

Life satisfaction for children with profound and multiple disabilities: What is it?

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Association for the Welfare of Child Health**

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Handout Notes to accompany PowerPoint presentation

Conference Theme: Healthy solutions for children: Making the right choice...
Have we got the right balance for healthy solutions for children?

Conference Stream: Child and adolescent health and lifestyle: Is it only
lipservice?

Presentation Title: Life satisfaction for children with profound multiple disabilities:
What is it?

Presentation Description: An appreciation of the potential richness of life
satisfaction for children with profound multiple disabilities is central to the work of
health care practitioners in meeting the emotional and social needs of these
children.

Presentation Abstract: Children with profound multiple disabilities (PMD) who
have no speech, little controlled movement and (reportedly) the most severe
intellectual disabilities rely on their communication partners to interpret and
respond to their interests, wants and preferences. What is life satisfaction for these
children? Can the life satisfaction of these children be discerned? How can
parents, carers and service providers be better informed about the children's
interests, wants and preferences? How can services, policies and programs really
embrace and respond to the core principal of improving quality of life?

The author's research addressed these questions. The study was a
qualitative one, embracing the theoretical perspective of symbolic interactionism
and adopting grounded theory methodology. It is the author's position that the life
satisfaction of children with profound multiple disabilities can be discerned, and
that a better understanding of factors which contribute to improved life satisfaction
can inform relationships and practices leading to a better quality of life for these
children.

This presentation will briefly describe the purpose, theoretical perspectives
and methodology of this study, and present and explain the findings. These
findings are presented as a narrative storyline with a conceptual scaffold that
outlines a grounded theory about the nature of life satisfaction for these children. A
better understanding of the nature of life satisfaction for these children could
empower carers, service providers and other professionals to respond better to the
interests, wants and preferences of children with PMD.

Presenter's Biography

Gordon is a lecturer in the School of Education at Macquarie University. One of his
research interests is about understanding quality of life for children with profound
multiple disabilities. His special interests are Karen - his wife, who travels to far
away lands every year, and Adam and Chrissy, his children - who grew up, moved
out and occasionally move back in.

The Research

Doctoral dissertation 2001-2003

- Problem... Can the LS of children with PMD be discerned?
- Question... What is LS for these children?
- Question... How do we learn about the LS of these children?
- Question... Does the Life Satisfaction Matrix (Lyons, 2000) 'make sense'?

The Study

- Guided by symbolic interactionism and grounded theory methodology
- 22 children (12 with PMD, 10 with HSN)
- 77 communication partners, including parents, teachers, teacher aides, carers, support professionals and family members
- 470 hours participant observation in school, home and community settings
- 130 interviews with communication partners (individual, group, repeated)

The Findings

- The LS of children with PMD can be discerned
- LS for children with PMD: A grounded theory
- 'Coming to know' children with PMD: A grounded theory
- The Life Satisfaction Matrix (Lyons, 2000) 'makes sense'.

LS for children with PMD: A summary storyline

Life satisfaction for these children is primarily about doing enjoyable things, by being engaged with people who - and in activities that - are needed, wanted, liked and/or preferred.

Life satisfaction for these children is the same as it is for all children, but is often expressed in very personal ways. The term life satisfaction doesn't make sense for these children, but quality of life and happiness do. Different people view life satisfaction for these children in different ways, depending upon how they understand disability. Unfamiliar others often see only disability in these children – and not how they are feeling, learning and growing. It must be remembered that these are children – not adults. They have a future - but they live mostly in the 'here and now'. This shows through a clear individuality in their expressions and character.

Life satisfaction for these children is about feeling both happiness and contentment. This should be 'day-by-day', because their lives are mostly experienced one day at a time. Contentment for these children can be 'just taking it all in'. It's about a personal balance.

Life satisfaction is also about comfort and wellbeing. Physical health is so important when acute and/or chronic pain is so prevalent, so daily wellbeing – just having a good day – is valued. Central to this wellbeing are relationships with others and belonging with others.

