one’s own self, or projecting their personal thoughts and feelings onto another, but through *sharing* their being with the ‘other’ who is present before them. As such it becomes possible to find an agreeable, communal language and communication with and through the other so that our stories may be narrated.”

We have found that the uniqueness of a person can be expressed in exchange, reciprocity and participation. This can be achieved through the communicating and sharing of one's own specific story. Even if a person has an Intellectual Disability or indeed is in a coma, they can be relational within the world through other people and the experience of togetherness. An individual's particular story can be communicated as a result of a shared prospective and communication skills, which in turn lead to authentic exchange. In this way the person is no longer defined by their ability, reason, will or cognition but by their story, presence and interaction with the world, be it passive or active.

For an understanding of 'action', we turned to Anna Arendt's writings on 'The human condition'. Arendt describes action as the taking of 'an initiative, to begin to act something into motion'.[31] This presented us with another question; "How can people with profound Intellectual Disabilities be part of this concept?"

If, as Arendt suggests, to act means to 'cause a motion' then also a person in coma or with very limited physical and cognitive ability can 'cause a motion' (as we see above in the experience of our married couple). Each person, irrespective of ability or consciousness, have their unique and incredible story, they act politically, even if they are placed on the margin or at the bottom of society. People with Intellectual Disabilities, through their communication skills and needs 'make people move', irrespective of what their own personal ability may be. This is a common act within humanity; we all have the capacity to make another move. What we have witnessed, in our research, is that People with Intellectual Disabilities have the capacity to 'move themselves and others' into a 'new and respectful concept of what it means to be human within a human community' (society). It is important that people who have an Intellectual Disability are not seen to exist so that people can be *moved into improving* themselves or to revisiting themselves, in any self psycho analytic way. Their presence in people's lives is not *functional*; instead mutual reciprocity must be sought, where all parties benefit from encounter. What we have discovered is that, through a sharing of stories, a hospitable space was created where positive and creative action took place, whereby 'we all came to a new understanding and a recovery of what it means to be equally human.'

Translating Philosophical Speculation into practise.

The journey that has been created as a result of this research project, *EveryBody Has a Story*, is important due to the space that it creates to exchange information as well as the opportunity to narrate and express oneself. Through the communication of stories, which was at the centre of the research, we observed the way in which each human person that participated, moved others within their own stories. The initial title of our research project suggested a philosophical position that seemed to suggest a 'them' and 'us' approach. This, however, shifted significantly as we developed a possible and hospitable way for people to *be* together, experience each other's story and find some way of expressing it, be it within social or religious practice. We consequently returned

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[31] (The Human Condition, p. 177, the University Chicago press, 1998)

to the title and changed the wording so that it reflected our shift in concept. The shift was therefore as such :

From : Enabling communities to *meet the religious* and spiritual needs of People with Intellectual Disabilities.
To : Enabling communities to *meet People with Intellectual Disabilities* and respond to their expressed need and hopes.

This research has developed a focus on building equal communities rather than enabling communities to *do for* disabled people. Our experience suggests that it is about *doing with them*. We found that, where agreeable reciprocity exists, an attitude that presents a 'them' and 'us' approach to human existence, cannot exist. Our research experience has suggested that positive and effective agreement, with people who have an Intellectual Disability, causes a cyclical movement to occur. The experience of encounter can provide society with an opportunity to question itself and the types of agreements that it enters into, as well as the nature of hospitality it offers.

Disability, therefore, challenges the paradoxical 'un-hospitable hospitality', that we have suggested exists within society, as well as its need for uniformity and collective thresholds[32] of what it perceives to be 'normal and perfect'.

As such we feel that the questioning and cyclical process *that has been followed in the journey*, identified throughout our research, has the potential to enable members of the human community to re-visit and re-turn to themselves. However, this should be done with a new awareness, a deeper understanding of personal concepts and with new skills in communication and relationship.

Our research suggests that the encounter with a disabled person, as with any other person within humanity, is indeed a meeting of *being*. As a result of the narration and exchange of stories, we were indeed sharing in a 'sense of life'.[33] We were all given, irrespective of presumed structures of ability, an opportunity to enter into unique and creative relationships with each other, discovering innovative and agreeable ways of expressing the spiritual experiences, which we shared as equal human beings.

