



THEMATIC SESSION – MALTA, NOVEMBER 2011

LEARNERS WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES

Introduction

Learners with profound and multiple learning disabilities are among the most vulnerable and excluded in society. They have been called the 'but what about' kids – and this is true particularly in context of inclusion – we can include most 'groups' but what about the learners with the most complex needs? If we can engage with and overcome barriers for these learners and find more creative ways of working, it will benefit all learners – and wider society.

Including these learners is a challenge – but it is important to consider what we mean by inclusion. If we see entitlement to a quality education as a human right – certainly these learners can be included – although until comparatively recently these learners were 'cared for' under health provision. If we see inclusion as valuing all learners and supporting their participation in school and community by overcoming barriers – yes they can be included. If we see diversity as a resource and impetus for schools and systems to review and re-structure – yes they can be included and if we see inclusion as a way to develop effective communication and relationships, attitudes and values for a more cohesive and caring society – yes they certainly can be included. So what's the problem?

Difficulties arise at the micro level not with these broader principles and they arise due to 'conceptual inconsistencies' which lead to debates about curriculum and pedagogy – mainstream vs specialist – often still rooted in deficit models, looking to remediate difficulties rather than change the culture and practice in schools. There are also dilemmas regarding outcomes. Do we have common aims for education such as 'a good/fulfilling life' – surely critical for all learners – or are we measuring progress and success against academic results which immediately excludes the learners we are talking about here.

The aim today is to address 3 key questions – see slide 1. My introduction will raise some key issues – other inputs will through accounts of practice raise possible solutions.

Who are learners with PMLD?

What are the key challenges around curriculum, assessment, pedagogy, multi-disciplinary support, and family/community issues?

There is lack of consensus around the definition of PMLD/complex needs. They are a heterogeneous group collapsed into one category and it is difficult to get an accurate view of prevalence but numbers are low. Small numbers make specialist grouping problematic. However numbers in many areas appear to be increasing due to the survival of premature babies and medical advances- learners needs are also increasing in complexity.

Learners have profound learning difficulties and other severe impairments – motor, sensory - and medical conditions. Alternative terms include complex needs, profound intellectual & multiple disabilities. Most important is the interaction of different impairments – do teaching strategies/interventions take account of this interaction which means that strategies developed for a 'single' disability may not be totally appropriate? Also the depth of need is profound /severe and needs span health and social issues. There will be a significant delay in reaching milestones and learners are likely to be working at a very early developmental level for most, if not all of their school career.

Learners with PMLD are always likely to require a high level of support in learning needs and personal care, communication, physical and health needs – also social/emotional



needs. They may be sleepy and there is a need to take account of behavioural state and behavioural rates. Learners may demonstrate some learned behaviours without real comprehension and will need careful assessment to see if they show 'thoughtful' behavior.

Communication may be pre-intentional – dependent on a supportive communication partner to interpret needs and wants and understand behavior. Learners may also remain dependent on highly personalized sensory-motor experiences which they find hard to generalize.

Learners are often dependent on technology in therapy and medical support – for motor, sensory and health needs. This can reinforce a medical model of disability as they may be seen as needing therapy rather than 'ordinary' learning.

If the criterion for inclusion is level of skills, knowledge, understanding or 'readiness' these learners are unlikely to ever be included.

Key Issue 1 – Curriculum

One frequently discussed dilemma is around a common curriculum vs specialist curriculum.

Certainly there have been difficulties with tightly prescribed curricula – e.g. subject based curriculum – which is often fragmented and possibly tokenistic, with little relevance to the learners perceived needs which usually centre on communication/social interaction. Such needs may require more than 'curriculum differentiation'.

Inclusion must be more than 'presence – or simply 'being there'. Learners need an activity based curriculum and functional outcomes NOT passive participation, myopic participation (taking account of narrow range of perspectives) piecemeal participation (not holistic/integrated curriculum), missed participation (exclusion from activities if student can't do all) but ACTIVE participation ... opportunities to practice real relevant school/community activities with support as necessary.

What are valued outcomes? Targets must take account of the full range of perspectives – including family and community - keeping the big picture of learning priorities, working towards greater independence and recognising that independence in this context is not necessarily 'doing it by yourself'. Some learners will only ever do part of an activity –so need 'shared participation' to develop control over some aspect of their life e.g. making choices – to make intermediate steps worthwhile in themselves.

Learners need the means, reason and opportunity to communicate and there is some evidence that learners with PMLD are more alert for a greater proportion of time in more inclusive - and responsive - environments (Forman et al 2004)

Key Issue 2 – Assessment

How do we view progress? Is it for example, increased awareness, use of different senses, increasing communication/interaction, reduced need for support, greater autonomy or transfer of learning.

How is this measured? Generalised assessments are often not appropriate and do not reflect progress that is idiosyncratic BUT the small steps approaches often used can also distort practice. They may impose meaning rather than taking a constructivist view of learning. It is difficult to set targets/predict progress due to the very varied nature of learning of this group that occurs due to the interaction of impairments, complex needs and health issues/epilepsy etc.



Recent approaches have made efforts to recognise the progress of these learners – and some advances have been made from ‘working towards’ irrelevant mainstream goals etc. For example work in 2006 by Welsh Assembly Government provides a flexible framework for recognizing progress, supporting teachers to provide experiences at an appropriate level of challenge. The framework takes account of preferred learning channels, ways of communicating, ways of integrating new experiences with prior learning, memory, approaches to problems solving and social interaction and guidance materials include a discussion about the nature of progress for these learners.

Other work has focused on indicators of ‘engagement’ in learning e.g. awareness/responsiveness, curiosity, investigation, discovery, anticipation, initiation, persistence. Further assessments focus on communication e.g. Affective Communication Assessment. Increasingly technology is used to communicate with these learners and video may be used for analysis and building of relationships. (e.g. Video Interaction Guidance work by Helena Kennedy at University of Dundee, Scotland).

Further work is still needed – in particular around often unrecognised mental health issues and ‘challenging’ behaviour. Behaviour that is challenging within a school environment may be an important means of communication.

Key issue 3 – Pedagogy

Is there a specialist pedagogy for PMLD? In the past, behavioural techniques such as conditioning, task analysis etc, were used. These had many limitations not least that they focused on training rather than education. The emphasis was on skills that can be measured and extrinsic reinforcement, often working to a hierarchical breakdown of behaviours that was primarily the adults’ agenda.

Now there is increasing recognition that teachers need to reflect/problem solve/engage with research, to understand the constructivist learning paradigm and support learners to be active in their own assessment and learning. There is a need to ensure motivation and opportunity from the earliest times to support cognitive development – opportunities for learners to act on their environment – and get a response. Increasingly, technology is used to promote access to communication and learning opportunities. However, there do appear to be some specific considerations such as: need for frequent repetition to learn; also although stimulation needed, this must be carefully structured i.e. learners should not be ‘bombarded’ with different sensory experiences without meaning; time is needed for processing and responding and consideration must be given to preparation for learning in terms of comfort/security (Maslow) .

If staff lack knowledge and understanding of this group, they may have low expectations and may ‘support’ learners in lessons by ‘co active involvement’ in activities which may not be relevant/appropriate and which may be tokenistic. e.g. history - patting old toys. So, while the pedagogy needed by learners with PMLD is in many ways similar to that needed by all learners, there is a need for some specialist training and expertise. (In England, Ofsted (2006) reported 2 factors key to success for SLD/PMLD – high quality, specialist teachers and a commitment by school leaders to create opportunities to include all learners. They also reported that pupils did best, at least in academic terms in resourced mainstream provision, where there was access to specialist expertise.

Key issue 4 – Multi-agency support

Family involvement is critical for this group of learners. Parents, grandparents and siblings know learners best particularly when communication skills are at an early stage. Learner needs are paramount.



The situation is made more complicated by the need for professionals from many disciplines to be involved. However, the interaction of barriers – e.g. caused by Cerebral Palsy, visual impairment–must be considered in a ‘holistic’ approach not separate assessments and programmes. Above all, there is a need to share information without keep going back to family and asking them to repeat their stories.

When actually working with the children/young people with such complex needs, it may be advisable to limit the number of people involved due to the difficulties in forming relationships – also to stress the importance of consistent approaches. That said, it is also important to develop friendships among peers and community contacts as well as paid carers. The approach of a team around the child – including professionals and parents is increasingly used. Here there is an opportunity to develop ‘collective competence’ through sharing and collaborative problem solving.

Multi-agency working also raises a number of practical issues such as pooling budgets, harmonizing pay and working conditions and flexible hours to ensure year round support for families, including school holidays – also joint training/professional development for team skills. For all professionals working to support this group of learners, there may additional challenges in identifying and supporting families which are ‘hard to reach’ due to linguistic factors, cultural attitudes, socio-economic circumstances etc – but who are potentially the most at risk of becoming marginalized.

CONCLUSION (from Ware J. 2010. Inclusion of Pupils with Profound and Multiple Learning Difficulties (PMLD) Round Table background paper. Prepared for ISEC, Belfast 2010)

Lessons for Inclusion

The enormous increase in the pace of change in the last half century means, as Ferguson (2008) points out, that all schools now have to prepare an increasingly diverse range of learners for a future that is only partly known. Having a vision for how things should be is important, but the incompleteness of our understanding means that it is not only the ways in which we try to achieve inclusion, but our view of what constitutes inclusion which is likely to be modified as we try to attain it. This iterative process, holding in tension the vision and the day to day reality, should be welcomed as a creative and productive way to tackle the problem.