In this issue:

Louise Campion
Sex and relationships education for young people with special educational needs

Katherine Corey and Bev Mars
Teaching self-regulation techniques to increase feelings of well-being through yoga and relaxation to young people with severe learning difficulties, autism and challenging behaviour to reduce anxiety and improve participation in education

Matthew Rayner and Dawn Male
Specialist support services received by pupils in special (SLD) schools in England: level of support received and head teachers’ perceptions of usefulness

Martin Goodwin
Listening and responding to children with PMLD – towards a framework and possibilities

John Bosley
Spiritual, moral, social and cultural development (SMSC) at Abbey Court School

Mark Fox
Developing children services to improve the quality of life for children and young people with severe learning difficulties

Cerys Jones
Materials review

Dawn Male
Recent research

What’s new?
In February the Children and Families Bill was published. This Bill signals the first major overhaul of the SEN system for 30 years. Although the Bill only applies to England, similar moves are afoot in Wales. For children with SLD and PMLD the proposed replacement of statements of SEN with education, health and care plans (EHCP) appears to hold out the promise of more integrated provision across services. However, the publication of the Bill has raised considerable concern from parents of children with a wide range of disabilities and from voluntary organisations, including Mencap. Some changes have been made as a result; for example a new legal duty on clinical commissioning groups to secure health services (such as speech therapy and physiotherapy) for children with SEN who have education, health and care plans. Other changes are likely as the Bill proceeds.

I hope that the new duty to secure health services for children with EHCPs will really make a difference to access to these services for children who need them; access to services such as speech and physiotherapy has been a problem for at least 30 years (Evans and Ware, 1987) and Matthew Rayner and Dawn Male’s article in this issue provides a sobering picture of the current availability of services, with some head teachers reporting not only that the availability of particular services was inadequate, but that the service itself was of little use, and co-ordination between services difficult. It is clear that issues of this sort will need to be addressed if replacing statements with EHCPs is going to make a real difference. The fact that the Children and Families Bill is progressing through parliament at present also makes Mark Fox’s article in this issue particularly timely. As Mark points out, in addition to the new integrated EHCP plans, personal budgets, which are aimed at giving people with SEN and their families more choice over the services they receive are also to be available to those families which want them. But if children and young people with SLD are really to have a say in what services they receive, more work is needed to ensure that we help them acquire the skills to express their own opinions. Accepting and acting on their views may prove to be an even greater challenge. In this context Martin Goodwin’s article on listening and responding to people with PMLD is also timely.

Louise Campion’s thoughtful account of a pilot project on Sex and Relationships Education, deals with a potentially controversial area. Much research suggests that people with learning difficulties have less opportunity than their peers to develop friendships of all kinds, and are also more vulnerable to exploitation, which makes projects of this sort particularly valuable. Also closely linked to personal and social education is John Bosley’s article detailing one school’s attempt to promote spiritual, moral, social and cultural development among its pupils. Katherine Corey and Bev Mars’ account of the use of yoga and relaxation with pupils with severe challenging behaviour is interesting because it provides evidence that the use of these techniques can make a difference in an area which often seems intractable. Finally, as always, Dawn Male provides an excellent summary of a piece of research that is both recent and relevant. For those working with pupils with few formal communication skills, the idea of a personalised multi-sensory story directed at helping the individual cope with a stressful situation must surely be one worth trying, especially given the tentatively positive outcomes obtained in the study.

This issue also carries for the first time, a materials review. I hope that this review, and those we intend to print in the future will help you to make best use of limited financial resources. If your school would like to join a list of potential reviewers for materials or books please email me.

Jean Ware
Editor
Sex and relationships education for young people with special educational needs

Louise Campion

Introduction
This article is based on a small qualitative study of a sex and relationships education (SRE) programme which was piloted in a special school in 2011. It focuses on the use of group work to explore relationships and sexuality with a post-16 “Transitions” group with special educational needs (SEN).

The study is part of a larger evaluation on a preventative education programme aimed at reducing abuse in teenage relationships. This national project was funded by Comic Relief. In the South West over 2,500 staff and pupils were involved in developing and piloting SRE resources. The work was based in four mainstream schools and one special school.

The following section aims to place the project in context by providing a brief overview of recent research on SRE provision for young people with SEN. This is followed by a description of the methodology for the study and a discussion of the findings.

Overview of research on SRE provision
The importance of consolidating good practice in sex and relationships education for people with SEN has long been highlighted by researchers and organisations involved in promoting sexual health such as the NSPCC and The Family Planning Association. There is strong consensus that effective and accessible SRE plays a significant part in empowering young people with learning difficulties to develop healthy and fulfilling relationships as well as safeguarding against abuse (Grieveo et al, 2006; Northway et al, 2004; Miller, 2002).

It is recognised that young people with SEN are particularly vulnerable to relationship abuse; research indicates that young people with disabilities (including learning disabilities) are more likely to experience sexual, physical and emotional abuse than people without disabilities. They are also twice as likely to witness severe domestic violence as their peers without learning difficulties, Emerson and Hatton (2007).

