

## Current Research

Research in the field of Intellectual Disability and Special Education is broad ranging and reported on by a number of professional peer reviewed journals, many of which can be found online eg

- Journal of Applied Research in Intellectual Disabilities
- European Journal of Special Needs Education
- British Journal of Special Education
- International Journal of Practical Approaches to Disability,
- International Journal of Disability and Education,
- Augmentative and Alternative Communication (AAC)
- Australasian Journal of Special Education

Independent and accessible research about issues relating to Intellectual disability and Special Education is available from eg

- The Centre for Developmental Disability Health (CDDHV), an academic unit established by the Victorian State Government to improve health outcomes for people with developmental disabilities through a range of educational, research and clinical activities. <http://www.cddh.monash.org/>
- British Institute of Learning Disabilities ([www.bild.org.uk](http://www.bild.org.uk)). This organization is a hub for training, publications and independent information. It produces the professional journal SLD Experience.
- MENCAP ([www.mencap.org.uk](http://www.mencap.org.uk)) originally a charity organized by individuals with intellectual disabilities and their parents, this organization, still a charity, now contributes to and commissions respected research investigating the lives of people with an intellectual disability.
- PMLD NETWORK, (<http://www.pmldnetwork.org/resources/index.htm> ) also in UK this network of professionals provides 'accessible to all' information about intellectual disabilities including special educational issues

## Definitions

### Intellectual Impairment

IQ classification is primarily used by health professionals to assess the presence and degree of intellectual or learning disability. It should not be seen as the only method of identifying the presence of learning disability in an individual and the language associated with IQ scoring is now seen as outdated.

- severe learning disability IQ= 20 - 35
- profound learning disability IQ = Below 20

NB There are problems in using IQ, in that measurements can vary during a person's growth and development but more importantly it doesn't capture the person's strengths and abilities very well. IQ is an important measurement, but only if it is carried out alongside other assessment and measurement including social functioning and adaptation. (British Institute of Learning Disabilities 2012)

### Profound Intellectual and Multiple Disabilities **PIMD**

### Profound and Multiple Learning Difficulties / Disabilities **PMLD**

#### Eg 1)

A severe or profound intellectual disability is defined as an IQ below 35. Generally speaking, a person with a severe or profound intellectual disability: recognises familiar people and may have strong relationships with key people in their lives, has little or no speech and relies on gestures, facial expression and body language to communicate, requires lifelong help with personal care tasks, communication. Tracy (2010)

#### Eg 2)

People with profound and multiple learning disabilities:

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need high levels of support
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge us. MENCAP (2010)

#### Eg 3)

Learners 'with profound intellectual disability have a profound cognitive impairment/learning difficulty, leading to significant delay in reaching developmental milestones. Such learners will be operating overall at a very early developmental level and will display at least one or more of the following:

- Significant motor impairments
- Significant sensory impairments
- Complex health care needs/dependence on technology'. Ware (2004)

#### Eg 4)

"People with profound and multiple learning disability (PMLD):

- have extremely delayed intellectual and social functioning
- may have limited ability to engage verbally, but respond to cues within their environment (e.g. familiar voice, touch, gestures)
- often require those who are familiar with them to interpret their communication intent
- frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments.

They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualized relationship with a carer." Bellamy, Croot, Bush, Berry & Smith (2010)

People with profound intellectual disabilities are likely to be pre-intentional communicators or may communicate with emerging intention. This means that they have extreme difficulty 'reading' the behaviours of others and also that they do not intend to transmit meaning or content by their actions or movements. Those around them must infer, attribute or interpret meanings from the person's behaviours.

Preintentional communicators might *demonstrate a small range of preferences* but may not be able to *make choices*. People with this level of intellectual disability are likely to be pre symbolic, ie they will not understand pictures or symbols, however through repeated experience over time, they may have learned to recognise links between a small number of pictographs and events associated with their presence.

It is worth considering that while a person might recognise or show interest in a picture or icon, it should not be assumed that s/he understands its potential communicative nature; ie that it can be used for communicative purposes.