Life satisfaction for these children is also doing and having favourite things. This is often about: being with others – caring and sharing; doing special things - with special people; the freedom, fun and belonging of playing in water; and enjoying a wicked sense of humour!

This box presents a summary storyline of my theory. This is the first and simplest layer of explanation of the theory. This summary storyline enmeshes with both the second layer provided by the conceptual scaffold and the third layer provided by the relational scaffold. This is a summary of the full storyline that makes up the fourth and most detailed layer of explanation. The fifth and final layer of explanation posits hypotheses to explain key interrelationships between the theory's categories.

Life satisfaction for children with PMD: A conceptual scaffold

Central category Doing enjoyable things... Life satisfaction for these children is primarily about doing enjoyable things. It's about being engaged with people who - and in activities that - are needed, wanted, liked and/or preferred.

Main category Just like other children but personal... Life satisfaction is the same for all children, but for these children it is often expressed in very personal ways.

Subcategory Life satisfaction discourses... 'Life satisfaction' doesn't make sense for these children, but quality of life and happiness do.

Subcategory Disability discourses... Disability is understood in different ways. Unfamiliar others often only see disability in these children – and not how they are feeling, learning and growing.

Subcategory Childhood and adulthood... These children are developing. They have a future, but they live in the here and now.

Subcategory Individuality... These children are individuals, and have their own characters and expressions.

Main category Happiness and contentment... Life satisfaction is about feeling both happiness and contentment.

Subcategory Day-by-day... Happiness and contentment should be daily, and life one day at a time.

Subcategory Just taking it all in... Contentment can be just taking it all in.

Subcategory Balance... Happiness and contentment is about personal balance.

Main category Comfort and wellbeing... Life satisfaction is about feeling both comfort and wellbeing

Subcategory Physical health... relief from acute / chronic pain is prerequisite.

Subcategory Daily wellbeing... Just having a good day is valued.

Sub-category Belonging... Relationships are central.

Main category Favourite things... Life satisfaction is doing and having favourite things.

Subcategory Being with others... Is caring and sharing.

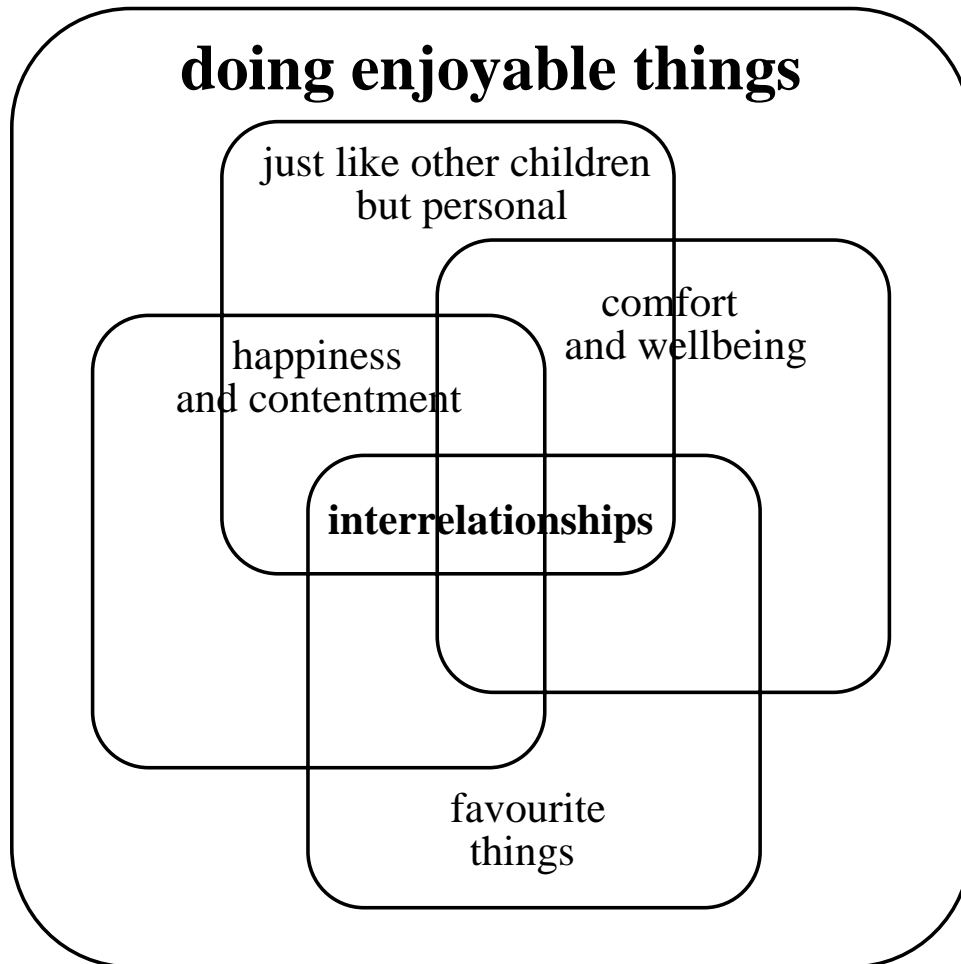
Subcategory Special things... Is doing special things with special people.