The right of people with learning disabilities to have equal access to sex education has been recognised in law in the Human Rights Act (1998, Article 8) and included in Government Policy through Valuing People Now, Department of Health (2009). Organisations such as CHANGE and the Family Planning Association argue that schools and other services which do not provide accessible sex education for people with learning disabilities fail in their duty of care under the United Nations Convention on the Rights of the Child and the Disability Discrimination Act, 1995.

However, despite legislation it must be recognised that,

‘People with learning difficulties face some of the biggest restrictions in terms of availability of sex education’ Shakespeare, Gillespie-Sells, Davies (1996) as quoted in Garbutt (2008, p 269)

A review of research in this field indicates

- young people with learning disabilities have lower levels of knowledge around sex and relationships than the general population, MacCabe (1999)
- receive a large amount of their information about sex and relationships from television and the internet (Garbutt, 2008, p 269)
- feel they have few opportunities to talk about sex and relationships, Simpson et al (2006), Garbutt (2008)

A wide-ranging study by CHANGE (2010) found that parents and SEN teachers are concerned that the messages young people receive may be confusing and inconsistent.’
These findings are supported by evidence from health and education professionals working with young adults with SEN in Bath and north east Somerset. They identify issues affecting their ‘clients’ as:

- social isolation from peers and therefore lack of experience of forming relationships
- naivety about media representations of young people’s relationships and social networking sites
- desire to fit into ‘social norms’ presented through media

(Sex and Relationships Training 2012)

Currently grant-maintained mainstream and special schools have a mandatory requirement to cover anatomy, puberty and the biological aspects of reproduction within the science curriculum. However, other elements of the SRE Curriculum are non-statutory. These include work exploring relationships, sexual consent and appropriate behaviour. As research from CHANGE shows this means that whilst most special schools provide some form of SRE it is not always delivered as a structured programme but often on a one-to-one basis, as a ‘reactive’ response to a crisis rather than being part of the shared curriculum.

The challenges for those working in this area are compounded by a lack of consensus amongst health professionals, educators and parents/carers of children with SEN.

The Relationships Project

The pilot project aimed to address some of these issues through a five-week programme of sessions. The school identified 10 young people who they felt were able to participate in a group and would benefit from the opportunity. In reality the ‘transitions’ group contained young people with hugely diverse needs and abilities, including students with limited speech and speech impairments, Down’s syndrome and those on the autistic spectrum. There were equal numbers of young men and women.

The sessions were led by a Domestic Violence and Relationships worker, supported by a teaching assistant who knew the young people well. After the first session the lead worked very closely with the support worker, using informal feedback and her own reflective practice to inform planning for the future sessions. This approach allowed for flexibility in responding to previous sessions and also related issues arising in school e.g playground disputes

The sessions’ objectives were:

- To prepare young people for the possibility of future healthy and fulfilling relationships
- To raise awareness of unhealthy behaviours in relationships, (including mental and physical abuse) and how and where to ask for support
- To create opportunities for young people to communicate their thoughts and feelings about relationships and be listened to

Social Group Work – an approach to SRE teaching

The lead worker based the programme on ‘social group work’ defined as:

‘… a method which helps individuals to enhance their social functioning through purposeful group experiences, and to cope more effectively with their personal, group or community problems.’ Gisela Konopka (www.infed.org/groupwork)

This involved using a circle-time format to encourage and support discussion and interaction between participants. It is linked to Lewis and Norwich (2007) conception of an inclusive learning environment, where students engage in:

‘… meaningful real-world learning in a social context, rather than the individualised programmes focused on isolated skill development.’

Through carefully establishing clear ground rules the project leader created a supportive environment where every member of the group had the opportunity to contribute. Through her own responses she modelled an acceptance that individuals would participate and engage in different ways according to their abilities and that the group would support each member to contribute. This resulted in ‘wait-time’ being extended so that every person was able to contribute without feeling rushed.

Examples of the kinds of activities piloted:
• **Warm-up/bonding activities** involving movement amongst the group
  
  **Hot seats** – Everyone who had toast for breakfast swap seats!
  
  **Pass the object** – passing a tactile object around in a circle, more objects are introduced as passing gets faster
  
  **My space** – group split into two equal lines facing each other (two metres apart). Individuals slowly walk towards each other and stop where they feel ‘their personal space’ begins
  
• **Discursive modes of learning**, encouraging members of group to respond to each other rather than ‘answer the teacher’ – Joe what do you think about what Lee has just said?
  
• **Raising self-esteem/ positive relationships in group** – asking individuals to identify something good/positive about another person in the group
  
• **Picture cards**
  Using images to talk about situations/feelings – is the person in the picture happy/sad/angry? Why?

