‘Go ahead... Make my day!’

Children with PMLD can have their own say: Life satisfaction for children with profound and multiple learning difficulties

What is life satisfaction for children with PMLD?
Relationships and happiness emerge as key themes in this research, which was designed to 'bring together and make sense' of children's expressions, feelings and emotions.

Gordon Lyons

Like most people who work with and for individuals with profound and multiple learning difficulties (PMLD), I strive to improve their quality of life. My earlier research (Lyons, 2000) culminated in the development of the Life Satisfaction Matrix for assessing and improving the life satisfaction of individuals with PMLD. My current PhD research (nearing completion!) sought to address a more basic problem: Can the life satisfaction of children with PMLD be discerned? Two key research questions emerged:

- What is life satisfaction for these children?
- How do we learn about their life satisfaction?

I hoped that the findings from this research would support the core assumptions that underpinned the Life Satisfaction Matrix. My continuing research agenda aims to substantiate the rigour of this instrument/procedure, and hopefully see it put into practice.

This article describes and explains the research findings relating to the first research question: What is life satisfaction for children with PMLD? The findings may not be 'surprising' but I hope they are interesting, and confirm some of what many intuitively feel and believe about this phenomenon.

Research generally suggests that individuals (especially children) with PMLD are unable to report meaningfully on their own quality of life, because of insurmountable problems with communication and the complexity of the phenomenon (e.g. Heal & Sigelman, 1996; McVilley & Rawlinson, 1998). Similarly, the rigour of proxy reporting by familiar others is widely questioned (e.g. Antaki & Rapley, 1996; Goode, 1996; Grove, 2002; Matikka & Vesala, 1997).

Nevertheless, a small and eclectic body of research supports the contention that communication between individuals with PMLD and their familiar communication partners is meaningful (e.g. Gleason, 1994; Goode, 1990; Goode & Hogg, 1994; Klotz, 2001; Porter et al., 2001; Wilcox et al., 1990) and that these individuals can reliably express their 'inner state' through observable behaviours (e.g. Green et al., 1997; Green & Reid, 1999; Grove et al., 1999; Hughes, 2002). I believe that individuals with PMLD can express ('report on') their life satisfaction, and that the knowledge of key communication partners is central to interpreting these expressions. Individuals with PMLD 'can have their own say' and guide others in how to 'make their day!'

The study

My approach to this research was a qualitative one. Symbolic interaction theory (Blumer, 1969; Lal, 1995) provided a scaffold for the grounded theory methodology (Corbin & Strauss, 1990; Strauss & Corbin, 1998) and for a facilitative perspective on the nature of communications between the children and their communication partners. I sought the children's understandings of the nature of their life satisfaction, but through their partners.

The findings were based on an analysis of data derived from three sources. Firstly, from around 400 hours of (participant) observations of 20 children with PMLD aged 4-18 years and 80 of their communication partners in school, home and community settings. These observations focused on the behaviours of the children as they interacted with teachers, teachers' aides, volunteers, therapists, other students, parents, siblings, other family members, friends - and myself.
Secondly, I conducted approximately 130 (semi-structured) interviews with individuals and groups of these communication partners. Thirdly, the analysis was informed by a broad-based literature review drawing from the fields of (special) education, disability studies, sociology, philosophy and psychology. All of this data was transcribed and analysed using an appropriate software program.

The analysis ‘enmeshed’ the observations and interpretations of multiple communication partners – usually the class teacher, the teacher’s aide, a parent and myself – for each child. Themes and patterns about the life satisfaction of these children were identified and explored, and compared and contrasted against the literature. The outcome of the analysis was a grounded theory - expressed as a narrative storyline and described by a conceptual scaffold of categories with properties and dimensions.

The findings
The grounded theory is most simply described as A Storyline (see below). This storyline is followed by Figure 1 - a diagrammatic scaffold of the theory. Life satisfaction 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. Life satisfaction is ‘best’ when a child experiences all aspects of the phenomenon in accordance with his/her own personal balance of ‘doing enjoyable things’.

Figure 2 is a conceptual scaffold of the grounded theory, which provides some structural detail for the storyline. A Discussion follows, which provides a brief explanation of selected aspects of the grounded theory and their potential to contribute to an agenda that seeks to improve the life satisfaction – and ultimately the quality of life – of children with PMLD.