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[32] 'Uniformity and Collectivism': here we intend a group of people that seek to meet and ideal. We have reflected on the fact that we feel that 'an ideal has been set', even within the disability rights movement and also within person centred plans, which seeks to enable autonomy and independent living. These ideals, however, risk forgetting a need for relationship and can sometimes even deny its possibility, leaving the person with Disability open to 'structured loneliness'. This can be disguised as individuality but if the person cannot meet the ideal, situations of failure and loss of self esteem can arise. Within collective movements there could be the danger of the loss of the unique nature and being of a person. Simone Weill, in her spiritual autobiography, *Waiting for God*, speaks of the danger of collectivism. According to Weil, collectivism can be dangerous when the individuality of one person is going to be obliged and obscured by ideals and power of the whole group. In the light of this and giving attention to the specific nature of People with Intellectual Disability, we feel it is important ***not*** to identify People with Intellectual Disabilities as a ***collective group of people***. What we need to do is to redefine a concept of humanity which is able to include every kind of person without losing the specificity and the radical oneness of every human being.

[33] The concept of a 'sense of Life' can be found in appendix 8, p. 64

Appendix 11: Ethics Application

ETHICS PROCEDURE

SECTION 1

Background

The College Ethics Committee will review all applications that are awarded funding by external funding organisations. This is to ensure that the University can comply with the requirements of that particular funding body and that a robust record is kept of the measures taken to ensure that ethical issues are recognised and addressed appropriately.

The attached form should be completed for *ALL* externally funded research projects.

Procedure

The process is detailed below:

1) When an application has been successful and the notification of award received from the funder, the researcher should complete the attached ethical approval form for the proposed project.
2) The form should be completed and returned to the Business Development Officer as soon as the award letter is received and certainly before the work commences on the project.
3) The Business Development Officer will forward the document under cover of an e-mail to the Convenor of the College Ethics Committee with his/her comments.
4) The Convenor will consider the proposal and make appropriate recommendations. If appropriate he will circulate the form to the entire College Ethics Committee for their comments (this is only likely to happen where the proposed research is complicated or involves a partner organisation).
5) If further information is required from the applicant during this process, the Business Development Officer will contact them. Researchers will be given an opportunity to address the College Ethics Committee in person if necessary.

EXCEPTIONS

This process only applies to externally funded projects. Schools/Departments retain responsibility for approving student projects and those projects to be carried out with internal funding.

Should the applicant require access to participants through other organisations then they must contact the organisation, establish the mechanism for obtaining consent and take appropriate action.

SECTION 2

Project Details

Name/s of Applicant/Co-Applicants: Professor John Swinton

Email address(es) and Telephone Number(s): j.swinton@abdn.ac.uk; 273224

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1. Project title.
Understanding the spiritual lives of people with profound and complex Intellectual Disabilities: a community oriented action research approach

2. Start Date. 1/6/08

3. Finish Date.1/6/10

4. Give a brief description of the aims of the research, including the research question/s, and/or hypothesis to be investigated. (maximum 100 words)

The University of Aberdeen's Centre for Spirituality, Health and Disability (CSHAD) (www.abdn.ac.uk/cshad) has developed a unique programme of action-oriented research that has sought to explore the role of spirituality in the lives of People with Intellectual Disabilities. The results of this research have shown clearly that spirituality forms a significant (if often unrecognized) dimension of the lives of People with Intellectual Disabilities and that many people want this aspect of their lives recognized and incorporated into care and support strategies. The role of spirituality in the lives of People who have profound Intellectual Disabilities with high support needs is an area about which we know very little. (ie people who have a profound Intellectual Disability which includes high support needs and communication difficulties that present major challenges to getting one's views and preferences heard and understood). The project will utilize a community oriented action research approach to examine the role of spirituality in the lives of People with profound and complex Intellectual Disabilities. It aims to achieve the following:

- develop knowledge and understanding of the role of spirituality in the lives of people with high support needs and use this to develop, implement and assess concrete practical strategies for enabling effective spiritual care and support;
- provide a protocol for developing models of inclusive community that can become practical and theological resources for people with high support needs;

- contribute to the body of methodological literature that seeks to discover effective ways of communicating and researching with People who have profound Intellectual Disabilities and little or no verbal communication;
- contribute to the developing methodological literature on Practical Theology and Qualitative Research;
- Contribute to the development of person-centred forms of care by developing an original care plan approach that will enable communities to recognize, support and value the spirituality of people with high support needs.