Subcategory Water play... Playing with water is freedom, fun and belonging.

Subcategory Fun... Is having a wicked sense of humour!

This box presents a conceptual scaffold of my theory. This is the second layer of explanation of the theory and enmeshes with both the first layer provided by the summary storyline, and the third layer provided by the relational scaffold. This scaffold introduces each of the theory's nineteen categories that are explained individually and in detail in the fourth layer of explanation of theory: the full storyline. The fifth and final layer of explanation posits hypotheses to explain key interrelationships between these categories.

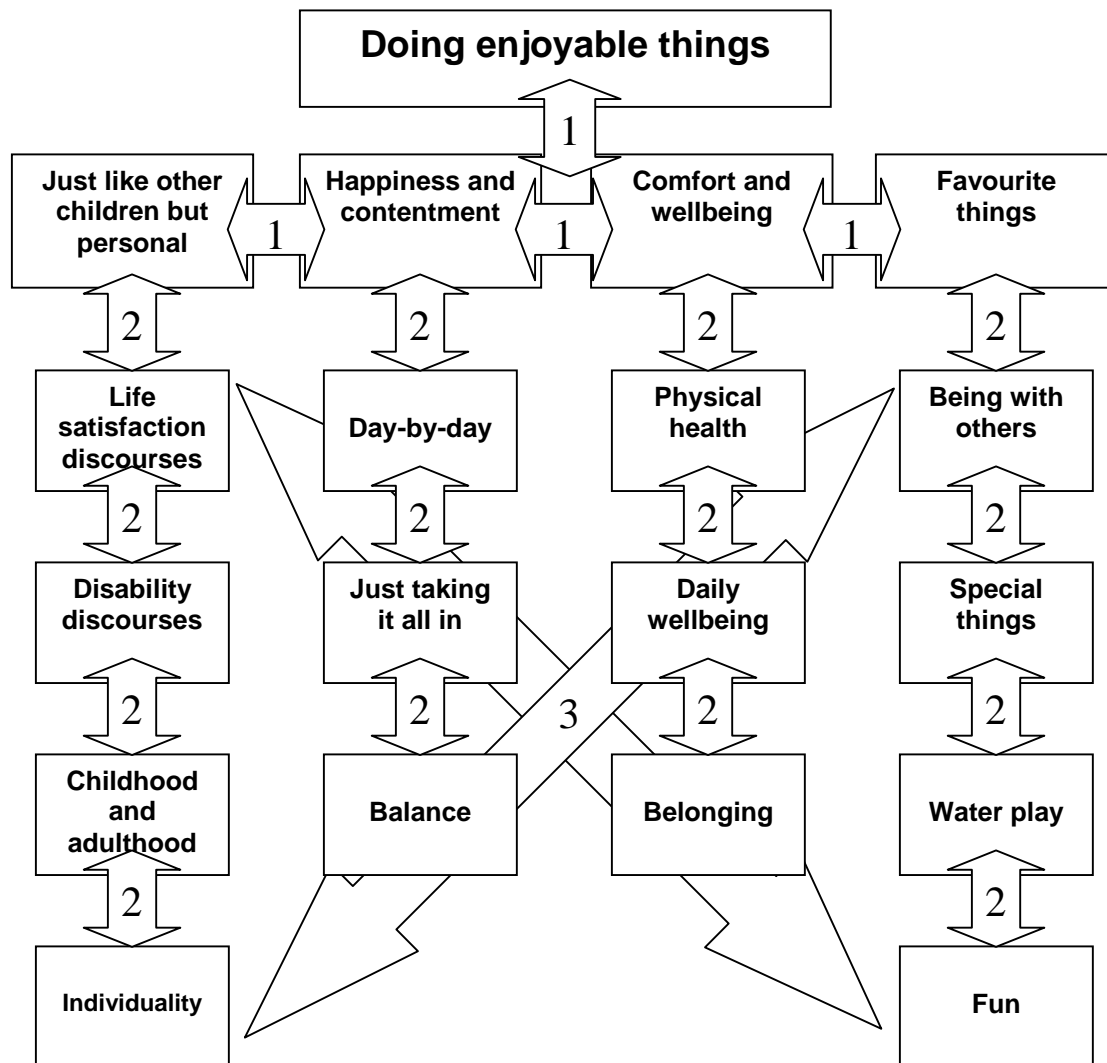
Life satisfaction for children with PMD: A relational scaffold



