LEARNERS WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES (PMLD)

Introduction

The thematic session, held in Malta in November 2011, aimed to discuss some of the key challenges around the inclusion of learners with the most complex needs in mainstream provision.

This paper will provide a summary of the key issues raised during presentations given by speakers from Malta, Sweden and UK (Wales) and discussions and further feedback provided after the meeting by Representative Board members and National Coordinators from 7 Agency member countries[1].

The session was framed around a number of key questions and these are used as headings below.

Who are learners with PMLD?

There is lack of consensus around a precise definition of PMLD. This term is commonly used to describe learners with the most complex disabilities who, in reality have very varied needs. For this reason, it is difficult to get accurate data, but numbers are low and this makes any grouping problematic. However, the numbers of learners falling into this category in many countries appear to be increasing due to the survival of premature babies and medical advances. Anecdotal evidence suggests that learner needs are also increasing in complexity.

Countries who responded to the questionnaire all agree that this group of learners:

- have profound learning difficulties and other impairments such as motor and sensory – as well as complex medical conditions.

- due to the interaction of their different disabilities, usually require the involvement of health and social services as well as education. The impact of these complex needs means that learners are likely to be working at a very early developmental level for most, if not all, of their school career.

- 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 their behavioural state and the need for extra time to respond when planning their learning.

- will usually communicate at a pre-intentional level and be dependent on a supportive communication partner to interpret their needs and wants and understand their behaviour. Learners may also remain dependent on highly personalised sensory-motor experiences that they find hard to generalise.

- are often dependent on technology to support their communication, motor, sensory and health needs.

All of the above points can reinforce a medical model of disability and these learners may be seen as needing therapy rather than 'ordinary' learning experiences. This defecit model needs to be overcome and positive attitudes developed to ensure that this group of learners are supported to participate to the fullest extent possible.

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[1] Iceland, Ireland, Poland, Slovenia, Sweden, UK (Northern Ireland) and 1 unknown.

In the thematic session, the need to move away from labelling learners was raised. It was suggested that the focus should be on general services and systems within countries and, that, within these structures, reference should be made to 'children who need additional help with most aspects of their learning'.

Learners with the most complex needs are never likely to be fully included if the criterion for inclusion is a certain level of skills, knowledge, understanding or 'readiness'. This raises the question; what do we mean by inclusion? Can you be ' a little bit' included – or included on a part-time basis? These issues need clarification in particular with regard to this group of learners.

How can the additional support needs of this group be met in inclusive settings with the involvement of multi-agency services and families?

If the key factors in developing policy to support effective practice for this group of learners can be identified – could such a model work for all learners? Are the needs of this group really so different? What is needed to successfully meet their additional support needs? A focus on similarities rather than differences is likely to provide a more positive way forward.

The thematic session inputs, discussion and feedback highlighted the following as key requirements:

- Joint services supported by legislation and effective funding models. Multi-agency working raises a number of practical issues such as joint budgets, harmonised pay and conditions and implementation of flexible working to ensure year round support for families. Effective assessment by a 'team around the child' should include a range of professionals and parents. Such multi-agency teams should develop collective competence by sharing expertise and specialisms. Learner centred programmes, including individualised learning goals must be agreed with families and care-givers.

- Co-operative (not competitive) systems of school governance. This could include increasing collaboration between special and mainstream schools and developing special schools and/or specialist provision into resource centres within mainstream schools. Examples of such practice, provided by speakers from Malta and UK (Wales) stressed the need for visionary leadership with a clear mission, aims and principles to guide policy and practice.

- Staff training. Initial teacher education and continuing professional development should better prepare all teachers to meet more diverse needs with a view to undertaking further specialist training during their careers. All training should emphasise the skills needed for collaboration between teachers and professionals from other disciplines and develop positive attitudes. Effective communication between teachers and their peers and also other professionals is needed – a shared language and shared contexts for inclusive education. The examples from Malta and UK also showed the role that resource centres can play in the on-going training of teachers and learning support assistants.