5. Will the research be carried out in the UK?

YES	
NO	**X**

If NO, indicate the geographical location(s) to be visited as part of the research

project below

UK and Ireland

6. Does the project involve the study of living human beings? ***(Please mark X in the appropriate box)***

YES	**X**
NO	

If YES, please answer the questions below. If NO, go to question 7.

a. Describe the intended participants in the investigation. Give details of the sample size and the methods to be used to recruit participants (if appropriate). (maximum 100 words)

The study involves People who have a profound Intellectual Disability which includes high support needs and communication difficulties that present major challenges to getting one's views and preferences heard and understood. The sampling will be purposive. In purposive sampling the researcher attempts to obtain "samples" that appears to him/her to be representative of the population being explored. Within qualitative research the object is not to produce data that is statistically representative. Rather, the key to good qualitative research is the richness and depth of the data. The study will focus on 6 people with high support needs who are embedded in different forms of Christian community. (e.g. Reformed, Catholic, Evangelical, Pentecostal, Intentional-L'Arche) This will provide a rich and wide range of beliefs, values, theologies and practices, all of which should offer different but complementary perspectives. Bearing in mind the circles of care that we will be working with, the total number of research participants could be as high as 100-120 people. Participants will be identified through various networks and connections that professor Swinton and the Centre for Spirituality, Health and Disability has gathered over their years of working in this area.

b. Outline the proposed methodology and the procedures to be used with the participants. (maximum 500 words)

The study is located within the discipline of Practical Theology (PT) and will utilise a qualitative research method drawing on insights from Participatory Action Research (PAR) and Person Centred Planning (PCP).

Practical Theology

Practical theology is a reflective, action oriented discipline that works at the interface between theory and practice, seeking to challenge and motivate religious communities to respond to the implications of their faith traditions and practices as they interact with wider society. Practical theology engages in forms of theological reflection based on a cyclical/reflective movement from practice-theory-practice, with a view to developing new forms of action/practice.

Participatory Action Research

PAR is a family of research methods which simultaneously pursue action (or change) and research (or understanding). PAR has a dual commitment to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. To enable this process of knowledge generation and change, PAR uses a cyclic process which moves between action and critical reflection on that action, with a view to initiating and sustaining new knowledge and effective change. PAR is necessarily participatory involving individuals, families and communities as *co-researcher* with responsibility and ownership of the process and the findings. It assumes *collaboration*, *partnership* and *community*.

Person Centred Planning

PCP is a set of values and strategies that can be used to assist an individual with an Intellectual Disability in creating a vision for the future and a plan for working with others toward realizing that vision. It is a way of planning strategies that focus on people rather than services or programmes. PCP sees people's capacities, building on the strengths, gifts, and abilities of individuals and their circles of support. PCP seeks to build communities that embody a social model of disability wherein the person's particular "problem" is assumed to be a product of society's negative response to their impairment. Its focus is on encouraging communities to change in response to the presence of people with disabilities rather than the other way around.