This figure presents a relational scaffold of my theory that indicates the milieu of interrelationships between categories. This is the third layer of explanation of the theory, and enmeshes with both the first layer provided by the summary storyline, and the second layer provided by the conceptual scaffold. This scaffold prefaces the fifth and final layer that posits hypotheses to explain these key interrelationships. Interrelationships occur at three levels.

The first and broadest level exists between the central category and the four main categories. The second level exists between subcategories within any one of the main categories. The third level exists between subcategories across the main categories.

Life satisfaction for children with PMD: A relational model



This figure presents a relational model of my theory that indicates the milieu of interrelationships between categories at three levels. The first level [#1] exists between the central category and the four main categories, and gives structure to the theory. The second level [#2] exists within the main categories and adds detail to the theory. The third level [#3] exists between subcategories and across the main categories, and enhances the cohesion of the theory. The model uses a diagrammatic analogy wherein life satisfaction for children with PMD is represented as a 'mobile'. For the purposes of this analogy, categories weigh differently upon the mobile, depending upon individual needs, wants, likes and preferences, and life satisfaction is best when the mobile is balanced. This balance is facilitated when the mobile has: structure, provided by the first level of interrelationships; detail, provided by the second level; and cohesion, provided by the third level.

'Coming to know' children with PMD: A summary storyline

The process of learning about the life satisfaction of these children is hard to explain. It's about 'coming to know' the children. It's the same as with other children, but takes longer. Eventually 'the penny drops'! The process of coming to know these children includes three concurrent sub-processes.

The first is observing – that is, watching and listening: for how the children show their feelings; for patterns of behaviours in daily routines; and for changes in these patterns of behaviour. Observing also involves being retrospective, and recognising in hindsight the significance of 'little' behaviours. The second sub-process is engaging with the children through working with them, playing with them, and just being with them. This usually means firstly 'going through the basics' – the usual, simple things - then 'putting yourself in their shoes' to inform your next move. This will probably be just 'trial and error', but you might 'experiment' and try something very intentionally. The third concurrent sub-process is questioning and discussing. You will need to ask the right persons – the key communication partners – the right questions. This takes some planning. You will also need to collaborate with important others who can inform you.