- Parental and family involvement. The parents from Malta who spoke at the meeting emphasised the need for parents to act as advocates for their children with more complex needs. They also recognised the need for support as they face fear, anger and possible social exclsusion. The impact of a child with very complex needs on the whole family must be recognised and should lead to the provision of appropriate and reliable services to address the needs of the family holistically. Support must enable parents to plan work and other commitments with some certainty. Parents need mechanisms for being involved: informal (open door policies in school, social support, opportunities to share experiences) as well as more formal structures (e.g. school councils and other bodies) where they have

a clear role and can contribute to decision making in particular about service provision. Finally, in the Malta meeting parents stated: 'there is no one answer – one size does not fit all' and they stressed that there must be scope for parents to choose the best options for their child.

- A system that takes account of social needs and the need for long-term provision and support. For this group of learners, it is important to develop friendships among peers and community contacts as well as paid carers. The parent representatives at the meeting spoke with great feeling about the need for lifelong learning opportunities for young people with complex needs. They stressed the need for services to continue beyond the end of compulsory education to sustain the benefits gained from the education provided to that point in time. Again, multi-agency collaboration was felt to be critical in the provision of lifelong learning opportunities.

Examples of effective practice provided during the thematic session and feedback from Agency member countries supported the points rasied above. In addition, speakers from Malta and UK (Wales) showed how resource centres can work in practice to provide support to parents and families and to work with mainstream schools to increase awareness of additional support needs and appropriate opportunities for individual learners (such as use of ICT, hydrotherapy etc). Such centres can also provide a convenient local base for multi-agency services with therapists holding regular clinics in the school.

A further example comes from Sweden where legislation states that school health and welfare services include a school doctor, nurse, psychologist and welfare officer, plus other services if required.

All of the above practices require visionary leadership and effective local and school level policy and planning processes.

What are the key challenges of ensuring that these learners' needs are met through full participation in the curriculum and activities within inclusive settings? How can these be overcome?

Curriculum

One frequently discussed dilemma is around a common curriculum versus a specialist curriculum. Where the curriculum is tightly prescribed e.g. subject based, there may be problems regarding 'access' and as a result, teaching may be fragmented and possibly tokenistic, with little relevance to the learners needs which usually centre on communication and social interaction. Such needs may require more than curriculum differentiation or 'watering down' content or adapting activities to 'fit' learners into an inflexible curriculum. Such a curriculum can, however, provide a common framework for planning and contexts for relevant and meaningful learning. Josephine Mamo from Malta spoke about the work to ensure that the National Curriculum includes all learners. Guidance has been produced providing a rationale and pedagogical strategies to teach all learners. Wendy Jones stressed the need for collaboration between teachers in the resourced provision and mainstream school to make curriculum links and promote shared understanding of the curricular contexts that provide a vehicle for inclusive practice. The Y Canol principles state that it is not appropriate to dilute either mainstream or specialist practice merely to achieve common ground.

All speakers expressed the view that Inclusion must be more than 'presence' – or simply being there. Learners need an activity based curriculum and functional outcomes. This is supported by research by Ferguson and Baumgart (1991) who show that, for this group of learners, participation can take many forms, including 'passive' participation. Other forms

include: myopic participation (taking account of narrow range of perspectives), piecemeal participation (following a fragmented rather than a holistic/coherent curriculum) and missed participation (where a learners is excluded from activities if they can't do all the tasks involved). As was seen in the school examples, active participation must provide the learner with opportunities to practice real, relevant school and community activities with support as necessary.

Finally, consideration must be given to the question 'What are valued outcomes'? Targets must take account of the full range of perspectives – including family and community – and keep in mind the big picture of learning priorities. These learners may be 'working towards' greater independence for long periods of time and it is important to recognise 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' and also the time and space to develop control over some aspects of their lives and to make sure that any intermediate steps are worthwhile in themselves.

Assessment

Due to the complexity of their needs, this group of learners are likely to require a high level of input into the assessment process from different agencies such as physiotherapists, medical practitioners, specialist teachers (e.g. for visual, hearing impairment) However, the interaction of barriers to learning (e.g. caused by Cerebral Palsy, visual impairment) must be considered in a 'holistic' approach and not through separate assessments and programmes. Above all, there is a need for professionals to share information from families without asking for it to be repeated.

