Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing International Conference.  13 and 14 March 2012

**Workshop:** From Community Learning Disability Team Psychology to Faith Based Ceilidhs with People with Learning Disability (LD)

2.15 Brief introductions round the room (name / role / where put self on flipchart quadrants – see p2)

*For later:*
Envisage a person (with learning disabilities) you have worked with at some intensity /duration in the past and have a sense of personal connection with.
S/he is not currently open to you.
Put yourself and him / her on flipchart quadrant sheet – see p2


2.25 How did I get there? See p 4 / 5

2.35 Case Study Dilemmas based on real situation

Complete worksheet (p5) with **first thoughts**
Record on flipchart (p6) how much Rules / Relationships influenced your decisions

2.40 Discuss in pairs

2.50 Plenary 
What was most tricky?
What surprised you about your responses?
To what extent did the Rules or Relationship govern your responses?
Is that something you would have wanted to be different?

2.48 Brief case study, later questions / afterthoughts (p 7 ) and references (p 8 / 9)
Me

Patient / Client / Service User
How did I get there? Brief personal / Professional resume

Last 10 years
- Practising faith from youth
- Family of faith
- P/T Career in LD Clinical Psychology
  - CLDT includes psychiatry, CLDNs, OT, Physio, SaLT, Dietician, Psychology
  - Liaises with GPs at one end of the patient journey to hospital /palliative care at the other, as well as Social Work and Voluntary sector care providers.
- Adults with global LD – slow learners, complex array of physical and mental health needs, family histories and living circumstances…often socially excluded, vulnerable to bullying and harassment and worse
- Psychologist who happened to be a Christian
- Maintained boundaries with faith based care providers eg L’Arche
- Family member’s mental health crisis
- Several years involvement with mental health services
- Impact on professional self – reduced hours
- Advice conflicted with faith, apparently not seeing faith (community) as resource
- One professional shared own allegiance – experienced as supportive
- Faith community as life raft for each family member

Fast Forward
Job ad in church bulletin: development worker for Prospects in Scotland. *Would be a good job for someone…..why not me?…..applied, but didn’t get. Continued tentative involvement with local Prospects group.*

Colleagues retiring at 55; shall I?

Promoting Health, Supporting Inclusion Grant / 2 month career break in 2009 / exhilarating/ passionate hard work
Spiritual lives of PLD / should CLDT staff enquire? How?
- Absence of spiritual care except when admitted as inpatient (tick box)
- Curious whether it is important to PLD / what it means for them
- Identify barriers / balance of responsibility
- Share findings

Literature review / Visits to faith based groups / interviews with faith based agency representativess, provider agency managers and parents / focus group.

Essential Outcomes:
Qualified support for the idea that the spiritual lives of PLD are a legitimate topic for health care professionals to enquire about during clinical contacts, and that accessible information and communication passports might be helpful. There was little awareness of any training for health staff on spiritual issues. Broad recommendations to promote / support PLD’s religious / spiritual interest and experience across the lifespan.

See reference list  p 8 / 9
Spiritual Care and Health Conference. 13 March 2012.  Workshop: From Community Learning Disability Team Psychology to Faith-based Ceilidhs with People with Learning Disability

Participation in Chaplaincy Collaborative Research Project

Proposal to audit what CLDT staff do in relation to the spiritual needs of their clients didn’t fit LD strategy and was perceived as ‘about me.’

This overlapped with developments in my faith community (church) of ‘Missional Expressions’ – working out faith in areas we have a God given passion for.

Elders inviting proposals: out of combination of my study leave observations and own spiritual journey the idea of ceilidhs as format and the name Square Wholes appeared in a light bulb moment. …. as a structured but accessible way of church members being involved in welcoming PLD, featuring ceilidh dancing, worship songs, sacred stories either as drama or storytelling….They've been going well.

Continued working but energy diverted.

Decided March 2011 to retire at the end of 2011, attracted to spiritual care and people with learning disabilities as an arena for future endeavour but not sure exactly how.
Case Study Dilemmas Worksheet  5 minutes to jot first thoughts

You are working your notice as a health professional or paid carer.

On axes, mark where describes you in terms of

no religious faith…….. active religious faith
spiritual ……………… not spiritual

Envisage a person (with learning disabilities) you have worked with at some intensity / duration in the past and like as a person. S/he is not currently open to you.

On axes: mark where describes him/her in terms of

no religious faith…….. active religious faith
spiritual ……………… not spiritual

Before you leave, the team hears that:

S/he has a terminal illness and is in hospital

Do you visit? Do you share observations with the relevant team?

After you leave

What do you do if a team member spontaneously updates you about him/her?

How do you decide whether or not to
a) visit (again) or
b) go to the funeral?

If you decide to visit, how do you make clear (to someone with a learning disability) that it is in a non work capacity?

How would you come to your decision?