You have to remember that how well and quickly you learn about the life satisfaction of these children is influenced by how well you know yourself. What you bring to the process is important. This includes your experience – your familiarity with other children helps here - and your presumptions and assumptions about the children and your relationship with them. Remember that these presumptions and assumptions can help and hinder your learning. For some people learning about the life satisfaction of these children is harder, and for others it's easier. Some have 'just got it!' - and come to know the children quickly – naturally.

'Coming to know' children with PMD: A conceptual scaffold

Central category Coming to know... The process of learning about the life satisfaction of these children is hard to explain. It's about coming to know the children. It's just the same as with other children, but takes longer. Eventually 'the penny drops'.

Main category Observing... Just watching and listening.

Subcategory Looking for feelings... You've got to learn how they show their feelings

Subcategory Patterns and routines... Looking for patterns in daily routines

Subcategory Changing behaviours... Looking for changes in patterns

Subcategory Retrospectives... Recognising 'new' behaviours – in hindsight

Main category Engaging and doing... Being with, working with, and playing with the children

Subcategory Going through the basics... Try the simple things – the usual things first.

Subcategory Putting myself in (child's) shoes... How would I feel? What would I want? What would I do?

Subcategory Trial and error... Trying different things and hoping for a response.

Subcategory Experimenting... Trying something specific and looking for a specific response.

Main category Questioning and discussing... Asking the right people and asking the right questions.

Subcategory Gatekeepers and key communication partners... You have to ask the right people.

Subcategory Collaboration... Engaging with important others

Subcategory Questioning... You need to know the right questions to ask.

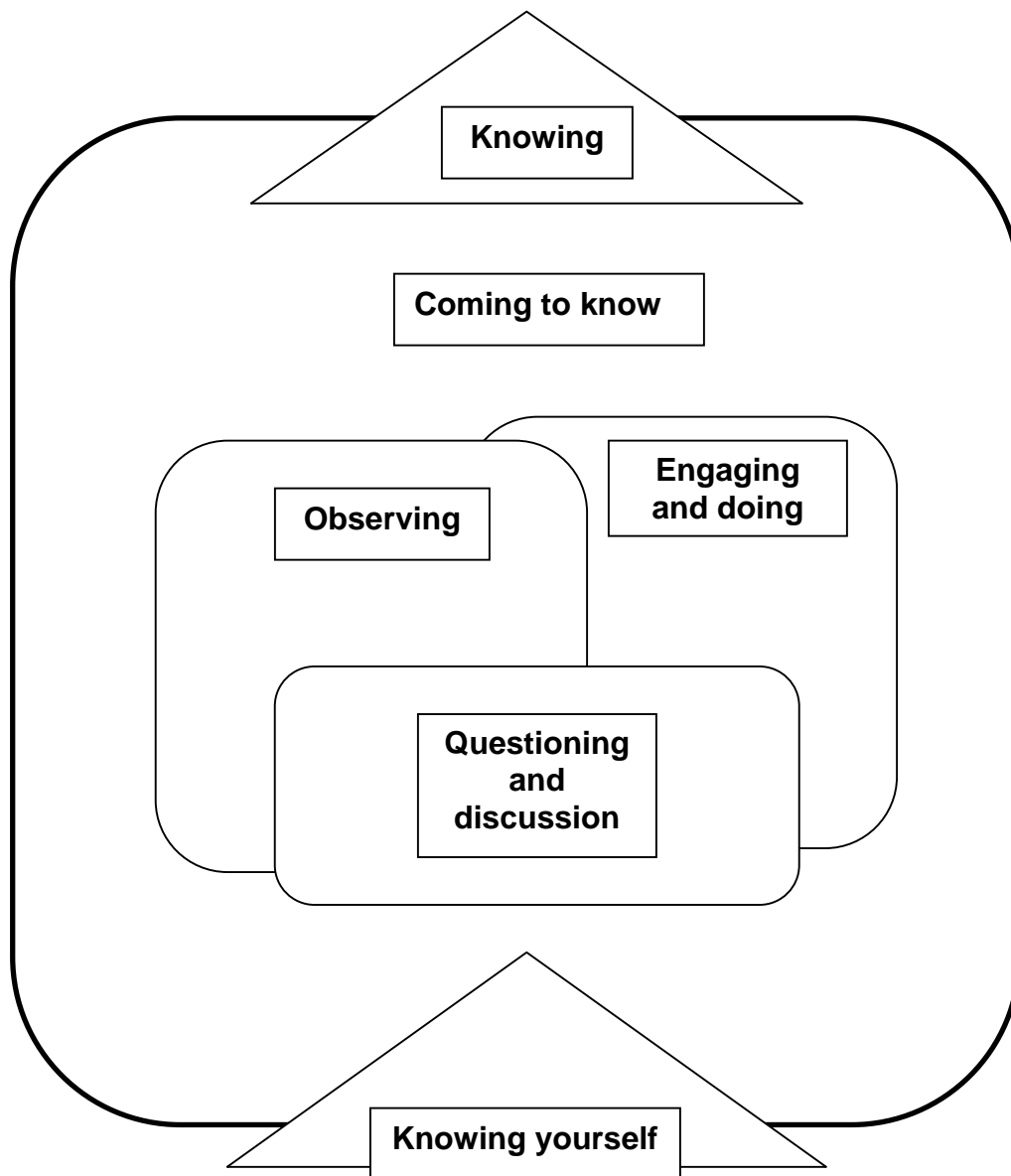
Main category Knowing yourself... What communication partners bring to the process is important.

Subcategory Experience... Having a familiarity with (all) children helps.

Subcategory Presumptions and assumptions... Presumptions and assumptions can help and hinder.

Subcategory Some people have 'just got it!'... Some people just 'come to know' the children quickly – naturally.

'Coming to know' children with PMD: A diagrammatic scaffold



This diagram represents a graphical scaffold for my grounded theory of how we learn about the life satisfaction of children with PMD. The process is represented overall by the central category, which embraces the four main categories of concepts. Each of these main categories has properties with dimensions, and sub-categories with properties with dimensions. The categories and sub-categories are inter-related, and these inter-relationships are explained through hypotheses. The process is quicker and more thorough when a communication partner engages in all aspects of the process in accordance with his/her own personal balance of 'coming to know' the child.

The Life Satisfaction Matrix 'makes sense'

That is...

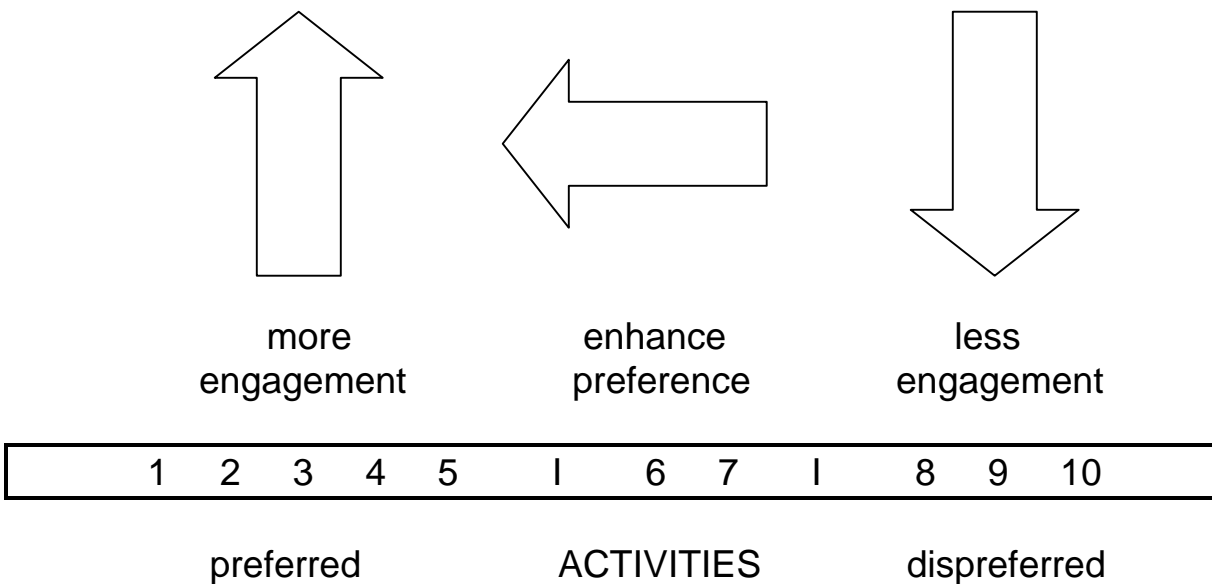
The basic assumptions underlying the Life Satisfaction Matrix (Lyons, 2000) are supported by the findings of the research study.

That is...

- LS is improved when more time is spent on preferred, and less time on dispreferred activities
- Individuals with PMD express their inner states through consistent behavioural repertoires
- These behavioural repertoires can be discerned by familiar others
- These behavioural repertoires can be validated by an independent other
- An individual's routine daily activity preferences can be determined from their behavioural repertoires

The Life Satisfaction Matrix (Lyons, 2000)

**A simple, practical, research-based instrument and procedure
for assessing changes in and improving life satisfaction
for individuals with PMD**



Initially: identification and ranking of 'regular' activity (dis)interests, wants and (dis)preferences; based on observable idiosyncratic behaviours; and validated by key communication partners and an independent observer.

Subsequently: three monthly reviews of engaged time and preference rankings; analysis of and changes to engaged time and the 'nature' of activities.

Challenges

1 These children, like all children, want to do enjoyable things. Given their pervasive dependence on those close to them, just how actively engaged are they? Given that a 'full life' seems a good life, how can we make (routine) 'activities of daily living' – which occupy so much of the day – (more) enjoyable (for both the children and their carers)?

2 These children, just like all children, are often content to be just taking it all in. Obviously it's essential that the children's communication partners can discern between contentment and boredom. Maybe it's OK for these children to have time to just 'enjoy their own space' – even during school time. It's about a personal balance...

3 These children seem quite reasonably happy – at least in comparison to other children - but their (objective) quality of life is totally in other's hands. In general, infanticide and euthanasia, particularly as they relate to infants with PMD, are argued for primarily on the basis that these children will experience an unbearably poor quality of life...

4 These children generally enjoy fun – have a wicked sense of humour – and display some considerable 'emotional intelligence'. Prevailing discourses of disability appear inadequate to embrace emotional intelligence as an indicator of social validity or value...

5 These children, like all children, come to school to learn. Special education curriculum for these children generally embraces the 'common' curriculum with a functional skills orientation. If a core goal of education is to empower individuals to pursue a better quality of life as a contributing citizen, then education for fun, not (just) education with fun, might be worth reconsidering...

6 These children regard water play as a favourite thing, and as meaning freedom, fun and/or belonging. Water play seems to have an almost universal appeal. How prominent is water play in the lives of most children with PMD?

7 These children have 'special things' – special ways of engaging with particular people. This demonstrates a unique quality of intersubjectivity – a communicative strength to work with to empower them as social beings. Could communication training embrace these special things, and adopt rather than adapt them to empower other communication partnerships? So often these special (and valuable) things remain undisclosed...

8 Generally these children are happy children – when they are not in pain and experience a balance in doing enjoyable things. If the 'quality of life' paradigm prevailed, this could be seen as some reassurance to parents and other primary carers that they are 'doing a good job'...