## **Incidence**

Australian Institute of Health and Welfare statistics identify an incidence of about 351,000 people having a severe or profound intellectual disability (1.8% of the total population), of whom 215,100 were aged under 65 years (1.2% of the under-65 population). AIHW (2008)

## Causes of profound intellectual disabilities and complex needs

There are many causes of profound intellectual disabilities and complex needs (DHS Victoria (2011)) A specific cause can be identified in approximately two-thirds of cases. Known causes include:

- Brain injury or infection before, during or after birth
- Growth or nutrition problems
- Faulty chromosomes and genes
- Babies born long before the expected birth date – also called extreme prematurity
- Health problems during childhood
- Drug misuse during pregnancy, including excessive alcohol intake and smoking
- Environmental deprivation
- Exposure to toxins
- A range of medical disorders

## Additional difficulties

(Acknowledging PMLD Network UK)

‘Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound intellectual disability. All people who have profound and multiple intellectual disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with autism and Down’s syndrome may also have profound and multiple learning disabilities. All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of daily life’.

‘Some examples of conditions and syndromes that are more usually associated with profound and multiple learning disabilities are:

- Rett syndrome,
- Tuberous Sclerosis,
- Batten’s Disease’

NB for the rest of the document follow this link

<http://www.pmldnetwork.org/pmld%20definition%20factsheet%20-%20standard.pdf>

## Approaches to teaching

Traditionally, the assessment and teaching of students with complex intellectual disabilities has been heavily influenced by behaviourist thinking. However, as Collis and Lacey (1996) summarise, there are concerns resulting from the nature and use of behaviourist methods, including:

- problems with generalisation, Sugden, (1989);
- learning without understanding, Farrell, (1991);
- an emphasis on products rather than processes of learning, Smith et al, (1993);
- concern only with the observable, Sugden, (1989);
- casting the learner in a passive role, Jordan and Powell, (1991);
- learners becoming compliant rather than independent

In early 1990s 'Interactive Approaches' to teaching (Collis and Lacey 1996) began to emerge. These approaches to teaching focus on supporting the development of fundamental communication skills through process-based rather than product-based behaviourist learning.

Supporting interaction is seen as more important than teaching the performance of communication.

Interactive approaches moved teachers away from focussing on teaching small sequential steps through extrinsic rewards, and instead focus on social interaction and learning through supported involvement. While students with severe intellectual disabilities might be helped to acquire linear skills through these techniques, learners with more profound intellectual disabilities are more likely to learn simply to comply.

The principles of the Interactive Approaches are that:

- the quality of the teaching and learning process is as important as the performance of the objectives;
- teaching is not always dependent on dividing that which is to be taught into its constituent parts."Rather than using explicit teaching methods based on the transition of information and the direct teaching of skills, the teacher's role...is to create learning situations which provide opportunities to solve real problems."  
Westwood, (2001)

### **Implications for Teaching and Curriculum**

Clearly recording progress in quantifiable terms is much more convenient when teaching linear skills using the behavioural approaches which focus on rewarding appropriate or desired behaviour or compliance. Indeed identifying and defining progress can be much more complex when teaching focuses on 'process' rather than product.

ACARA's 2012 document 'Curriculum, Assessment and Reporting in Special Educational Needs and Disability: A Thematic Overview of Recent Literature', the authors highlight the quality of two documents which support this style of teaching:

- **Routes for Learning.**(2006) Assessment materials for learners with profound learning difficulties and additional disabilities created by the Qualifications and Curriculum Group, Department for Education, Lifelong Learning and Skills, Wales (ACCAC, 2006).
- **Quest For Learning** (updated 2012)
- *NB For a free download of this public document go to;*  
[http://www.nicurriculum.org.uk/inclusion\\_and\\_SEN/SEN/pmlD.asp](http://www.nicurriculum.org.uk/inclusion_and_SEN/SEN/pmlD.asp)
- *NB for the teacher guide and other resources (free download)*  
[http://www.nicurriculum.org.uk/docs/inclusion\\_and\\_sen/pmlD/Quest\\_Software\\_Quick\\_Start\\_Guide\\_Teachers.pdf](http://www.nicurriculum.org.uk/docs/inclusion_and_sen/pmlD/Quest_Software_Quick_Start_Guide_Teachers.pdf)

### **Strategies**

Without doubt, the most important learning for students and indeed all people who have complex or profound intellectual disabilities is communication learning. Communication underpins all aspects of life and all other learning. Communication is essential for maintaining mental health, social connectedness and emotional wellbeing, as well as being central to gaining some level of independence and control.

The most recent, independent and comprehensive enquiry into strategies used to meet the communication needs of people with 'complex needs' ; *Communication and people with the most*

*complex needs: What works and why this is essential* was carried out by Goldbart and Caton (2010) of the Research Institute for Health and Social Change Manchester Metropolitan University (MMU) UK.

Within “complex needs” the study includes people with profound intellectual impairments, people with severe autism, and people whose severe learning disability or autism is complicated by behaviour labelled as challenging. Evaluation notes are based on evidence in the research literature as well as surveys of family carers and practitioners, researchers, previous surveys of speech and language therapists:

The study is extensively referenced in the following section;

### **Communication passports.**

The communication of people with complex needs is frequently more easily understood by familiar than unfamiliar people. To help less familiar people recognise and make sense of potentially communicative behaviour, and to facilitate interactions, a range communication passports, communication dictionaries and personal passports are frequently used to capture and enable the sharing of information. ie photographs, texts, video

*While the authors could find no published formal evaluation of communication passports, it was noted that parents, researchers and practitioners supported the use of communication passports. They were used more with adults than children. Goldbart and Caton (2010) express the urgent need for formal evaluation of their introduction and use.*

### **Intensive Interaction**

Intensive Interaction is an approach to developing interaction and communication between people with complex communication needs and the people around them. It is based on the on work by Nind and Hewett. Its use with children and adults appears widespread in the UK, and is increasing in Australia, supported by training courses, conferences and websites. Intensive Interaction is described primarily as a way of supporting people with complex communication needs to enjoy, explore and learn about sustained interaction. Any reductions in stereotyped or challenging behaviour are seen as secondary. The approach is recognised by Australia Psychological Society as ‘an evidence based practice’

*There is reasonable, and growing, research evidence and practitioner support for Intensive Interaction and there is an extensive amount of professional and practitioner literature about the approach. Intensive Interaction was the most widely reported approach by practitioners, with over 85% of speech and language therapists in the survey using it. However, it was mentioned by very few parents. Hanging Out Program (Forster, 2008) is a broadly similar and may be easier for staff to implement, especially in adult services*

### **Cause and effect switches**

Switches (sometimes called micro-switches) and other “cause and effect” activities are ways of helping people with profound intellectual impairment understand that their actions have consequences; ie that they can make things happen. Learning to make things happen can be seen as a step on the way to making things happen by communicating with other people. Researchers have shown that people with profound impairments can learn to use micro-switches to make and convey choices and attract the attention of other people (eg Lancioni et al, 2006). Most of this work, however, has been carried out in research rather than everyday contexts, though Barber has discussed their use in classroom (eg Barber, 1994; Barber and Goldbart, 1998). One application of this work on switches has been the development of a single message communication device called a BIGmack, a device on which a message can be recorded and might be seen as a precursor to the use of high-tech AAC

*There is an extensive evidence base for development of early communication through switching and resources and practitioner articles are widely available. Despite the extensive research demonstrating the effectiveness of this approach as a route into communication, there is rather limited use by practitioners and very little evidence of their use by parents. Access to information, technical support and equipment, along with the cost and reliability of equipment, may be barriers.*

### **Objects of Reference**

Objects of Reference can be used to signal what is about to happen and to offer choices. They may also act as a concrete link to more abstract, 2D symbols and then language, by helping learners to move through increasingly abstract representations of things and events. Again however, the recognition of an object (eg 'a cup'), does not necessarily signal the learner's recognition of its potential communicative use (ie 'drink')

*There is a very limited amount of evidence for the effectiveness of Objects of Reference or any other use of object cues in communication, however, more than 70% of practitioners surveyed reported using Objects of Reference in both child and adult services. However they were rarely mentioned by the parents and family carers. Although it seems an intuitively 'sensible' way of working, there is a great need from further research on the effectiveness of this strategy*

### **Picture Exchange Communication System (PECS)**

PECS is a picture-symbol-based approach which emphasises the transactional nature of communication (Bondy and Frost, 1994). In other words, at its most basic level, it aims to establish the idea of communication by teaching children to exchange a picture symbol for something they want through highly structured training. It was designed for children with autism, but has become more widely used.