A key factor in assessing learners with the most complex needs is a clear view of what is meant by progress. Is it for example, increased awareness, use of different senses, increased communication/interaction, reduced need for support, greater autonomy or transfer of learning? Even when a clear view of progress is agreed, are there appropriate assessments to record the progress made by learners in these areas that are often hard to observe and to measure?

In order to try to capture progress, the curriculum framework or developmental profiles may sometimes be broken down into smaller and smaller steps. However, such approaches do not support a constructivist view of learning, where the learner takes an active part in making sense of information. Breaking down either curriculum content and /or skills may lead to a focus on tasks which, in themselves are not relevant or meaningful. It may be difficult to set targets and predict progress for these learners due to the very varied nature of their learning, but effective learning should not be constrained by the need to produce data.

Recently, efforts have been made to recognise the idiosyncratic progress of these learners. Work by the Welsh Assembly Government (2006) provides a flexible framework that takes account of preferred learning channels, ways of communicating and interacting, ways of integrating new experiences with prior learning, development of memory and approaches to problem solving. Other assessments have focused on indicators of engagement in learning (e.g. awareness/responsiveness, curiosity, investigation, discovery, anticipation, initiation and persistence) and on communication skills. Increasingly video may be used to support assessment, allowing in-depth analysis of responses. A list of resources including the assessment materials referred to here is included in the Annex to this paper.

Pedagogy

Is there a specialist pedagogy for PMLD? In the past, behavioural techniques such as conditioning and task analysis 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 as mentioned above.

Now there is increasing recognition that teachers need to reflect, problem-solve and engage with research, to understand constructivist approaches and support learners to be active in their own learning. Learners need opportunities to act on a responsive environment from the earliest times in order to support their cognitive development. Increasingly, technology is also used to promote access to learning opportunities. Although stimulation is needed, this must be carefully structured - 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, making sure that learners are comfortable and secure. Consistency of approach is also vital and it may be advisable to limit the number of people involved with some learners due to the difficulties in forming relationships.

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 or appropriate and which may be tokenistic. So, while the pedagogy needed by learners with very complex needs is in many ways similar to that needed by all learners, there is clearly a need for specialist training to develop appropriate expertise.

At the thematic session, Daniel Östlund outlined 3 cultures operating within the classroom - learning, care and peer cultures. He suggested that 'horizontal ' relationships are critical for supporting the best experiences for learners with complex needs and also best opportunities for inclusive education. Learners with PMLD need opportunities to develop 'equal relationships' with others in order to develop some control over their environments and living situations. Learning and care cultures tend to support vertical relationships (more time spent with adults) with a consequent impact on, for example communication and social opportunities. For this reason, Daniel proposed a model of flexible grouping as a pedagogical resource, with a large 'core' group and smaller groups – either more homogenous or heterogenous depending on the situation – to provide the best learning opportunities and also social and communication opportunities - for all learners.

Daniel also suggested that 'informal' pedagogy would be more effective with this group of learners than the common 'initiate-respond-evaluate' interaction often used in teaching – and this would also benefit a much wider group of learners.

As Ware (2005) says: '.. even where techniques appear highly specialised, they share common characteristics with 'good' teaching in general'.

Conclusion

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). In England, Ofsted (2006) also reported that learners did best, at least in academic terms in resourced mainstream provision, where there was access to specialist expertise.

There is a need to increase the awareness of the potential of this group of learners and their ability to develop control over some aspects of their lives. The Mission Statement of San Miguel School states a belief in : *..a caring, stimulating working environment for all, where pupils receive their entitlement to an education which yields a better quality of life.*

The Y Canol Principles Guiding Inclusion state: *The broad aims of education are pertinent to all children. There are ample opportunities to seek out similarities and points of contact.*

The key messages from the thematic session which would improve provision for learners with the most complex needs – and be beneficial for all learners - can be summarised as follows:

- joined-up services, appropriately funded should provide an assessment of needs and appropriate, on-going support for learners and their families;

- local schools/resource centres should collaborate to provide:

    o an inclusive ethos and positive staff attitudes;

    o a relevant and meaningful curriculum with coherent and well-planned learning opportunities;

    o teachers and support staff who communicate effectively and use a range of pedagogical approaches to encourage learner participation and support learning;

- opportunities for lifelong learning and opportunities beyond school must be available to prepare learners for their future lives.