  Collaborative games – arranging cards in order (events in a relationship, talking on the phone, holding hands, kissing, argument) choosing cards to identify healthy and unhealthy behaviours in relationships or identifying different kinds of relationships (parents, siblings, friends, intimate relationships)

**Methodology**

This was a qualitative study in which participant observation and verbal staff feedback provided the main sources of data. All sessions were observed and notes written up directly afterwards. Field notes were kept during visits to the setting which captured informal feedback between the project worker and support worker, before and after each session, and included their immediate observations on the activities and the responses of individual participants. A formal interview with the support worker at the end of the project also provided reflective commentary on the teaching approaches used. In addition the group was observed during a sex education session delivered by a school nurse. This provided an opportunity to see how another professional interacted with the group and allowed a very brief comparative analysis of teaching methods.

Despite the challenges of attempting to collect formal feedback from the participants, balancing teacher feedback and interpretation of learning outcomes with the voices of the young people was seen as an important element of the enquiries methodology.

Participant feedback was collected on two occasions: during the final session of the project and in a ‘follow up session’ four months later when the young people were asked to comment on the emergent findings. In the initial feedback the young people were asked to think about what they had gained from the sessions. A range of resources were provided to make contributing as accessible and engaging as possible. Students drew pictures, wrote comments and recorded verbal feedback using a dictaphone. A set of image cards showing the main topics covered were also used to prompt responses.

Through comparing the young people’s feedback, observation notes from the sessions and formal and informal staff feedback it is possible to identify certain themes. Of the 9 participants who provided feedback, 7 gave responses which could be cross-referenced with themes identified in other sources.

**Findings**

In reviewing the project a majority of the young people, the support worker and project leader all identified the group work approach as an important factor in the overall effectiveness of the work. In their initial feedback, five (out of eight participants present) referred to the positive benefits of group work in their responses without prompting. All members showed through their willingness to be in the group (they were free to go to another classroom if they got bored or didn’t want to join in) that they enjoyed the sessions. In follow up feedback four months later, six (out of eight) young people indicated that they agreed with the statement that working in a group had been a positive experience.

The main findings from this project suggest that for this group of young people using a social group work approach for SRE provided important opportunities to develop interpersonal skills as well as raising awareness of issues surrounding relationships.

In the formal interview the support worker identified individuals who had developed specific interpersonal skills which he attributed to the group work approach. These included:

• increased ability to listen to others (two participants)
● Development of empathy (eight participants)
● Increased understanding of how to contribute to a discussion (five participants).

‘Doing a chart on empathy in a group where there are four young people with autism is a challenge for any of us. So to be able to create the environment, create the discussion and really have a sense of … you are listening to what you are hearing from others’ is significant.’

Support worker

On contributing to group discussions:

‘He found a way of making sure he got his point across but it wasn’t long and unwieldy and he understood that … i.e. take your turn, and for some young people that’s a huge leap’.

Support worker

These comments were supported by the young people’s responses.

‘I like listening to what other people say. I enjoyed playing different games with the group because that is the way to know each other.’

Female participant

‘I usually spend a lot of my time studying in this room so I guess it’s a bit healthy to get out and talk with the others and actually interact … express an opinion … the atmosphere that has been created during these sessions has been definitely calm and welcoming, I think people have felt comfortable to be who they are … gaining more trust.’

Male participant: (identified as autistic by support worker)

Developing confidence to speak

The emphasis on inclusion and the equal rights of every participant to contribute were identified as a key element in the group work’s effectiveness. During sessions it was observed that the project leader provided clear ground rules for speaking and listening, including an expectation that the group wait for individuals to finish before interrupting or changing the subject. An analysis of the field notes indicates that the two young people with speech impairments increased their contributions in later sessions whilst other participants reduced the number of times they interrupted, spoke across or ‘rushed’ other members of the group.

The support worker also noted that two of the young people were contributing ‘more than usual’ to discussions.

Creating opportunities to talk about relationships

Over the sessions, three young people spoke about relationship issues they had experienced or were experiencing. These included a disclosure about witnessing domestic conflict and the subsequent break-up of a student’s parents, bullying in school and a student’s sense of missing his brother who was spending more time with his girlfriend. In these cases the support worker and project leader felt that the young people had not previously spoken about these issues and that they did so as a result of growing trust within the group. These examples suggest that creating a supportive environment provides a much needed opportunity for young people to talk about relationship issues which affect them. For staff, listening to these experiences can help in the planning and provision of effective support for individuals through pastoral care.

Discussion

The support worker also highlighted the fact that it was unusual for students to experience a social group work approach.

Whilst group work was ‘on the menu’ as a teaching method, the support worker differentiated between the young people being taught as a group and using a group work approach to support the young people in learning from and engaging with each other.

‘Working in a group … in a sense of the exchanges, in the sense of taking turns, listening to other people’s views, isn’t the norm’. (Support worker)

This analysis was supported by observations made during a separate sex education session with the same group. It was noted that a larger proportion of time involved ‘teacher talk’ and that the majority of interactions were between the teacher and individuals answering specific questions.