9 These children need communication partners who can respond to their wants, interests and preferences. 'Turnover' amongst staff in respite care services, support services and schools can be high – sometimes as a result of policy. Should services encourage and support greater staff stability – possibly at the expense of other apparent priorities? Relationships are central to life satisfaction. How can we make sure that these children 'belong'?

10 For these children, life satisfaction is very much about happiness, and happiness is relatively easy to discern. Is the assessment of the happiness of these children a priority?

11 The life satisfaction of these children can be discerned. Maybe 'Individual Service / Support / Transition Plans' should focus on an individual's wants, interests and preferences, rather than (just) their 'best interests'. 'Person Centred Planning' seems to be 'going along the right track'...

12 For many of these children pain is pervasive. Until this pain is addressed, a focus on life satisfaction seems to lose importance for carers. Are frequent regular (preventative) medical checkups a priority for these children?

13 These children, who usually live at home, are generally happy. Adults with PMD, who more usually live in supported congregate care, seem less so. (A personal observation / judgment.) Is there something wrong, or is this 'just the way the cookie crumbles'?

What is life satisfaction for children with profound multiple disabilities?

Tell me honestly, I challenge you – answer me: Imagine that you are charged with building the edifice of human destiny, the ultimate aim of which is to bring human happiness, to give them peace and contentment at last, but that in order to achieve this it is essential and unavoidable to torture just one little speck of creation, that same little child beating her chest with her little fists, and imagine that this edifice has been erected on her expiated tears. Would you agree to be the architect under those conditions? Tell me honestly!

(from Foyodor Dostoyevsky's The Brothers Karamazov)

Here we are, human beings, possessed of needs, feelings, capacities and aims that are for the most part not our creation but are simply part of our endowment as human beings. These are the grist, the data, and the subject matter of morals. The problem is how to get from where we are to where we want to go. It is on our answer to this question that our whole happiness and our worth as human beings depend. Our problem is not whether our answers accord with nature or even with truth. Our problem is to find those answers that do in fact work, whose fruits are sunlight, warmth, and satisfaction in our lives as we live them.

(from Richard Taylor's Good and Evil)

Can the life satisfaction of children with profound multiple disabilities be discerned? My answer to, and position on, this research problem, based primarily on the findings of this study, is yes. The last words, though, go to the children who participated in this study. If they could answer for themselves, I believe their collective reply might be best encapsulated in the following adaptation of the summary storylines of the two grounded theories:

You can come to know us, and about our life satisfaction. (The term doesn't make much sense, but quality of life and happiness do!) It's mostly about doing fun things with the people that we like. It's the same for us as it is for other children, but we show how we think and feel in very personal ways.

Different people see us in different ways. It depends on how they understand our disabilities. People who don't know us usually only see our disabilities, and not how we are feeling, learning and growing. We are individuals in what we do and how we feel. We are children and we have a future, but we live mostly in the here and now. A good life is having happiness and contentment each day, although contentment can be as simple as just taking it all in. It's about being in balance. A good life is also about comfort and wellbeing. Many of us have lots of pain, so our health is very important. Just having a good day is great.

Being friends is most important. It's about belonging. A good life is also about our favourite things. This can be just caring and sharing, or doing special things with special people, or playing in water, or just joking around!

It can be hard to come to know us, and this is hard to explain. It's the same as with other children, but takes longer. Eventually the penny will drop for you! To come to know us, you need to do three things at the same time.

First, you need to watch and listen for how we show our feelings, for 'patterns' in what we do every day, and for changes in these patterns. You need to be able to look back to learn to understand the little things we do.

Second, you need to spend time being with us and playing with us. You need to do the usual, simple things with us, and then put yourself in our shoes. What you do will probably be just trial and error, but you can experiment on purpose.

Third, you need to talk to the people who know us, and ask the right questions, and work together with others. This takes some planning.

How well you come to know us depends upon how well you know yourself. Your time with other children can help, and how you feel about us and what you presume about us is important. For some people this is hard, and for others it's easy. Some people have just got it!