Developing the method

Using communities as loci for research

A basic assumption is that it is not the Person with profound Intellectual Disabilities who needs a plan for change, but the person *and* the people they count on to interpret their vocation and then to create the conditions in which they can pursue that vocation. What is required is an '*us* plan,' rather than a '*me* plan': a 'me plan' would trap the research into trying to work through ways of making first person statements for the individual. The project requires an approach that reflects reality for the person with high support needs, silent of words though perhaps not of physical expressions, obviously different from others in the amount of assistance she needs to be comfortable through a day. What's required is a particular form of research *community*. We might describe such a community as a 'community of resistance,' i.e. a community that has made a conscious decision to resist accepting culture's devaluing assumptions about people with profound disabilities and its consequent failure to craft valued social roles that allow everyone to bring their gifts to their community and who are, in different ways, dedicated to being with and for the individual during the research process and afterwards. Within such a research community, vital questions should emerge: "How might we discover what spiritual gifts the person might bring us and we to her?"; "How might common stereotypes of disability and our own discomfort and even fear of difference and obvious dependence distort our attempts to discover her vocation and support her in it?"; "Where and to what can a community of resistance bring her too?". The presence of the person with high support needs poses a dilemma: our society values individual choice above many other things (in fact it is a factor in society's devaluation of her) but she depends on us to discern who she is and under what conditions she might thrive. "How do we know that she wants to belong to us and how could we know if she assents to what matters to us (in this case spirituality) and what do we do if we can't work out how to be sure?"; "Might we be held back by a fear of taking responsibility for action based on incomplete knowledge of her own will and wishes?". All of this assumes that such questions are a matter of significance for whatever community the person finds herself welcomed by. A major strength of this project is that it will bring all such assumptions and speculation down to earth and reveal what real questions and dilemmas emerge and the tensions that exist as resolution is sought.

The research process

To facilitate this, the research process will utilise a four stage cyclical framework for data gathering, reflection, analysis and change:

Stage 1: Exploration

The researchers will work with individuals who have high support needs and those closest to them to bring together a 'research community.' This will develop a provisional community of people who are ‘around’ the person with high support needs, supporting them, spending time with them, being friends, advocates, etc. Through this process, these people seek to come to ‘know’ that person on a spiritual level and find ways of communicating that knowledge. This stage of the research is not simply about a person getting what she wants, but about a community working out how to embody their spirituality with someone who communicates differently.’ It is assumed that it is not the person with severe disabilities who has whatever trouble there may be, it is the community. Following consultation with an internationally acknowledged expert in the field of PCP (John O’Brien), the PCP tool of choice to facilitate this stage of the research will be MAPS. (Making Action Plans) MAPS combines imagery, words and relationships to produce a plan that offers a meaningful picture of the needs and capabilities of the individual and provides a vital community oriented way of bringing together baseline research data. MAPS requires two facilitators (one to facilitate the group and the other to record the proceedings) and is typically used in a meeting lasting 2-3 hours with the person and those who form her community of support.

Stage 2: Planning

In this phase, goals will be established and a plan for meeting these goals will be developed. The research community will decide upon specific goals and how these goals can be achieved. Goal setting will relate to describing what is important to the person with high support needs and the ways in which that person can be supported in order to achieve those goals. This phase will include planning and strategies which relate to the individual and her community.

Stage 3: Action

An action plan will be put into place and the progress of the plan evaluated and documented. This phase emerges when the goals and strategies developed in stage two are agreed upon and people feel ready to move from exploration and reflection to action. The precise shape of this phase is dependant on what emerges from stages one and two. The key thing about this phase is that it is action oriented, designed to implement the strategies and/or interventions that have emerged. Progress will be closely monitored by the research team and if the goals are not being achieved or are appearing unrealistic, it may be necessary to return to phase two and re-strategise.

Stage 4: Reflection

In this stage the team will reflect on the work that has been undertaken to assess whether or not the goals have been achieved, and whether or not they have been achieved in the ways we had expected, if they were not achieved why not. Here we will assess and evaluate the strategies and plans and if necessary return to stage one with revised and deeper practical knowledge and a clearer perspective.

