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CURRICULUM DEVELOPMENT FOR STUDENTS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES: HOW ABOUT A QUALITY OF LIFE FOCUS?

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ABSTRACT

The education of students with profound intellectual and multiple disabilities (PIMD) challenges practitioners, families and policy makers. These challenges have philosophical, ethical and moral dimensions and variously impact curriculum, assessment and pedagogy for these students. The imminent arrival of the Australian Curriculum throws a spotlight on education generally and curriculum development specifically for these students. This paper reviews the nature of education for students with PIMD as a context for putting forward (the improvement of) quality of life as a preferred focus for curriculum and program development. The authors argue that this focus is consistent with the tenets of inclusion, has an emerging evidence-base, and is facilitative for policy and practice development.

PREFACE

In Australia the terms severe intellectual disabilities and high support needs generally refer to a heterogeneous group of students with extensive additional needs. This paper focuses on those students with profound intellectual and multiple disabilities (PIMD) as identified by the International Association for the Scientific Study of Intellectual Disabilities, the leading professional body in the field. That is these students '...are individuals with such profound cognitive disabilities that no existing standardized tests are applicable... who often have profound neuromotor dysfunctions (and) sensory impairments... are a physically very vulnerable group of persons with a high dependence on personal assistance for everyday tasks, 24 hours a day...' (IASSID, 2011). It is important to emphasise the distinction between persons with PIMD and others because much of the relatively limited extant literature is undifferentiated (Imray, 2011). PIMD is a heterogeneous classification but the profundity of these individuals' intellectual disabilities and the complexity of their widely varying concomitant sensory disabilities set them apart from others. Indeed persons with PIMD are widely regarded as experiencing a very low quality of life (Lyons & Cassebohm, 2010).

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INTRODUCTION

Students with PIMD find learning more difficult than others and consequently their teachers find them very difficult to teach (Bayliss, 2005; Foreman & Arthur-Kelly, 2005). Their education is often very different from that of others (Arthur-Kelly, Foreman, Bennetts & Pascoe, 2008). The inherent challenges have philosophical, ethical and moral dimensions (Slee, 2011) and impact curriculum, assessment and pedagogy (Bayliss, 2005). The reasoning for people with PIMD to be educated is widely accepted (Stolk, 2011) whereas the nature of this education is historically contentious (Ware & Donnelly, 2004).

The Australian Curriculum will commence (at least in part) in 2013 (ACARA, 2011). This curriculum is for all Australian school students and prescribes what all need to learn including common educational goals, core learning areas defined by requisite knowledge, skills and understandings, general capabilities and cross-curriculum priorities. Each part has or will be put for public consultation. The imminent arrival of this curriculum throws a spotlight on the nature of education for students with PIMD. Although it is referred to as a common curriculum substantial concerns have been expressed over its suitability for and relevance to these students (AASE, 2011). According to the Australian Curriculum and Assessment Authority (ACARA) students with 'special education needs' will be granted 'appropriate adjustments' in terms of content and assessment. Students with a 'significant intellectual disability' unable to benefit from these adjustments will be provided with 'additional curriculum content and achievement standards' (ACARA, 2010). (At the time of writing ACARA had promulgated two 'draft for discussion' curriculum documents for students with special education needs.) Recent research and international initiatives suggest alternative foci for developing curriculum for students with PIMD (European Agency for Development in Special Needs Education, 2009; Ware & Donnelly, 2004). One is a quality of life focus.

THE DEVELOPMENT OF SCHOOL EDUCATION FOR AUSTRALIAN STUDENTS WITH PIMD

Prior to the 20th century education for people with PIMD was nonexistent. These people were widely disregarded as sub- or non-human (Lachs, 1986), incapable of participating in most activities of daily living and frequently subjected to infanticide and euthanasia (Hogg, 2007). During the first half of the 20th century and despite legislated compulsory schooling children with PIMD were generally committed to residential institutions (Konza, 2008) because they were classified as untrainable or custodial; fit for care but not for an education (Bray, Macarthur & Ballard, 1988). The expectations and engagement of most staff were very limited so much of the children's day probably passed in a non-alert, bored or frustrated state leading to challenging behaviours (Foreman, Arthur-Kelly, Pascoe & Smyth King, 2004).

The second half of the 20th century saw the emergence of the international equity and rights movements (Foreman, 2011). The principles of normalisation, least restrictive environment and social role valorisation found increasing public support and led to the deinstitutionalisation, special education and integration movements (Konza, 2008). Public special schools for students with intellectual disabilities were opened alongside those previously established by government-supported charitable organisations. With increasing public and government expectations and professional acceptance of the principle that all children were educatable the prevailing care paradigm shifted to the education paradigm (Simmons & Bayliss, 2007).

In the 1960s progressive special educators introduced the 'developmental' curriculum model wherein students were instructed in skills matched to their mental age with the belief that learning would follow normal developmental pathways (Kontu & Pirttimaa, 2009). This model: was primarily informed by early childhood education (which was far less developed than that typical to school education); was conceptually limited by the belief that individuals with PIMD would not develop cognitively beyond the early childhood stage (Nietupski, Hamre-Nietupski, Curtin & Kala, 1997); lacked authenticity because it prescribed learning which frequently lacked functionality (Stephenson, 2006); and was often age-inappropriate (Foster, 2010). During this period behaviour change for moderating challenging behaviours was overemphasized rather than teaching adaptive skills to facilitate better communication and engagement (Butterfield, Arthur & Sigafoos, 1995). Prior to this time pre- and in-service training for teachers of students with PIMD had been very limited (Nietupski et al., 1997) and the expertise of staff was more in providing care rather than teaching, but instructional techniques did become subject to increasing professional scrutiny. Most special education teachers were not offered any special education training and although many pedagogical practices were (are) generic the education of students with PIMD held (holds) unique challenges (Jones, 2010).

In the mid 1970s the 'functional' model of curriculum emerged (Roberts & Ridley, 2009) wherein the notion of 'criterion for ultimate functioning' guided the design of a core curriculum based on the development of authentic, functional knowledge and life skill sets for the home, school and community domains. This aimed to empower students to function as independently as possible in these environments (Nietupski et al., 1997). Emphases given to different elements of the core curriculum were negotiated with parents as part of an IEP development process (NSWDET, 2005; Roberts & Ridley, 2009). This model was widely supported for its practicality and authenticity (Resource Support Unit, 1991). Behaviour change interventions were still promoted but improving instructional techniques meant that more realistic outcomes were achieved. Around the same time professional recognition of the pedagogical demands of teaching these students led to increased training opportunities. Although knowledge about ABA techniques had become more accessible (Bray et al., 1988) there was too little emphasis on learning about students' non-observable cognitive processes (Nietupski et al., 1997). The pedagogy around IEP design and implementation had though improved greatly with an increased recognition of the need to plan collaboratively and across the curriculum (Centre for Developmental Disability Studies, 2004). Although teachers using the functional model were achieving creditable learning outcomes generally (Browder & Cooper-Duffy, 2003) criticisms were emerging that this progress was at the expense of essential cognitive skill development (Jackson, 1993; Sabatino, Miller & Schmidt, 1981).

By the 1990s integration philosophy had gained precedence and so conceptualisations of functional skills shifted to fit in more with mainstream curriculum. This shift provided mainstream teachers with the opportunity to better understand the educational needs of students with PIMD and facilitate their integration into regular settings (Olley, 2005; Westwood & Graham, 2003). It also meant that special education teachers had to re-scaffold their functional curricula to align with the academic scaffold of mainstream curricula (Nietupski et al., 1997). IEPs still provided for the individualised

needs of students with PIMD but these were mostly seen as 'special education business' by mainstream educators (Jones, 2010). This worked against the call for mainstream teachers to take collaborative responsibility (Ryndak, Moore, Orlando & Delano, 2008-9). With integration and ultimately inclusion taking philosophical precedence (Slee, 2011) and the emergence of a worldwide policy shift towards common inclusive curricula pressure was brought to special educators to share their specialised pedagogical knowledge (Foreman, 2011). Notwithstanding that best practice pedagogy for students with intellectual disabilities was widely viewed as 'special education' (Jones, 2010) a growing collaboration of professionals identified strong commonalities (Dixon & Verenikina, 2007; Killen, 2005). Another major change was a re-emphasis on communication, relationships and social skills development (Boyd, Seo, Ryndak & Fisher, 2005; Hewitt, 2009; Imray, Gazquez & Bond, 2010). Assessment, curriculum and pedagogy and intricately related (Nixon, 2010) so knowledge about assessment for students with PIMD is central to understanding their education (Browder, Spooner & Bingham, 2004). Special educators spearheaded the development of best practice curriculum-based assessment and programming (Arthur-Kelly, 2008). For students with PIMD all forms of assessment are critical to best practice and outcomes (Dowrick, 2002) as their individual learning needs are idiosyncratic and learning improvements relatively incremental (Bauder & Simmons, 2005; Hewitt, 2009).

Since 2000 discourses of inclusion have become the prevailing ideology impacting Australian students with PIMD (Arthur & Foreman, 2002; Bain & Lancaster, 2006) but given the diverse policies of individual jurisdictions the nature of their education varies widely. Australian students with PIMD are mostly educated in segregated special schools although some have placements in special and regular classes in regular schools (Konza, 2008). Different interest groups support different placement options (Dempsey, 2011) but these options are restricted if a potential enrolment involves unjustifiable hardship (Dempsey, 2003). National and state disability legislation (e.g. the 1992 Disability Discrimination Act & 2005 Disability Standards for Education) applies. In most cases Australian students with PIMD have a collaboratively negotiated IEP based on their additional educational needs (Dowrick, 2001; Roberts & Ridley, 2009) although for some younger students content is drawn more heavily from and scaffolded by State curriculum / syllabuses (Roberts & Ridley, 2009).

CONTEMPORARY SCHOOL EDUCATION FOR AUSTRALIAN STUDENTS WITH PIMD

Contemporary Australian government policy, as evidenced in the Australian Curriculum documents, is to teach all students using common inclusive curricula and assessment processes. This poses considerable challenges particularly for those involved in the education of students with PIMD (Dixon & Verenikina, 2007; Dempsey, 2011; Pepper, 2007; Roberts & Ridley, 2009).

The recent focus on evidence-based and/or best practice pedagogy in school education has seen resurgence in professional interest in examining and improving pedagogy (Killen, 2005). It is widely acknowledged that teacher competency is the strongest variable effecting student learning. Stephenson (2006) for example argued that the central focus on intellectual quality in the NSW Quality Teaching model has clear relevance to the teaching of cognitive and communication skills to students with PIMD. Special education in Australia

(and internationally) already benefits from reasonable consensus on what constitutes good practice (Chalmers, Carter, Clayton & Hook, 1998; Stephenson & Carter, 2010). There is considerable corporate knowledge about what is needed to improve outcomes for students with disabilities generally (Arthur & Foreman, 2002; AASE, 2010) and a reasonable research base informing developments in inclusive policy and practice and the education of students with disabilities in Australia; much of which has relevance to students with PIMD.

Evidence-based practice for students with PIMD includes for example: a balance of behavioural and developmental strategies; explicit, systematic, data-based instruction and assessment; the use of augmentative and alternative communication technologies; collaborative approaches to student-centred educational planning; behaviour state assessment; ABA and Positive Behaviour Support; curriculum-based assessment and programming; inclusive school renewal; person-centred transition planning; flexible Government funding; appropriate professional development; and a curricula focus on communication and social skills development. These evidence-based practices are variously identified, described and explained in for example Bain and Lancaster (2006), Carroll, Forlin and Jobling (2003), Centre for Developmental Disability Studies (2004), Clarke, Worcester, Dunlap, Murray and Bradley-Klug (2002), Dowrick (2002), Foreman and Arthur-Kelly (2005), Hewitt (2009), Konza (2008), Loftus, Ware and Donnelly (2005), Munde, Vlaskamp, Ruijssenaars and Nakken (2011), Renzaglia and Dymond (2005), Roberts and Ridley (2009), and Stephenson (2006).

In Australia (as it is in many countries) diverse interpretations of the principles of inclusion and pertinent policy mean that educational policy and practice is similarly diverse. For students with PIMD evidence-based practice is not widely evident. A variety of restraints impact progress. These include for example: inadequate funding, staffing, teacher expertise, support services and collaboration; attitudinal barriers; the regular/special education 'divide'; a changing socio-political climate; discordant curriculum pedagogy and assessment policy and practices; widely diverse educational needs; and inconsistent definition and funding. These restraints are variously described and explained by for example AASE (2010), Australian Teacher Education Association (2006), Bayliss (2005), Dempsey (2003), Dowrick (2002), Ferguson (2008), Forlin, Loreman, Sharma and Earle (2009), Konza (2008), NSW Disability Discrimination Legal Centre (2010), Public Schools Principals Forum (2009), Roberts and Ridley (2009), Sigafoos et al. (2010) and Slee (2008).

The nature of and place for special education for students with disabilities continues to be questioned; particularly in the context of the inclusion movement (Simmons & Bayliss, 2007; Slee, 2011; Smith, 2007). Their learning goals and intended educational outcomes are often so individual, and their post-school adult lives so different from those anticipated for most of their same-age peers due to their total lifelong dependence on their carers in all activities of daily living . It has been said that the nature of their education is in some ways fundamentally different from that of most other students (Lyons, 2003a). Although inclusion (in educational and other contexts) prevails as a widely supported principle the realities of diverse interpretations and shortages in human and financial resources mean that it remains an unlikely outcome for many. For most students with PIMD who are widely regarded as the most challenging to educate, inclusion seems an unlikely outcome.

FUTURE PATHWAYS FOR EDUCATING AUSTRALIAN STUDENTS WITH PIMD

Where is the education of Australian students with PIMD heading? The Australian Curriculum mandates an inclusive direction but there is a diversity of possible pathways. ACARA states that students with a 'significant intellectual disability...will be provided with additional curriculum content and achievement standards' (ACARA, 2010) but at the time of writing had promulgated only limited information. International precedents suggest diverse options including for example: the Scandinavian (Finnish) 'full' inclusion pathway (Karakoski, 2008; Saloviita, 2009) ; the American federal legislative pathway mandating placement in the 'least restrictive (educational) environment' with an appropriately funded IEP (Curcic, 2009); the 'cascade of placement options' pathway offered in Great Britain and Australia (Curcic, 2009); the 'pre-curriculum' pathway adopted in Great Britain where eligible students are provided with curricula 'routes' which precede the foundation levels of the national curriculum (Government of Britain, 2009; Imray, et al., 2010; Loftus, et al., 2005); to the emerging British 'exclusion' pathway wherein students attend '24/7' residential schools with coordinated teaching/learning across 'home', school and community domains (McGill, Tennyson & Cooper, 2006). Another pathway is to focus curriculum (development) on improving individual quality of life.

Curriculum development focused on improving individual quality of life

A rationale for this focus is that the overarching goal of education should be to empower individuals to seek and experience a good or better quality of life (QOL) for themselves and others (Lyons, 2003b). Most curriculum documents (including the Australian Curriculum) commence with broad and overarching educational goals which make implicit and even explicit reference to improving present and future QOL. Note: QOL has been widely defined over the last 30 years as it has emerged as a prominent and respected field of social theory, research and practice (Schalock, 1996). Overall QOL is composed of objective QOL (akin to standard of living) and subjective QOL (composed of happiness and life satisfaction or subjective well-being (Lyons & Cassebohm, 2010). For the purpose of this paper Schalock's definitions of (individual) QOL are representative. That is '...QOL is experienced when a person's basic needs are met and he has opportunities to pursue and achieve goals'...(and)...'QOL reflects a person's desired conditions of living and health and wellness...' (Schalock, 1996). (For further reading on this complex phenomena / topic see e.g. Brdar, 2011; Lyons & Cassebohm, 2010; Schalock, 2010.) Most pertinently the Preamble to the 2008 Melbourne Declaration on Educational Goals for Young Australians states that '...Australia's capacity to provide a high quality of life for all...' is dependent upon the education it provides to young Australians (Ministerial Council on Education Employment Training and Youth Affairs, 2008). Governments and school systems are taking an increasing interest in teaching about wellbeing and happiness. (See e.g. Morris, 2010 and Smith, Reid & Jones, 2010).