*There are several recent studies which provide only modest support for the use of this approach with children and/or adults with autism. eg Ganz et al, (2009); Rehfeldt and Root (2005). Further research is needed to identify the types of learners who would benefit most from this approach.*

### **Visual Supports**

"Visual timetables, schedules etc are a group of approaches whose aim is primarily to let the person know what is going to happen or what is available to them. Typically, a visual timetable is made up of a clear plastic frame or set of plastic pockets. Pictures, symbols or photos showing activities or things that are available then go on the frame or in the pockets. They might be organised by time, showing what a person is expected to do or may choose to do at different times during the day. This technique seems to be derived from the TEACCH2 approach for people with autism" (p14 Golbart & Caton 2010)

*Although there is a long history of research supporting the use of symbols for communication with adults with a learning disability and for children with autism) the authors found no formal evaluations of their use with people with more severe communication needs. While 30% of surveyed practitioners reported using symbol-based or similar approaches, none of them reported using visual timetables. This may be because the focus of the study was on people with PMLD not autism. There is general support from parents and practitioners and also some evaluation of effectiveness, but good research is needed on their use with people with the most complex needs..*

### **InterAACtion**

This Australian approach, mainly involves staff training, has a small but growing research base.

*The intervention was developed from the assessment known as 'The Triple C' (Bloomberg et al, 2009) which has been evaluated rigorously (Iacono et al, 2009). The intervention approach was not mentioned by parents or practitioners, but 16% of surveyed practitioners were using the Triple C assessment. The attention to evaluation and the links with sound assessment recommend it highly*

NB For those wishing to see the full Goldbart & Caton 2010 document, follow the following link for a free download;

<http://www.mencap.org.uk/all-about-learning-disability/information-professionals/communication>

## References

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## Suggested readings

ACARA (2012) Curriculum, Assessment and Reporting in Special Educational Needs and Disability: *A Thematic Overview of Recent Literature* Australian Curriculum: Students with Disability

[http://www.barryprizant.com/files/asq5\\_aba\\_only\\_way\\_part\\_2\\_spring\\_2009.pdf](http://www.barryprizant.com/files/asq5_aba_only_way_part_2_spring_2009.pdf)

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Davis, P., & Florian, L. (2004) *Teaching Strategies and Approaches for Pupils with Special Educational Needs: A Scoping Study Research Report*

<http://orphansfamilyproject.pbworks.com/f/II.teaching%2520strategies%2520including%2520aspects%2520of%2520II.pdf> (Accessed 12 April 2012)

DHSVictoria(2011)[http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Intellectual\\_disability\\_facts\\_and\\_figures](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Intellectual_disability_facts_and_figures) (accessed 12 April 2012)

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## Links to Videos, website, strategies

### Australia

- Australian Association of Special Education Inc. (AASE) A broad-based non-categorical association concerned with all who have special education needs <http://www.aase.edu.au/>
- Centre for Developmental Disability Health Victoria. (Monash Univ) <http://www.cddh.monash.org/assets/documents/intellectual-disability.pdf>
- Centre for Disability Studies Univ Sydney <http://www.cds.med.usyd.edu.au/>

### UK

- PMLD NETWORK in UK <http://www.pmldnetwork.org/resources/index.htm>
- MENCAP; <http://www.mencap.org.uk/node/6167>
- <http://www.mencap.org.uk/all-about-learning-disability/information-professionals/more-about-learning-disability>

- Raising our Sights
- [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_114346](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346)
- PAMIS
- [www.pamis.org.uk/](http://www.pamis.org.uk/)
- PMLD network
- [www.pmlnetwork.org/](http://www.pmlnetwork.org/)
- PMLD link
- [www.pmlink.org.uk/](http://www.pmlink.org.uk/)
- PMLD fact sheet
- [www.pmlnetwork.org/pmldefinitionfactsheet-standard.pdf](http://www.pmlnetwork.org/pmldefinitionfactsheet-standard.pdf)
- Mencap's PMLD Communications Guide [www.mencap.org.uk/page.asp?id=1539](http://www.mencap.org.uk/page.asp?id=1539)