Who might you discuss the dilemmas with?

Would it be a subject of prayer?

Who gives permission?

NOW, put a cross on the graph (Flipchart – p6) to show how much Rules and Relationship influenced your decisions.
Rules:
0: ignored (unaware of)
1: aware of but actively disregarded
2: aware of and taken into account
3: aware of and followed to the letter

Relationship:
0: Patient status eclipses sense of friendship
1: Patient status outweighs sense of friendship
2: Sense of friendship equals patient status
3: Sense of friendship outweighs patient status

NB:
- Patient = client = service user
- Spiritual care for people with learning disabilities is thought to be articulated in the language of Friendship
- This begs the question of reciprocity of friendship – as relationships are constrained by roles
- Is it ever OK to violate the role expectations (enter the space) of someone who is at their most vulnerable?
Case study: Described the decision making process regarding an ex-patient with mild learning disability and unexpected end of life care – wanting to show that he was not only significant to family and paid carers - finding myself recognised and welcomed.

What is the balance between role boundaries / professional silos / doing things by the book and the human caring response to a feisty individual who elicits great loyalty?

a) Wasn’t it the human caring response that drew us into the caring professions in the first place?

b) In this situation what is person centred, good spiritual care?

Is a person with learning disabilities going to assume I’m there in a professional capacity?

Why would it be OK to attend the funeral but not to visit to say goodbye?

In the particular example used the siblings turned out to have a live faith / church connection. The minister mentioned at the funeral that the person had been happy to be prayed for by his siblings and affirmed his faith. Despite not knowing him, the minister captured something of who the person was, still surprising his family to the end with the ‘more’ about him than they suspected).

Later Questions:
- Was my visit, and his siblings prayers, for me /them or for the person with LD?
- How can we be authentic and allow their authentic selves to be heard / surprise us?
- What if he had said he didn’t believe / understand / want to know?
- What was the person’s capacity for formal ‘belief’?
- Or is faith expressed in trusting others – the concrete representatives of God’s love?

Afterthoughts I hope that I am honouring the person’s memory as someone who coped better than I would ever have expected with a traumatic terminal illness and sharing the lessons learned.

Hard on the heels of this person’s funeral, one of the Square Wholes team lost her father after a long slow decline. One of the regular ceilidh attendees who has profound and multiple disabilities lost his father suddenly. The father had told me how moved he had been that members of the Square Wholes Team came and chatted with him and his son…..when he had often felt that they were excluded and avoided in other churches. He and his family illustrated well the kind of forward thinking, person centred planning illustrated in Jim Mansell’s Report to the Department of Health, ‘Raising Our Sights.’ I never had the privilege of meeting Jim Mansell, CBE, but he was the open minded editor of Tizard Learning Disability Review when I approached him about writing up my findings….even though he did not espouse any faith position himself. (Wilson C.  Is there a case for community learning disability teams considering the spiritual needs of people with learning disabilities? (2011) Tizard Learning Disability Review. 16 (3) 31 – 40.)

I am thankful for the serendipity of contacts, references and events that have led to this conference and workshop. I hope it has been stimulating for you and I look forward to seeing where it leads.
References

Spiritual Care Matters: an Introductory Resource for all NHS Scotland Staff, 2009 NHS Education for Scotland.

Religion and Belief Matter – An Information Resource for Health Care Staff


Swinton J Why are we here? Meeting the special needs of people with learning disabilities 2004 London: Mental Health Foundation


Swinton J Spirituality and the lives of people with learning disabilities Learning Disability Review 7 (4) 2002b

Swinton J No Box to tick : a booklet for carers on meeting the spiritual and religious needs of people with learning disabilities. 2004 Foundation for People with learning disabilities

Swinton J What is important to you? A Booklet for people with learning disabilities 2004 Foundation for People with learning disabilities Downloadable from www.fpld.org.uk

Scottish Inter Faith Council: www.interfaithscotland.org

L’Arche UK: www.larche.org.uk

Crossreach: (Church of Scotland) www.crossreach.org.uk

Faith and Light Scotland: www.faithandlight.org.uk

Prospects: www.prospects.org.uk

Foundation for People with Learning Disabilities www.fpld.org.uk

British Institute for Learning Disabilities www.bild.org.uk

Spirituality, Health and Disability at the University of Aberdeen. Professor John Swinton (www.abdn.ac.uk/cshad)

Google Elizabeth M Boggs Center on Developmental Disabilities for publications by William Gaventa – billgaventa@umdj.edu
Reinders H. Receiving the Gift of Friendship: Profound disability, Theological Anthropology and Ethics (2008)

Mansell J (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities (Report and videos)

Wilson C. Is there a case for community learning disability teams considering the spiritual needs of people with learning disabilities? (2011) Tizard Learning Disability Review. 16 (3) 31 - 40

Chaplaincy collaborative Research Project: