

Submission  
No 27

## INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

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**Date received:** 3/02/2010

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Legislative Council

General Purpose Standing Committee No. 2

**Inquiry into the provision of education to students with a disability or special needs**

Preamble

May I thank the Committee for the invitation to provide input, and applaud the wide-ranging and timely Terms of Reference. Whilst there is much to be said on all 7 items I will restrict my comments to two: 5. Provision of suitable curriculum, and 7. Adequate teaching training for teachers and support staff. I should state that what follows is simply my perspective as an academic working in teacher education and special education research.

*The provision of a suitable curriculum for students with intellectual disability and conduct disorders*

I am focusing here on students with multiple and severe disability (MSD), expressed by the presence of severe intellectual disability and other needs including physical, sensory and other challenges. In my work with teachers and schools, and through our systematic research, it seems clear that despite every good intention, both the KLA and the Life Skills emphases are not always pitched appropriately to meet the needs of these individuals who are at once amongst the most needy and vulnerable in our community. The enclosed paper outlines some of the key issues that need to be at the centre of future research and the delineation of best practice for this group of learners. By way of example I have regularly observed students with these complex needs passively participating in subject areas and activities that are appropriate age-wise for their non-disabled peers but are not engaging or relevant to the present or future needs of students with multiple and severe disability. Of course this time is then lost in terms of learning opportunities that will better equip them to be maximally engaged in their future life with their families and in the wider community.

**I am entirely supportive of efforts to be inclusive of all students in curriculum provision and reporting. My point is that for some students with complex needs, more attention to the question of identifying priority learning goals, on an individual basis, and delivering the most appropriate individualised instruction is warranted. One variable in this situation is teacher training.**

*The provision of adequate teaching training, both in terms of pre-service and ongoing professional training*

As a person with extensive classroom teaching experience as well as tertiary professional education and development in special education, I am concerned that courses on offer through various pathways do not provide teachers of individuals with multiple and severe disability (MSD) the specialised training in instructional design and delivery that is reflected in the literature base for this field. Whilst not advocating a return to categorical approaches, **I argue that more specific training for these teachers is required across all educational systems to enable them to better work with families and maximise learning outcomes in students with such complex and high support needs.**

I hope the attached paper may be of assistance with respect to the points I have made here, and I would welcome the opportunity to assist the Committee further if this is considered appropriate.

Yours sincerely

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# Interaction, inclusion and students with profound and multiple disabilities: towards an agenda for research and practice

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**Key words:** behaviour states, communication, inclusion, profound and multiple disabilities, socialisation.

The needs of students with profound and multiple disabilities (PMD) have received more attention in the educational research and best practice literature over the past decade, especially in relation to the importance of maximising their social and communicative engagement. However, perhaps as a function of their low incidence rate and resultant difficulties in obtaining research funding, there appears to be little in the way of a coherent vision for research in the international literature. In this paper we argue the need for a systematic programme of research into the nature of learning processes and outcomes for members of this group. Several issues emerge from a review of selected literature and from some recent observational data and descriptive case studies collected in special and inclusive classrooms. First, there is the importance of identifying ways of better understanding the complex experiences of members of this population, with particular attention to the ongoing contribution of behaviour state assessment as a means of measuring individual alertness and responsiveness. We argue that improved uptake of this approach will do much to advance our knowledge of life quality for this population and assist in more fully evaluating the effectiveness of educational interventions. Second, we explore the potential of social and communicative engagement in a variety of settings as a means of enhancing learning and participation in this group. We suggest that interpersonal variables are the key to improvements in educational support for this vulnerable group. Potential directions in research and practice are explored.

## Introduction

In most western countries, the past 20 years have witnessed enormous improvements in the design and delivery of educational programmes for students with profound and multiple disabilities (PMD). Functional or life-skill curriculum opportunities, access to the regular curriculum, community-based living and learning, integration and inclusion, augmentative and alternative communication

supports are just a few examples of initiatives that have encouraged the membership and participation of members of this group in the wider community (Agran, Alper & Wehmeyer, 2002; Arthur-Kelly, Bochner, Center & Mok, 2007; Snell & Brown, 2000).

In this paper we propose some directions for research and practice that we believe will further inform how best to understand, engage and educate students with PMD. The Special Interest Research Group (Profound and Multiple Disabilities) of the International Association on the Scientific Study of Intellectual Disabilities (IASSID) has noted that 'individuals with profound multiple disabilities form a heterogeneous group. The "core group" consists of individuals with such profound cognitive disabilities that no existing standardised tests are applicable for a valid estimation of their level of intellectual capacity and who often possess profound neuromotor dysfunctions like spastic tetraplegia as well. Apart from profound intellectual and physical disabilities, it has been demonstrated that they frequently have sensory impairments. Individuals with PMD form a physically, very vulnerable group of persons with a heavy or total dependence on personal assistance for everyday tasks, 24 hours a day' (IASSID, 2007). Clearly, members of this group will typically require professional input from a range of personnel (e.g., physiotherapists, speech therapists, special educators), as well as ongoing family support across the lifespan.

In light of the range and fragility of daily learning and participatory needs experienced by members of this population, three themes will guide this discussion. The first is the importance of identifying instruments that can assist teachers, therapists, families and others to more fully understand existing and potential levels of engagement and responsiveness, and analyse the impact of specific instructional approaches upon levels of alertness in students with PMD. Specifically, we argue the need to translate what have mainly been research protocols in behaviour state assessment into practical aids for classroom personnel. Second, we argue that interaction as a function of rich, engaging human ecologies holds much promise for the

enhancement of best practices to support students with PMD. Finally, we provide two descriptive case studies from a recent study that compared eligible students in regular and special school enrolments, with particular attention to the social and communicative indicators we observed. At the end of each section we pose questions for consideration in the design of future research that informs evidence-based practice to enhance the educational outcomes achieved by persons with PMD.

*Measuring engagement and responsiveness in individuals with multiple and severe disabilities*

The identification and delivery of meaningful and inclusive curriculum for students with PMD is a critical issue for debate in many educational systems around the world (Agran, Alper & Wehmeyer, 2002). Researchers, parents, teachers and policy-makers are engaged in useful dialogues around the questions of relevance and achievability: what should be taught to members of this group, should it be positioned within regular syllabi or stand alone, and how will it impact life-long learning and functioning (Arthur & Foreman, 2002; Foreman & Arthur 2002)? Likewise, what types of instruction are most effective in maximising learning outcomes for individuals with PMD, and can these approaches be delivered in the range of settings that currently provide educational programmes for members of this group (Helmstetter, Curry, Brennan & Sampson-Saul, 1998)?

One factor that underpins both curriculum and instruction is the individual levels of engagement and responsiveness demonstrated by students with PMD. Considerable evidence gathered over several decades highlights the importance of maximising the arousal and connectivity of individuals in this group, who are typically affected by a myriad of intrapersonal complications including sensory, intellectual and physical challenges. Research into the use of behaviour state assessment for students with multiple and severe disabilities has emerged in the last 10 to 15 years, centred on the work of Guess, Roberts and their colleagues (see Guess, Roberts & Rues 2002; Guess, Roberts, Siegel-Causey & Rues, 1995), and before that, the contributions of Brazelton (1984).

Briefly, behaviour state measures provide an index of the observed level of engagement and responsivity in students with PMD, examples of which include Awake, Active-Alert, Crying and Agitated, Asleep, and so on. Data have been collected in several studies suggesting a promising relationship between socio-communicative variables (such as partner cues) and improved levels of responsiveness in people with PMD, as well as the role of individually tailored supports and collaborative efforts to maximise interactions and thereby enhance student participation in learning (Arthur, 2004; Arthur-Kelly et al., 2007; Ault, Guy, Guess, Bashinski & Roberts, 1995). In one recent study, Mellstrom, Saunders, Saunders and Olswang (2005) demonstrated the reliable use of behaviour state assessment as an index of alertness in adults with profound needs who were exposed to various switches that aided in the use of a

preferred leisure activity. Clearly, research of this kind with adults has enormous potential for planning and delivering individualised supports for partial participation in the daily activities and exchanges of life, and measuring the ongoing effectiveness of such interventions on the basis of changes in alertness. However, as we note a little later, more attention is required to the development of user-friendly coding protocols that are practical and useful in applied settings.

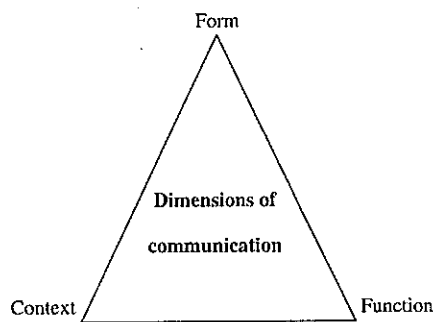
For school-aged children with such complex needs, there is also much to be done in relation to more fully utilising behaviour state protocols in educational programmes. We therefore pose the following research and practice questions:

- Is it possible to devise a practical system of behaviour state recording that is viable in the inclusive classroom, typically staffed with a paraprofessional and teacher?
- How can behaviour state codes inform the process of programming and reporting as demonstrated in the Individual Education Plan and Review documents, by providing continuous evidence of changes in engagement and involvement in learning activities?
- What are the implications of this approach for tracking changes in child involvement across home, school and community/life situations?

In our view, simply identifying the level of responsiveness and alertness in students with PMD without also considering relevant aspects of the contextual variability they experience is a flawed exercise. The last decade of research into student behaviour states has emphasised the importance of understanding the interplay of intrinsic and extrinsic factors that shape the functioning of people with PMD. In the next section, the role of the socio-communicative milieu available in educational settings is explored with specific attention to the human interaction potentials available for the improvement of student connectedness (Arthur-Kelly et al., 2007; Siegel-Causey & Bashinski, 1997).

*Communication, socialisation and setting*

Butterfield and Arthur (1995) provided a series of simple communication cycles and emphasised the importance of ensuring that individuals with PMD enjoy positive communication experiences. This was especially pertinent given the earlier findings by researchers such as Houghton, Bronicki and Guess (1987) suggesting a tendency for these individuals to be overlooked by adults in relation to their communication initiations. It was anticipated then, on the basis of the extant data, that inclusive settings would be an ideal context for the achievement of high quality and high numbers of communicative interactions involving members of this group and their non-disabled peers. The presence of heterogeneous learning arrangements and a potential for the introduction of a wide range of peer-assisted instructional modes are examples of advantages offered by an inclusive classroom. Despite the intensive personal care needs of many children with severe, multiple and often complex

**Figure 1: Interrelated dimensions of communication**

trajectories, daily learning activities in the company of peers without a disability offer, potentially, the best social forum for experiences such as turn-taking, requesting and greeting (see, for example, the results of an observational study by Foreman, Arthur-Kelly, Pascoe & Smyth King (2004) discussed later in this paper).

Figure 1, describes three related dimensions of communication highly relevant to the education of students with PMD. It should be noted that the same interactive relationship can be articulated in terms of social behaviour, and more especially, the functional assessment of anti-social repertoires. Briefly, communication *form* is simply the way (or ways) in which an individual communicates. This may be pre-intentional, intentional or symbolic and therefore involve quite idiosyncratic or conversely, quite sophisticated behaviours (Siegel-Causey & Bashinski, 1997; Sigafoos, Arthur-Kelly & Butterfield, 2006). Likewise, augmentative or alternative communication (AAC) supports can be quite sophisticated (e.g., photonic wands) or quite simple (simple line drawings or photographs). Perhaps the most important point to make about communication form, especially in relation to individuals with PMD is that it can and should be interpreted by partners as functional for the person who is displaying such behaviour. This principle of responsivity and acceptance of what students give us communicatively is central to the approach known as Intensive Interaction (Nind & Hewett, 2005). Drawing on what is known about early childhood development and melding this with partner reflection and sensitivity to existing abilities, Intensive Interaction encourages those engaging with students with PMD to recognise what the child provides in an interaction, and seamlessly scaffold the communicative exchange by affirming such efforts (Barber, 2007).

Notwithstanding the nuances that may surround the use of such means to communicate, form is only one of three interlinked aspects: the second to consider is the purpose or function of the communication.

Communication *functions* are the messages that are conveyed and usually relate to needs and wants (e.g., request object, reject object, express emotion) or aspects of

the social context (e.g., acknowledge, greet, farewell). In everyday life, humans intuitively connect various pragmatic messages in their exchanges with others. For persons with PMD, an educational team may decide to support the expansion of functions achieved, improve the way (form) in which such functions are achieved, or some other combination of goals. Again, such approaches can be enhanced by an understanding of existing student abilities and an empathic yet strategic perspective on the enhancement of communicative effort. Nevertheless, such planning will be weakened if aspects of the communication context are ignored.

*Context* includes the people with whom one communicates – locations, times and activities (Siegel-Causey & Bashinski, 1997). An increasing amount of attention is being paid in current research to the question of how to enhance both the quality and the range of communication contexts experienced by people with PMD. For example, many tools for assessing the communication abilities of students with PMD are reliant on the reports of partners (Sigafoos, Arthur-Kelly & Butterfield, 2006) and it is therefore critical that partner skills and knowledge are recognised as a critical variable in programme design and implementation. Similarly, there is some evidence that inclusive contexts facilitate more communicative engagement and peer interaction for students with PMD when compared with those attending segregated settings (Foreman et al., 2004).

### Summary

The central point we want to make here is this: communication in students with PMD is a synergistic process, driven by intra-personal, interpersonal and external influences that are typically complex and wide-ranging. The connection of how, why and under what circumstances a person engages with others is relevant to all learning and participation. For this reason, it is our contention that the dynamics of inclusive classrooms deserve further study in terms of their potential to scaffold and maximise the communicative and social engagement of students who have traditionally been regarded as difficult to reach and teach. We therefore pose the following questions:

- What is the nature of communication opportunities provided to students with PMD by peers, teachers and related professionals in inclusive classrooms?
- Is peer networking or peer tutoring involving able-bodied students and their counterparts with PMD effective in increasing the alertness and engagement of these individuals?
- Are there generalised benefits that accrue for students with PMD in other contexts as a function of in-class interactions and membership of a social milieu?

With these questions in mind, it is now appropriate to provide some illustrative case studies from a recent observational study of the experiences of students with PMD in Australian educational settings.

**Table 1: A day in the life of Katya**

Katya is 7-years-old and attends her local neighbourhood school (Year 2). She has an identified level of intellectual disability in the severe to profound range, and is totally dependent on others for the daily activities of toileting, dressing and moving around. This is because of the presence of several physical difficulties that restrict her fine and gross motor abilities, including ambulation and grasp.

Katya has several very distinct facial expressions that indicate pleasure and displeasure, and these are usually accompanied by definite sounds (a squeal for delight and a coughing noise when she is not happy).

The major goal in Katya's individualised education programme, agreed upon by her parents, teacher and the related professionals who assist in the classroom, is the improvement of social and communicative relationships. Katya has no siblings and so it is even more important that she forms and maintains healthy connections with peers in and beyond the classroom. There are 24 children with Katya in this Year 2 class and they have all been together since kindergarten. Aside from a small number who are struggling with basic literacy and numeracy skills, none has the type of support needs experienced by Katya.

The most significant observation one makes when entering the classroom is the physical proximity of Katya and her peers. Katya is usually positioned in an adapted chair that can easily be shifted to her wheelchair when the class moves outside, and the teacher uses small groups of 5 children to facilitate learning. Katya, like all of the students, rotates to different seating groups each month.

This physical proximity is the basis for rich and constant interaction that almost envelopes Katya. Learning tasks presented to Katya are the same as for the rest of the class and the principles of partial participation ensure that Katya has as much input as possible. Assisted by peers and occasionally by the paraprofessional or the teacher, Katya is constantly asked to make choices (What colour would you like here? Can you point to the juice, Katya?). Peers are observed to make eye contact at Katya's level, smile and ask a question that is relevant to the task or activity that is taking place. The peers seem especially adept at both waiting for a response and then 'reading' what Katya is conveying. Similarly, the boys and girls who count themselves as Katya's friends are responsive to her utterances, body shifts and facial expressions, using questioning to ensure that they have correctly interpreted the intended meaning. In Katya's case, the interplay of communication form, function and context is a daily and empowering educational experience.

#### **Our recent findings: two illustrative case studies**

In a recent study we observed eight matched pairs of students, ranging in age from 6–11 years, in either special classrooms (segregated schools) or regular classrooms. All participating students met a minimum of 80% of the following criteria in addition to an identified severe intellectual disability: major sensory impairments, severe motoric difficulties, absence of verbal skills, dependence upon others to meet basic daily needs and an apparent lack of engagement with the environment. Our data were based on one full day observing each student, during which time we recorded student behaviour states, learning activities, communicative functioning and several other contextual variables (Foreman et al., 2004). A partial interval recording system was used that involved observing the target student for 10 seconds, then recording against a specified series of codes for the next 10 seconds. Inter-observer agreement levels on all codes were above 90%.

For the purposes of our discussion here, two findings are noteworthy, underpinned by the fact that there were little data of the same type in the literature with which we could make comparison. First, there was a significantly higher amount of communicative activity in the general (inclusive) classrooms. On average, almost half the day was spent in communicative interactions involving students with PMD and others, compared with 27% in segregated classrooms. Not surprisingly, then, our second related finding was that there were major differences between dyads in terms of peer interactions: in regular classes the partner was a peer 17% of the time, as opposed to 4% in special classes. What

brought about such differences? To explore this finding, we have provided a descriptive composite of Katya, who represents several children we observed in the study (Table 1).

In light of the dimensions of form, function and context in communication (Figure 1), Katya's case study generates several potential questions for research and practice:

- Are there benefits for students with PMD to be obtained through teacher use of socially mediated instructional strategies such as cooperative learning?
- Following the principles of Intensive Interaction, how important are teacher intuition, reflection and responsiveness in promoting interactions involving students with PMD and their able-bodied peers?

In Table 2, below, several issues in the daily school experiences of Jenny, a young girl attending a special (segregated) school, are described.

Like Katya, Jenny experiences a wide range of needs that are usually driven by physical, medical, sensory and other factors. Clearly, her quality of life is strongly influenced by the responsiveness and skills of those around her: the key players in her communicative and social world. Questions that arise from this case study include:

- What do we know about how to maximise partner skills in interpreting the communication behaviours of students with PMD?

**Table 2: A day in the life of Jenny**

Jenny is an 11-year-old girl who is enrolled at a special school for specific purposes closest to her residence. Jenny has severe and multiple disabilities. She has a severe to profound intellectual disability and severe physical disabilities. Because of the severity of her physical disabilities Jenny is dependent on others to meet her daily needs including toileting, dressing, moving and the provision of meals. Jenny has limited fine and gross motor skills, resulting in her inability to reach, grasp or point.

Jenny is one of six students in the classroom with varying abilities. Three of the students are verbal and mobile, one student is verbal and non-mobile and one student is mobile and non-verbal.

Jenny has very expressive facial cues which she uses to indicate if she is happy, sad or in pain. She will smile widely when happy and cries and grimaces when she is in pain, she cries very loudly when she is unhappy. Jenny has very good vision and will use eye gaze to make choices from real objects.

In a teaching-group situation, Jenny attempts to interact mainly with her teacher and teacher's aide. She appears to understand the communication partners who will be able to meet her needs. Of the student peers in Jenny's classroom, two are aware of her communicative attempts and are concerned when she is distressed.

In whole-group teaching situations Jenny is asked to choose between two symbols (line drawings) to make a selection for songs or stories, using eye gaze. Jenny is always positioned within the classroom group, in close proximity to peers and teaching staff.

At times Jenny becomes quite distressed and her teacher and teacher's aide assume her discomfort is due to a hip complaint, always offering to reposition her. This may or may not alleviate her distress. There are many examples throughout the day when teaching staff attempt to interpret her communicative attempts. They try a sequence of interventions to try and ascertain what will ease her discomfort and bring back her smile.

Jenny demonstrates a range of communication forms that can be interpreted as pre-intentional and at other times intentional. It is vital, thus, that she be assisted to become more consistently intentional in her communicative repertoire. She uses facial expressions and vocalisations to indicate discomfort, happiness and displeasure. Her communicative functions are limited to the expression of emotion and several simple binary choices in a morning circle situation. The success of her communicative attempts relies very heavily on the interpretation of those attempts by the communication partner (context). If the communication partner is incorrect in their interpretation this leads to an increase in the frustration of both Jenny and the communication partner. A goal identified in Jenny's individualised education programme was to provide a more systematic means for her to make choices in her daily routine, and to have the skills to communicate what is causing her distress. With the development of a communication programme which provides Jenny with a reliable means of expressing her needs in a range of contexts, she will not be solely reliant on the communication partners' interpretations. The communication system could involve a small range of highly iconic visual symbols that provide Jenny with the vocabulary to express her needs and make choices (functions). For example, a line drawing of a cup will be used to allow Jenny to selectively indicate her desire for a drink from a range of two symbols. The number of choices will be systematically increased on the basis of progress data.

Once a communication form has been designed which allows Jenny more independence in her communicative interactions, a further goal would be to be to expand the context in which Jenny communicates, to include her peers in and outside of the classroom. Providing Jenny with an independent and reliable form of communication will allow for an increase in the functions she can convey, in turn expanding the contexts in which she is able to communicate and interact.

- How can augmentative and alternative communication (AAC) resources be used to complement a focus on partner skills and knowledge in communication programming?

### Conclusion

In this paper we have raised several questions for discussion, based on our reading of the current literature and our recent research in classrooms serving students with profound and multiple disabilities. In our view, the human ecology surrounding members of this population is an area rich for investigation, with wide-ranging potential to inform the nature of educational programming delivered to this complex and vulnerable group. Inclusive settings, with their inherent age appropriate and normalised social milieus, need detailed and longitudinal examination if we are to continue to improve both our understanding of individual needs and the role of peers, teachers and related personnel in maximising participation, a sense of 'belongingness' and engagement for students with such pervasive and complex support needs.

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