Life satisfaction for children with PMLD - A 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 is the same for these children 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 understand the life satisfaction of 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 they are children – not adults. They have a future – but they live 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 is a ‘day-by-day’ happiness, because their lives are mostly experienced one day at a time. Contentment for these children can be ‘just taking it all in – in their own space’. It is about a personal balance. Life satisfaction is about comfort and well-being. Physical health is so important when acute and/or chronic pain is so pervasive, so daily well-being – just having a good day – is encouraging. Central to this well-being are relationships with others and belonging with others. Life satisfaction for these children is about 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!
Central category: Doing enjoyable things... Life satisfaction for these children is primarily about doing enjoyable things. It is about being engaged with people and 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.

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

Sub-category: 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.

Sub-category: Childhood and adulthood... These are children who are developing. They have a future, but they live in the 'here and now'.

Sub-category: 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.

Sub-category: Day-by-day... Happiness should be daily, and life one day at a time.

Sub-category: Just taking it all in... Contentment can be just taking it all in – in our own space.

Sub-category: Balance... Happiness and contentment is about personal balance.

Main category: Comfort and well-being... Life satisfaction is about feeling both comfort and well-being.

Sub-category: Physical health... Acute and/or chronic pain is pervasive.

Sub-category: Daily well-being... Just having a good day is encouraging.

Sub-category: Belonging... Relationships are central.

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

Sub-category: Being with others... Is caring and sharing.

Sub-category: Special things... Is doing special things with special people.

Sub-category: Water play... Playing with water is freedom, fun and belonging.

Sub-category: Fun... Is having a wicked sense of humour!

**Figure 2 Life satisfaction for children with PMLD - A conceptual scaffold**

**Discussion**

This (very brief!) outline of a grounded theory about the life satisfaction of children with PMLD should 'ring some bells' with those who are significant communication partners to children like these. This is what life satisfaction is about for these children – as demonstrated / communicated / 'reported' by them through their communication partners. The theory of symbolic interaction supports the truth and reality of the intersubjectivity that exists between communication partners – the truth and reality upon which these findings, and my argument and position, are based.

The life satisfaction (and hence quality of life) of these children can be discerned. The nature of this life satisfaction is less 'complicated' than it seems for many others, and closer to happiness and contentment. The level of life satisfaction is more readily discerned by experienced communication partners, although 'novice' communication partners (like myself!) can usually learn to read the children’s affect and expressions of feelings. This affect is manifest as an individual behavioural repertoire that consists largely of readily 'readable' behaviours, but often includes subtle and unexpected idiosyncratic expressions that can be difficult to discern.

Interestingly, although experienced communication partners are more astute interpreters of these children’s feelings, they are generally unable to explain how they came to be so. Conversely, novice communication partners are much better at reporting on how they 'came to know' the children!

To the 'hands on' practitioner, (basic) research like this may seem a little esoteric or 'obvious'! It can sometimes be difficult to see the utility in, and find application for, findings like these.
However, I would like to juxtapose some of these findings against contemporary discourses, policies and practices that do impinge upon the lives of children with PMLD - I'm sure there is some 'fuel for a few fires' amongst the following remarks and questions...

- 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)?

- At the same time, these children are often content to be 'just taking it all in'. Obviously it is 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...

- 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 PMLD - are argued for primarily on the basis that these children will experience an unbearably poor quality of life...

- 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...

- 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...

- These children often 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 PMLD?

- 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...

- Generally these children are happy children - when they 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'...

- 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'?

- 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? (See Flo Longhorn's excellent article in The SLD Experience, Summer 2002)

- 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 (Holburn & Vietze, 2002; Reid et al., 1999; Sanderson, 1998) seems to be 'going along the right track'...

- 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 and regular (preventative) medical checkups a priority for these children?

- These children - who more usually live at home - are generally happy. Adults with PMLD - 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'?
This research does not seek to make sweeping generalisations about life satisfaction for all children with PMLD. The analysis was my best effort to 'bring together and make sense' of the children's expressions, feelings and emotions, and the interpretations of their communication partners who participated in this study. I sought to tell the stories of the participants, while acknowledging my contribution to, and impact upon, the study as a participant and researcher. My (grounded theory) methodology empowered me to embrace diversity as a central characteristic of data analysis and reporting – and diversity is so 'obvious' in the heterogeneity of these children.

So listen carefully to the children (with PMLD) when they say:

'Go ahead... Make my day!'

(It is anticipated that the full research report – the author's doctoral dissertation – will be available on-line early in 2004 i.e. as Lyons, G. S. (2003). Seeking eudaemonia: life satisfaction for children with profound multiple disabilities. Unpublished PhD thesis. The University of Newcastle, Australia.)

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References