In order to achieve these aims, we may need to take a more radical view of provision and move to more flexible 'learning communities for all' to provide the best of special education within a mainstream setting.

To conclude with a statement made during the thematic session - policy for inclusive education cannot have groups of 'but what about' kids! Policy for inclusive education must be for all learners.

References

Ferguson, D and Baumgart, D. (1991) Partial participation re-visited. *Journal of the Association for Persons with Severe Handicaps,* 16 (4) pp218-227

Foreman, P., Arthur-Kelly, M., Pascoe, S. and Smyth King, B. (2004). Evaluating the educational experiences of students with profound and multiple disabilities in inclusive and segregated classroom settings: An Australian perspective. *Research and Practice for Persons with Severe Disabilities,* 29 (3), pp183–193.

Ofsted (2006) I*nclusion: Does it Matter Where Pupils are Taught?*

http://www.ofsted.gov.uk/resources/inclusion-does-it-matter-where-pupils-are-taught

(last accessed 02/02/ 2012)

Ware, J. (2005) Profound and Multiple Learning Difficulites in A. Lewis and B.Norwich (eds) *Special Teaching for Special Children – Pedagogies for Inclusion.* Maidenhead: Open University Press

Welsh Assembly Government (2006) Routes for Learning

http://wales.gov.uk/topics/educationandskills/schoolshome/curriculuminwales/additionaleducationalneeds/routeslearning/;jsessionid=Zqy6NHfVyjsG98hTF9NZ1SQ8XJLKXqTDrHKr4vwLQ1hvNFHyqb7q!1531853584?lang=en (last accessed 06/02/12)

Additional Reading (relating to the research by Daniel Östlund)

Corsaro, W. (2005) *Sociology of Childhood*, 2nd ed. Thousand Oaks: Pine Forge Press.

Froenes, I. (1995) *Among Peers. On the Meaning of Peers in the Process of Socialization.* Oslo: Scandinavian University Press.

Rosenqvist, J. (2010). The Special Educator and the Special Teacher in co-operation for optimal learning occasions for all students in: Ellger-Rüttgardt, S. L. & Wachtel, G. (red.). *Pädagogische Professionalität und Behinderung: Herausforderungen aus historischer, nationaler und internationaler Perspektive.* Stuttgart: Kohlhammer, s. 149-159.

Resources for learners with PMLD

These resources were used, although not specifically referred to, in the development of this paper. As most of the resources below are from the UK, information about resources used in other Agency member countries would be welcome. Please send any additions to verity@european-agency.org - these will be added to the list below and shared on the Infodesk.

1. Routes for Learning (Welsh Assembly Government , 2006)

http://wales.gov.uk/topics/educationandskills/schoolshome/curriculuminwales/additionaled ucationalneeds/routeslearning/;jsessionid=Zqy6NHfVyjsG98hTF9NZ1SQ8XJLKXqTDrHKr 4vwLQ1hvNFHyqb7q!1531853584?lang=en

2. Quest materials (U.K. Northern Ireland)

http://www.nicurriculum.org.uk/inclusion_and_SEN/SEN/pmld.asp

based on Routes for Learning

3. Developing thinking for all learners (Welsh Assembly Government)

http://91.198.29.68/dtaafl/eng/dtaafl.htm

includes a section on learners with more complex needs

4. Specialist Schools Trust Complex learning Difficulties project

http://complexld.ssatrust.org.uk

 includes an Engagement Profile and Inquiry Framework for Learning

5. PMLD link journal   http://www.pmldlink.org.uk/

6. Sales of hardware/software/switches etc   http://www.inclusive.co.uk/

7. Communication toolkit and links to range of resources http://www.rettuk.org/rettuk-public/rettuk/families/therapies/speech-and-language.html

8. Articles and resources   http://www.pmldnetwork.org/

9.   Guide   to   involving   learners   with   PMLD   in   decision   making http://www.mencap.org.uk/involveMe

10. Mencap guide on communication   http://www.mencap.org.uk/all-about-learning-disability/information-professionals/communication/communicating-people-pmld