Conclusion

Whilst the findings from this small-scale enquiry are limited in scope, it is hoped that they highlight some significant issues for future research. The analysis suggests that using a group work approach to SRE can be beneficial in helping young people with SEN to develop interpersonal skills and the confidence to discuss issues around relationships. The evidence indicates that the positive experience of participating in an inclusive and supportive
group environment is, in itself, an important part of learning about relationships. The way that schools approach and deliver SRE is vitally important.

‘For young people with learning disabilities schools are central in fulfilling many of these needs, both in the formal SRE curriculum and in the pastoral and extracurricular activities that enable friendships and relationships to develop’. (Blake, 2002, p 81)

Louise Campion is currently Education and Outreach Officer at the Holburne Museum in Bath. She has worked in Arts Education for over 15 years, becoming increasingly involved in creative approaches to Emotional Health and Well-being work and Sex and Relationships Education. She has worked in a wide variety of different formal education and community settings, including special schools. She is currently completing an MA in Education at Bath University.

References

Final report of sexuality project by CHANGE (2010) Talking about sex and relationships: the views of young people with learning disabilities CHANGE and University of Leeds

Department of Education (Jan 2011) SFR on Special Educational Needs in England

Emerson E, Hatton C (2007) The Mental Health of Children and Adolescents with Learning Difficulties in Britain Institute for Health Research, Lancaster University


Teaching self-regulation techniques to increase feelings of well-being through yoga and relaxation to young people with severe learning difficulties, autism and challenging behaviour to reduce anxiety and improve participation in education

Katherine Corey and Bev Mars

Abstract

The focus of this research project is the use of yoga and relaxation techniques with young people with severe learning difficulties, autism and challenging behaviour, to teach self-regulation and increase feelings of well-being which may enable them to engage with their education more fully.

The inquiry took place over one academic year from September to July, within an independent specialist college for students with learning difficulties and/or disabilities. It consists of six case studies of young people in their first or second year within the college namely Claire, David, Daniel, Gabrielle, Mark and Liam (not their real names). Feedback from colleagues and parents were used to substantiate the research.

The outcome of the project research was the discovery of a significant reduction in recorded incidents of challenging behaviour in college within the observed group of young people. Feedback from parents noted a reduction in incidents at home and use of yoga techniques within the home environment.

Introduction

In education we can often feel that our job as teachers is to create targets, record progress against the targets and to check targets off as achieved. This is important; it is after all why we are funded and why that funding is maintained over the years.

However, over my career I have come into contact with young people for whom educational targets could not be set or achieved. We have had young people with such high levels of anxiety that keeping them safe on college grounds was the chief consideration. Yet even though it was obvious to all that these young people were having an extremely difficult time, as were their families, discussions concerning their progress frequently centred on traditional educational achievements. Obviously, we have to have achievement but do we have to have achievement in the traditional curriculum areas?

Experiencing well-being does not mean that one is happy all the time, it does mean that feeling okay and not suffering emotional, mental or physical distress is the typical state for most people. Well-being is increasingly linked with the ability to learn; and interest in exploring this symbiotic process is growing, according to Nind (2006). In my opinion, well-being is as important as, if not more important than, many of the things we teach children and young people with autism. There seems little point in teaching personal care if a person feels so negative about themselves that they are simply following a routine rather than doing it to make them feel good.
Literature review

Literature that provides an insight into autism, particularly highlighting the difficulties that people with autism have in their communication, social interactions and flexible thinking includes Leo Kanner (1943), Simon Baron-Cohen (1993), Lorna Wing (1996) and Francesca Happe (1994). Rita Jordan (2001) focussed on a particular grouping within the autism spectrum; that of people with autism and severe learning difficulties. She writes that:

‘There is a good case for classifying individuals with autism and SLD as among the most vulnerable in our society.’ (2001:4)

Clements (2000), Gobrial (2005) and Gillott (2004) demonstrate that anxiety can compound life even more for this particular group particularly with regard to challenging behaviour and their well-being. Cronin de Chavez (2005), Clements (2010) and Ryff (1989) define well-being and how this needs to happen for this group of people. Finally, research from Tickle (2008) who researched the most suitable method to collect evidence.

Methodology

To investigate the impact of self-regulation on increasing well-being through yoga and relaxation techniques to increase educational participation, I decided to use face-to-face interviews, direct observations, records and case studies as the main research methods. As I was researching behaviours, and as my research group had learning and communication difficulties, observations were the most suitable method to collect evidence. I also employed face-to-face interviews with professionals who work with the research group and interviews with their families. The records consisted of behavioural incident graphs over the period of the research. To research and illustrate the results from the interviews, observations, incident reports, I presented a case study for each of the students.

Presentation and analysis of data

The programme lasted for forty minutes; this was practised once a week. A shortened programme was used during registration; this lasted twenty minutes and was practised three times a week. The research project ran from the September to the July in one academic year. The students were directly observed during these sessions, but the observation was also on-going as all six students had high levels of challenging behaviour and as such were constantly monitored. This provided evidence of their ability or inability to cope with situations of stress that occurred outside of the yoga session. Behavioural incident sheets were completed after each incident of challenging behaviour. These were analysed each month by the behaviour co-ordinator. I would be given a monthly chart of each student and, each term, a summary report of all incidents. Figure 1 shows the number of behavioural incidents per student per month for the year.

There was a high level of discussion amongst the staff working with the students as to the benefits of the programme, and also with the families. Three of the six case studies are reported in detail in this article.

Claire

Claire has limited verbal communication, restricted to single words and learnt phrases, such as, ‘I want toilet please’. Claire is able to respond to simple instructions as long as they are familiar words in a familiar context. She will respond better if verbal instructions are supported with gestures and visual supports. She is able to respond to Picture Exchange Communication system (PECs) requests/instructions from staff and peers. Claire cannot answer simple questions. She may respond to ‘What is it?’ but often needs a verbal prompt, e.g. ‘It’s a …’

Claire often tidies obsessively, she likes to ‘straighten’ her own things and wipe tables etc. This is usually restricted to certain times, such as before a session starts and when it ends. It is difficult to direct Claire away from her ‘tidying’ without her becoming anxious so it is usually best to allow her to complete what she needs to do.

If Claire becomes distressed it may be necessary to remove others from the environment. If upset or confused Claire can display self-injurious behaviour: screaming, hitting her head with her fists, hitting her head on the walls, floor and hard furniture surfaces; grabbing her clothes and her chest. She rages and cries with frustration; these episodes could last up to 20 minutes and could occur several times a week.

In general, auditory stimuli cause distress to Claire. She displayed high levels of sensory defensiveness, wearing headphones.

Claire has lots of energy; she paces the room, walks quickly and throws herself into physical tasks. We introduced Claire to yoga during her first term, after the initial anxieties related to a new activity, Claire showed an eagerness to copy the activations and energy block releases.
As Claire displays echolalia and echopraxia frequently, she began to reproduce the movements, sounds and regular breathing patterns with a high degree of accuracy. During her first term, Claire was unable to lie down, be still and quiet; she left the session room at this point to walk around outside. During her second term, however, Claire frequently remained in the entire session, lying prone on a mat and tolerating tranquil music. The asana and activations are supported with visual aids; Claire learned the names of each one and would move into the pose independently. Her vocabulary has been extended and her imagination used, for example, she shakes off imaginary water from each body part when prompted by the ‘wet dog’ picture. During some of the more difficult positions, such as the sphinx, Claire will spontaneously laugh at some of the other students struggling to raise their heads from the floor; this demonstrates her increased social awareness and ability to work within a group.

Now in her third term of yoga, Claire anticipates the yoga sessions by moving furniture and choosing music for the relaxation segment.

Liam is a verbal communicator although he is a reluctant social communicator. Liam is able to understand simple verbal questions and instructions although he will become angry if there are questions to which the answer is glaringly obvious. Liam does not generally initiate conversation unless requesting his needs be met but even this is under duress; he would prefer not to have to talk to people. Liam likes solitary activities such as playing on a computer. Liam makes group activities very challenging and he prefers not to have to be with others.

Liam is very intolerant of others, particularly his peers, but staff can also annoy him. He can become agitated and unpredictable due to his interpretation of events or others. He will punch, grab people by the throat and hit people with objects.

Liam has good fine and gross motor skills. Cognitively, Liam has the most skill in the college. Liam is very sensitive to noise and he wears ear plugs. He hates the noise of people singing and laughing in particular. Liam listens when spoken to but may refuse to comply. He has limited amounts of energy and hates exercise of any description. In fact he generally only likes diet coke, burgers and playing computer games in his room. He has no interest in communication or interaction unless it is absolutely necessary. When in good form he has a good sense of humour and can be a joy to be around.

As Claire displays echolalia and echopraxia frequently, she began to reproduce the movements, sounds and regular breathing patterns with a high degree of accuracy. During her first term, Claire was unable to lie down, be still and quiet; she left the session room at this point to walk around outside. During her second term, however, Claire frequently remained in the entire session, lying prone on a mat and tolerating tranquil music. The asana and activations are supported with visual aids; Claire learned the names of each one and would move into the pose independently. Her vocabulary has been extended and her imagination used, for example, she shakes off imaginary water from each body part when prompted by the ‘wet dog’ picture. During some of the more difficult positions, such as the sphinx, Claire will spontaneously laugh at some of the other students struggling to raise their heads from the floor; this demonstrates her increased social awareness and ability to work within a group.

Now in her third term of yoga, Claire anticipates the yoga sessions by moving furniture and choosing music for the relaxation segment.

Liam is a verbal communicator although he is a reluctant social communicator. Liam is able to understand simple verbal questions and instructions although he will become angry if there are questions to which the answer is glaringly obvious. Liam does not generally initiate conversation unless requesting his needs be met but even this is under duress; he would prefer not to have to talk to people. Liam likes solitary activities such as playing on a computer. Liam makes group activities very challenging and he prefers not to have to be with others.

Liam is very intolerant of others, particularly his peers, but staff can also annoy him. He can become agitated and unpredictable due to his interpretation of events or others. He will punch, grab people by the throat and hit people with objects.

Liam has good fine and gross motor skills. Cognitively, Liam has the most skill in the college. Liam is very sensitive to noise and he wears ear plugs. He hates the noise of people singing and laughing in particular. Liam listens when spoken to but may refuse to comply. He has limited amounts of energy and hates exercise of any description. In fact he generally only likes diet coke, burgers and playing computer games in his room. He has no interest in communication or interaction unless it is absolutely necessary. When in good form he has a good sense of humour and can be a joy to be around.
We had been experiencing a lot of challenges around Liam as he appeared very intimidating, so in his first year we were testing the boundaries with him and any exercise would have created challenges. However, as we got to know Liam and be able to feel more confident around him, I decided that it was time for yoga in his third term. When yoga was first mentioned to Liam his reply was, ‘Yoga! I hate that, I’m not doing yoga!’ When given further information that it was good for his heart, the response was, ‘What … I don’t give a f*** about my heart’. I realised that convincing Liam that yoga had positive benefits was going to be challenging. For the first few terms, the target was for Liam to tolerate the others and remain in the room. Unfortunately, during this period, this target was rarely achieved due to Liam’s resistance and a particular student goading Liam to react angrily.

We began to realise that Liam associated exercise with his heart beating faster; this was a sensation that he did not like and it was difficult to explain to him that this was a good thing. Liam has a very competitive nature so I tried to incorporate that into yoga. I would say that we had to do a pose for a certain amount of time; or if it involved repetitive movements I would give a certain number that the students had to aim for. This strategy worked, and Liam began to be able to stay in the session. By the end of his second year he was able to do so for the full duration of the session. After yoga, Liam was offered time to relax with visualisation or to have a massage. Both of these options appealed to Liam and his participation level within the yoga session increased.

Liam often complained of numerous aches and pains. He would get a lot of sympathy from home and not turn up for college. We began to suspect that it was an excuse to opt out of activities. For example, I heard him complain of a sore head yet minutes later be very happily sitting with headphones, screaming at the computer, jumping up and down on his seat. I explored poses that would help with his most common complaint, that of a sore back. Shortly afterwards, his mother phoned to tell of her amazement that Liam was doing yoga at home. She had never witnessed Liam do any sort of physical activity other than physically fighting with his parents or reacting to a computer game. When Liam started at the college, he had an exceptionally high level of incidents of challenging behaviour (an average of 10 a week) which all involved physical aggression to his peers or staff. There had been a small decrease over his second term but his poor attendance probably helped to achieve this. However in his second year we had a greater decrease in incidences and his attendance was improving. This has continued into his third year. Liam not only involves himself in yoga, he now participates in walks of up to 2 miles and he is an eager participant in hall based sports sessions. He is generally more happy himself and in the company of others.

Daniel is a verbal communicator. On the commencement of college he is generally very quiet. However feedback from others describes a very talkative young man who does not recognise when a conversational partner has lost interest in a topic. Daniel can talk to a great extent on favoured topics. He is aware of his condition and at times may like to discuss it. However this recognition also causes difficulties for Daniel. He can become quite depressed and suffer from paranoia. He can have unrealistic desires for the future.

He is quite challenging at home but not so in college. He may punch the air in frustration, and has been known to be aggressive to his parents. Daniel is able to understand quite complex instructions. He is often better able to understand information and instructions if presented in a written format, although he thinks sometimes that this is ‘babyish’. Daniel will initiate a conversation on preferred topics or if he is confused about something he has heard, even when not involved in conversations. Daniel has crystal hearing and can pick up on things that one would have thought he was not listening to.

Daniel was a natural at yoga from the first minute that I introduced it. He had the ability to tackle all of the positions without stress or strain. He could also maintain a pose – sometimes for longer periods than the teacher. Very soon he had memorised all of the images and could therefore predict what the next position was. This was incredibly important to Daniel and it has built his confidence and self-esteem as he received a lot of praise. I decided that Daniel should demonstrate the postures to the whole group rather than me.

Daniel was also aware that he had autism, but no one spoke to him directly about it. Shortly after starting on the course he asked me. I told him that people with autism thought in one way and people without autism thought a different way. His opinion of himself was quite low.

Yoga gave Daniel confidence and a responsibility because he could use his skills to teach others. He felt very pleased with himself after yoga and this set him on a high note for the rest of the day. Daniel didn’t have any
obvious challenging behaviour in the way the others did, his was more subtle – he would go in on himself. Often, he would be found behind a screen not wanting to speak to people. According to Clements and Zarkowska (2000), the person struggling with low feelings of well-being may have a distorted view of themselves and believe that they are worthless. A person may become more aware of their emotional responses leading to outbursts and loss of control, or become less inhibited.

After learning the yoga techniques Daniel would often ask for a mat to do poses at lunch time rather than sit behind the screen. He would also use the weighted blankets that were available during the relaxation part of the yoga session at other times of the day when he was feeling stressed. Daniel's change in behaviour was not a reduction in physical contact but an increase in mental well-being.