As part of the processes of documenting the Research Fellow will draw on the tools of ethnography to build up a rich, thick description of the particular settings in which the team is working. This will provide deep insights into the particular communities that are participating and throw light on some of the wider issues. E.g. Reasons why things are done in particular ways, why things work well in one context and not in another, what and why particular beliefs, values and practices prove to be beneficial and others are problematic.

c. **Outline the procedures you intend to use for obtaining informed consent from all participants, including where appropriate parental consent for children.** ***If possible, include copies of information for participants and consent forms/letters.*** **(maximum 200 words*)***

This project is funded by the AHRC speculative route. Part of the aim of the project is to develop new methods and ways of researching in this area. To date there are various procedures for gaining informed consent from People with Intellectual Disabilities or for working with proxy consent from parents. Discovering precisely which way of gaining consent would be most appropriate is part of the project's objectives. At the moment the intention is to hold an initial meeting within which the individual would be invited to participate. Communication would be facilitated in the most appropriate fashion for the individual in collaboration with family, carers and support workers. All participants will be assured that participation in the research is voluntary and that they may withdraw at any time without affecting their care or support. They will be assured that all data will be handled confidentially and that it will not be possible to identify individuals from the results. All of this will be incorporated in a standardised letter of informed consent. With regard to those who are not able to understand formal consent forms information and consent forms would be prepared in easy to read language, by using Makaton, (a form of sign language for People with Intellectual Disabilities) or/and via symbols. Professor Swinton has used this approach in previous research and has found it to be accurate and appropriate. It would also be intended to use Talking Mats or Boardmaker software if required[34]. It is accepted that this dimension will have to be explained carefully in person, as the needs of each individual will be different. Proxy consent will be the least preferred option.

d. **Do you plan to conceal the identity of your subjects during the data analysis phase of the project and for publications? If so, how will you protect their anonymity? (maximum 200 words)**

Yes, all participants will be anonymised. Only the research team will know people's identity. Any data that readily identifies the participants will be held on a university computer with password protection. Only professor Swinton and the research Fellow working with him will have access to this data.

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[34] Boardmaker is a graphics database containing over 3,000 Picture Communication Symbols (from PCS Books I, II, & III) in bitmapped clip art form.

e. **Do you plan to conceal your own identity during the journey of the research? Please explain why you feel this is necessary and outline the benefits and risks involved. (maximum 300 words)**

No

f. **If you will require access to personal information about participants from other parties (e.g. teachers, employers, or any other agencies), databanks or files, please give details. (maximum 200 words)**

As can be seen from the method, we will be working in collaboration with the social networks of individuals. We will not require formal access to personal information but we will require people to inform us about aspects of the person's style of communication.

g. **Outline the potential risks to participants (eg psychological stress, discomfort, personal safety) and indicate the actions to be taken should these risks materialise. (200 words)**

Because we are exploring personal issues it may be that certain things that we discuss with people are upsetting. We do not anticipate this judging from past experience, however it remains a possibility. The entire project is focused on the person's extended relational network. We will therefore always be working alongside of people who are close to the individual with an Intellectual Disability. Support and assistance if any issues arise will be present at all times.

h. **If the participants reveal sensitive information (eg their involvement in illegal activities), how will this information be handled?**

This is unlikely with regard to the population that we are working with. However, if, for example, a person told us about an abusive situation that they were involved in then we would feel it our moral duty to respect the person, ensure beneficence and inform the appropriate authorities.

i. **If the collection of data involves the use of audio/video recording, how will the recordings be used and what are the plans for archiving this data? (maximum 200 words)**

The project will involve audio recording and may involve video recording. All of the data will be kept on university computers which are password protected. Only professor Swinton and the research fellow ill have access to this information. It will be stored for 5 years.

7. Please provide any further information you think relevant.

It should be noted that the project comes via the AHRC speculative route. This being so it is very much experimental in its ethos. The ethical procedures outlined above are appropriate according to the literature within this area of research and have been tested effectively by others and by Professor Swinton. Nevertheless, it may be as the project develops that more effective ways of, for example, gaining informed consent, might be developed in which case the procedures would be modified to ensure more effective ethical protection for participants. This is a unique project that will require unique approaches in terms of method, practice and ethical responsibility.

Declaration:

I hereby declare that the programme of research has taken account of ethical guidelines issued by the relevant professional body for this research and complies with the University of Aberdeen's Policy on Good Research Practice and Procedure (http://www.abdn.ac.uk/hr/policies/grpp.shtml)

Signature/s of applicant/co-applicants:
Date: 23/5/08

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