QOL wellbeing and happiness are now regarded worldwide as guiding principles in the development of support services for adults with intellectual disabilities (Gomez, Verdugo, Arias & Arias, 2010; Vos, De Cock, Petry, Van Den Noorgate & Maes, 2010) and are widely used to guide the design of person-centred support plans for adults with PIMD (Schalock, 2010). An obvious incongruity exists when adults

support services for people with PIMD now generally adopt a QOL focus in service design and delivery whereas school education systems persist with alternative foci (Nakken, 1997).

To reasonably conceptualise a comparable and consistent QOL focus for the education of students with PIMD various questions need answers. These should at least include - What is ('good' and 'better') QOL for children and young people with PIMD? How can the QOL of children and young people with PIMD be improved? Does the prevailing international / Australian movement to educate students with PIMD within the scaffold of a common inclusive curriculum really empower them to experience a good/better QOL in the present and future? Is there a legitimate alternative/ complementary focus for curriculum development that is consistent with the broader principles of inclusion and QOL? Lyons' grounded theory of life satisfaction for children with PIMD (Lyons, 2003) and his Life Satisfaction Matrix (Lyons, 2005) are informative. Lyons posits that the core goal of education for students with PIMD should be to improve their continuing QOL by providing them with teaching/learning experiences which improve their ability to experience happiness, life satisfaction (or subjective wellbeing) and ultimately QOL (Lyons & Cassebohm, 2010). Lyons' argument is not simplistically that schooling should be about having fun. He explains that schooling (and indeed continuing education) should be about learning the knowledge, skills and understandings which can empower these students to experience (improved) happiness, subjective wellbeing and subjective QOL.

There is wide 'in principle' support in the extant literature for a QOL curriculum focus for students with more severe intellectual disabilities generally (Shearer, 2010) and for students with PIMD specifically (Loftus et al., 2005; Ware & Donnelly, 2004) as well as practice precedents (Bayliss, 2005; Imray, Gazquez & Bond, 2010; Longhorn, 2002; Ware & Donnelly, 2004). Bayliss for example describes initiatives taken by a growing group of UK schools for students with PIMD to introduce curricula specifically focusing on the development of QOL. Imray, Gazquez and Bond (2010) similarly describe a curriculum for students with PIMD which has moved well away from the common curriculum model that otherwise prevails in Great Britain.

A QOL focus is one that embraces and reflects the needs, wants, interests and preferences of individual students, consequently leading to improvements in their individual QOL. Current research around family QOL suggests in turn that as the QOL of a child with PIMD improves so does that of their immediate family (Zuna, Summers, Turnbull, Hu & Xu, 2010). Notwithstanding that individuals with PIMD are unlikely to impact the QOL of the wider community (because of their lifelong dependency and very limited community engagement) improvements in their own QOL would clearly impact their significant others.

LIFE SATISFACTION (SUBJECTIVE WELL-BEING) FOR CHILDREN WITH PIMD: A GROUNDED THEORY

Lyons' (2003b) research investigated the phenomenon of life satisfaction for children with PIMD. It also sought to inform a continuing research agenda into understanding how communication partners come to know these children, and to inform the development of the Life Satisfaction Matrix (Lyons, 2005) a procedure for improving the life satisfaction (and QOL) of persons with PIMD. The study was a qualitative one, adopting symbolic interaction as the guiding theory of inquiry and a grounded theory methodology. The participants consisted of 22 school

age children (12 with PIMD and 10 with high support needs) and 78 of their communication partners (parents, other family members, paid carers, teachers, teacher aides and other professionals.) Data was gathered from over 400 hours of participant observations and semi-structured interviews with communication partners in school, home and community settings, and a broad review of extant literature.

The nature of life satisfaction for these children was described and explained by a grounded theory, consisting of a storyline and 19 interrelated categories of concepts. The findings of the study were that: the life satisfaction of children with PIMD is discernible; there was strong evidence for the face validity of the Life Satisfaction Matrix and its four underlying principles; the research informed a continuing agenda investigating how communication partners come to know these children; and the study contributed towards the small body of research into life satisfaction and quality of life for persons with PIMD.

IMPROVING LIFE SATISFACTION FOR PEOPLE WITH PIMD: THE LIFE SATISFACTION MATRIX (LSM)

Four evidence-based principles underpin the LSM i.e. individuals with PIMD express their inner states through consistent behavioural repertoires; these behavioural repertoires can be discerned by familiar others and validated by an independent other; the routine daily activity preferences of individuals with PIMD can be determined from their affective behavioural repertoires; and their life satisfaction is improved when more time is spent on preferred activities and less time on non-preferred activities. This last principle underpins more recent research into 'stretching': a closely related strategy for enhancing enjoyment of preferred activities for people with PIMD as explained by Lyons, Cassebohm and Mundy-Taylor (in press).

Inherent in the LSM is a five-step general procedure for ascertaining and improving life satisfaction (subjective wellbeing and subjective QOL) for individuals with PIMD. This procedure, although now used by a growing number of carers of and service providers for adults with PIMD, could be readily adopted by teachers of students with PIMD for use in curriculum development in schools; and particularly for IEP development. It is compatible with many of the aforementioned evidence-based practices for students with PIMD.

First, two or more of the individual's most familiar communication partners (usually the class teacher and/or teaching assistant, and a parent or other primary carer) independently annotate/record their interpretations of the individual's affect profile i.e. the usual but often idiosyncratic range of observable behaviours used by the individual to express a range of preferences for engagement in familiar and usually regular daily activities. (In the case of preference and positive affect this is often but not always as typical as eye contact, smiling, 'happy/contented' vocalisations, discernible movements towards a person/object/activity or 'excited' repetitious movements. In the case of neutral preference this might be loss of eye contact / closed eyes, expiration of other positive affect, deteriorating behaviour state, 'bored' vocalisations etc. In the case of dis-preference and negative affect, this might be typical 'withdrawal' behaviours, grimacing and 'unhappy' vocalisations, discernible movements away from a person/ object/activity, or stereotypical 'agitated' movements. It is preferred that the two or more communication partners are from independent settings (e.g. one from school and one from home)

Second, an affect profile is then

collaboratively negotiated i.e. the participating communication partners collaborative 'compare, contrast and consolidate' their observations about the typical affect behaviours used by the student. Consensus here is usually commonplace although there is likely to be differences of view/opinion about what activities/experiences actually invoke these affect behaviours. (This though is not at issue at this point in the procedure.)

Third, these communication partners then identify a discrete set of activity periods/ experiences that occur routinely in the person's day; some preferred, some dis-preferred, and some of neutral preference. These activities are then ranked from most to least preferred. (These might include e.g. bus travel time, morning toilet, (various parts of) morning circle', morning tea time, particular free play activities, TV viewing / music time, peer learning periods, Intensive Interaction time, afternoon rest time etc. Clearly in longer activity periods a range of affect might be discernable, so activity periods/engagements can be 'segmented' to simplify their review. Preferably this set should be drawn from school-, community and home-based experiences to emphasise the very collaborative nature of the LSM.

Fourth, an independent other (usually a teaching colleague) uses the affect profile to observe and ascertain a third comparative view about the individual's preferences for some of the chosen activities and other additional activities. When ascertained preference rankings coincide for aforementioned activities and are appropriately predictive for the other additional activities, the affect profile is validated as a very reasonable indicator of the individual's internal state and preferences for these activities. (Note: It is the authors' experience that this validation is usually 'easy' to ascertain and agree upon. This means that this step can often be very brief or based on a sample of activities / experiences only.)

Finally, in line with the fourth principle above, daily routines in school community and/or home settings can be reviewed and variously adjusted so that activity periods/ experiences can be modified to enhance their preference ratings. This may mean changing their nature (usually following systematic task analysis) and/or duration - when appropriate. These modifications are often subtle and call for considered behavioural observation. A 'similar' activity period / experience (say e.g. bathing) in one setting often invokes a very different affect rating in another. Variables might be environmental, interpersonal and/ or procedural but a systematic analysis of primary and dependent variables is necessary here.

Considerations of curriculum, assessment and pedagogy are obviously all important here. This work would be demanding of an experienced and trained teacher of students with PIMD (as it is of experienced and qualified residential support workers who work in similar ways with adults with PIMD.) The LSM (and this procedure) can contribute particularly towards the development of IEPs; but clearly changes here have implications for group instructional planning and scheduling. Modifications to the nature and duration of routine activities must be reviewed periodically with the intention to enhance any improvements to life satisfaction specifically and QOL generally. The nature of these modifications/changes and the identification of prerequisite and/or facilitative skills determine the evolving curriculum (and related pedagogy and assessment aspects) of the individual's education. Shorter term teaching/learning objectives should focus more on 'making a better day' but this must be balanced against important longer term teaching/ learning goals. The focus (at least in school settings) remains on learning (not 'just'

care) but this learning aims more directly at the development of knowledge and skills which in turn facilitate more immediate and longer term enjoyment of life. This means teachers will (continue to) teach a diversity of developmental and functional skills which might find application only in the longer term. It also means that teachers will probably be more closely attuned to those activities and engagements which best motivate each student's learning.

CURRICULUM DEVELOPMENT FOR STUDENTS WITH PIMD: A QOL FOCUS

A QOL focus for curriculum development for students with PIMD targets individual needs, wants, interests and preferences. Acting upon these will improve individual student life satisfaction, subjective wellbeing and QOL. Making changes to what is taught (and how this is taught and assessed) obviously requires the support of policy makers; particularly given the imminent arrival of the Australian Curriculum. Curriculum and IEP development for students with PIMD should already be collaborative processes but any shift to embrace a valid and authentic QOL focus mandates a fully collaborative approach. It is the authors' view (like that of Slee, 2011) that the most facilitative milieu for this QOL focus to curriculum development might be in a regular comprehensive school milieu which can provide the best resources and options. A common or inclusive curriculum on the other hand may well struggle to respond to individual needs, wants, interests, preferences and strengths so would not be the most facilitative of QOL improvement.

CONCLUSION

The education of students with PIMD presents continuing challenges to practitioners, families and policy makers. The impending Australian Curriculum is an inclusive curriculum but shows limited capacity to address the particular educational needs of these students. Contemporary research and practice initiatives suggest alternative pathways for curriculum development so taking a QOL focus to curriculum (and thus IEP) development is an alternative supported by the authors. A QOL (improvement) focus is consistent with the tenets of inclusion and current evidence-based practice in services and care for adults with PIMD. It now has an emerging evidence base in education. It broadens and illuminates options for curriculum development practice at the individual, school and systemic levels. Hopefully ACARA's 'additional curriculum content and achievements standards' for students with a 'significant intellectual disability' will at least embrace the principles of a QOL focus. One collective professional responsibility for special and regular educators is to keep up with research, policy and practice developments. With this in mind the authors encourage their peers and colleagues to consider the nature and potential worth of adopting a QOL focus towards curriculum development for students with profound intellectual and multiple disabilities and to proactively engage in providing ACARA with feedback on any promulgated draft curriculum documents.

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Figure 1
Life satisfaction for children and young people with PIMD:
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 experienced daily, and life lived 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.

Subcategory *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!