‘According to Clements and Zarkowska (2000), the person struggling with low feelings of well-being may have a distorted view of themselves and believe that they are worthless.’

Conclusions
An overall evaluation showed:

An overall reduction in the number of challenging incidents exhibited by the students who followed the yoga/relaxation programme evident in observations and incident recordings.

Significant reduction in incidents involving those students identified as having the most frequent occurrences of challenging behaviour (namely Claire, Liam, Gabrielle and Mark) evident in observations and incident recordings.

Interview data from colleagues who had noticed that the reduction in behavioural incidents resulted in the students remaining in the sessions for extended periods and ultimately for the entire session; thereby improving their participation in their education.

Interview data from parents who noted a decrease in challenges at home and attempts at practising different relaxation techniques at home such as ‘lion breath’ and yoga poses. One mother said she now had the child she always expected to have.

The remarkable increase in confidence and self-esteem levels in one student in the group as he took pride in his accomplishments and ability to demonstrate poses/movements to staff and peers.

Students have obviously enjoyed the yoga/relaxation sessions as they continued for the year with increased participation levels as challenging behaviour incidents decreased.

The sessions continue after the research project has been completed, further demonstrating their value. The students have been able to transfer certain techniques as self-calming strategies into some settings outside the session.

The presentation of data illustrates that there were a number of positive results in my research project; decrease in behaviour and increase in education participation. However, I cannot prove conclusively that yoga/relaxation on its own led to an improvement with regard to well-being and increased participation in wider education.

If there is a possibility of a non-pharmaceutical strategy that can decrease anxiety, we owe it to people who have difficulty advocating and communicating for themselves to research this option extensively as it would be less restrictive and have no side effects. I believe that my findings in the teaching of self-regulation techniques through yoga/relaxation to people with autism and severe learning difficulties warrant further exploration in this.

Katherine Corey has taught students with autism and SLD for 10 years, and is now Deputy Head of The Royal College Manchester (part of the Seashell Trust).

Bev Mars started her career as a teacher working with children and young people with complex needs, she then transferred to an advisory role working with deafblind children. A move to the voluntary sector provided her with the opportunity to work with children and families across the south east of England whilst working in partnership with local authorities to provide specialist services for children and young people with low incidence sensory impairments. Bev joined the Seashell Trust in 2010 as part of the senior leadership team where she is responsible for managing referrals and admissions across the Trust.

References


Ryff, C (1989) Happiness is everything, or Is it? Explorations on the meaning of psychological well-being Journal of personality and social psychology 57, (6), 1069–1081


Specialist support services received by pupils in special (SLD) schools in England: level of support received and head teachers’ perceptions of usefulness

Matthew Rayner and Dawn Male

Introduction
This article focuses on specialist support services received by pupils of special schools in England which were designated by the Department for Education (DfE) as being for children and young people with severe learning difficulties (SLD). It reports the findings from a larger study which enquired into the pupil population of SLD schools in England (Male & Rayner, 2009).

National surveys have indicated significant increases in the number of children identified as having severe learning difficulties or profound and multiple learning difficulties (PMLD); for example, in a survey of 50 per cent of LEAs in England conducted by the Audit Commission in 2002, a third of respondents perceived a significant increase in the number of children with PMLD. More recently, between 2004 and 2009 the number of pupils with severe learning difficulties has been reported to have risen by an average of 5.1% and the number with profound and multiple learning difficulties to have risen by an average of 29.7% (DCSF, 2009).

Furthermore, factors such as increased survival rates have been identified which are likely to lead to further increases in the incidence and prevalence rates for individuals with severe/profound and multiple learning difficulties in England over the next two decades resulting in estimated sustained growth in the region of 14% (Emerson & Hatton, 2008).

This rise in the incidence and prevalence rates of school age children identified as having more severe and/or complex needs will have implications for the provision of specialist support services to schools.

The study
A questionnaire was sent to all maintained SLD schools in England. This was a total sample size of 321 SLD schools. The questionnaire comprised six sections requesting information about the school, the
staff, the pupils, and support services received, inclusion opportunities, and perceived challenges. Categories of SEN covered in the questionnaire were: severe learning difficulties; profound and multiple learning difficulties; challenging behaviour; degenerative and/or life-limiting conditions; autistic spectrum disorders. Only findings relating to specialist support services received and perceived usefulness of these services are reported here.

With regards to specialist support services head teachers were asked to estimate the approximate amount of time (to the nearest hour) they received from specialist support services either termly or weekly and to indicate how useful they felt these services to be.

Response modes were intended to elicit primarily quantitative data, with head teachers being asked to respond either in actual figures or to select from a range of options. In the case of perceived usefulness of support services the options were ‘very useful’, ‘moderately useful’, ‘of some use’, ‘of no use’. Opportunities were also given for respondents to provide qualitative data.

**Results**

**The respondent schools**

Of the 321 schools surveyed 167 replied, giving a 52% response rate. This represents in excess of 10,000 pupils.

The schools varied considerably in size between small schools, with populations well below 50 pupils, to larger schools with populations over 200 pupils. The majority of schools had pupil populations between 51 and 100; the majority were all age (e.g. 2–16 years or 2–19 years).

Geographic regions represented by the respondent schools were East of England, East Midlands, London, North East, North West, South East, South West, Midlands, Yorkshire and Humberside. The distribution of respondent schools according to geographical region was broadly representative of the geographic areas of all SLD schools in England i.e. no geographic region was conspicuously under or over represented.

Twenty per cent of schools were in a rural or semi-rural area, just over 20% were in a mixed rural / urban / inner city area, just under 20% were in an inner city area and 40% were in an urban or suburban area.

Sixty per cent of schools were officially designated as SLD schools. Twenty per cent were officially designated as combined SLD and PMLD and just over one per cent were officially designated PMLD. The remaining schools had multiple designations e.g. complex learning difficulties or combined MLD (moderate learning difficulties) / SLD / PMLD / ASD in various combinations. In the earlier Male (1996) study all respondent schools were officially designated as SLD schools, although a minority of head teachers mentioned local authority proposals to broaden the designation of their schools, to include, for example, the terms ‘complex needs’ or ‘profound and multiple learning difficulties’. Findings from the present study relating to school designation may suggest a trend towards SLD schools increasingly being required to meet a range of additional and/or more complex needs.

**Hours of specialist support service received by schools**

Table 1 shows the number of hours of support received by schools from specialist services, either termly or weekly.

As indicated, the variation in the number of hours of specialist support received either termly or weekly was marked: in the case of occupational therapy, for example, whilst some

<table>
<thead>
<tr>
<th>Service</th>
<th>Mean number of hours</th>
<th>Range (hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational psychology</td>
<td>8.7 per term</td>
<td>0–40 per term</td>
</tr>
<tr>
<td>Clinical psychology</td>
<td>9.6 per term</td>
<td>0–125 per term</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>110.4 per term</td>
<td>0–2660 per term</td>
</tr>
<tr>
<td>Social worker</td>
<td>14.3 per term</td>
<td>0–112 per term</td>
</tr>
<tr>
<td>Specialist advisory teacher</td>
<td>24.8 per term</td>
<td>0–221 per term</td>
</tr>
<tr>
<td>Careers advice</td>
<td>18.5 per term</td>
<td>0–120 per term</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>4.8 per week</td>
<td>0–32 per week</td>
</tr>
<tr>
<td>Speech and language therapy</td>
<td>4.0 per week</td>
<td>0–16 per week</td>
</tr>
</tbody>
</table>
schools reported receiving no input one school reported receiving a total of 2660 hours input per term (i.e. full-time for one or more Occupational Therapists). Marked variation was also noted in the cases of specialist advisory teacher input, clinical psychology input, careers advice and social worker input. Fifty two head teachers (i.e. 31%) stated that the pupils in their schools also received music therapy and two head teachers reported that their schools were able to provide art therapy.

School Nursing
Just over three quarters of head teachers stated that they had a school nurse on site on a full- or near full-time basis. In the earlier Male (1996) study just over half of all schools (n=57) reported that they employed a nurse, most usually on a full- or near full-time basis. Prior to this, Evans and Ware (1987) reported less than a third of SLD schools surveyed employed a nurse on a full- or near full-time basis. The indications from the present study, therefore, are of an increasing need for specialist support for pupils’ medical needs.

Associations between different types of special educational need and support services received
Positive associations were found between:

- the number of pupils with PMLD and the number of hours of support provided by OT, physiotherapy and SaLT
- the number of pupils with degenerative and/or life limiting conditions and the number of hours of support provided by OT and physiotherapy
- the number of pupils with ASD and the number of hours of support provided by SaLT

Thus, pupils identified as having more severe and/or complex needs received a higher level of support from specialist providers.

Value of supporting services
The pie charts below (Figs. 1–8) indicate head teachers’ ratings of usefulness of the various support services received.
It will be seen from the pie charts that the highest rating of usefulness was accorded to the careers service, with just over 70% of head teachers rating it as being ‘very useful’ or ‘moderately useful’. Relatively high levels of usefulness were also accorded to specialist advisory teachers (57.6% of head teachers rating them as being ‘very useful’ or ‘moderately useful’) and clinical psychologists (50% of head teachers rating them as being ‘very useful’ or ‘moderately useful’). Just under half of head teachers (48.2%) rated physiotherapists as being ‘very useful’ or ‘moderately useful’ and in the region of 40% of head teachers rated social workers, educational psychologists, occupational therapists and speech and language therapists as being ‘very useful’ or ‘moderately useful’. Conversely, in the region of a third of head teachers rated clinical psychologists, occupational therapists and speech and language therapists as being ‘of no use’ and in the region of a quarter of head teachers rated social workers, physiotherapists and educational psychologists as being ‘of no use’.

**Head teachers’ comments on specialist support services**

Head teachers’ comments fell into three distinct categories:

- adequacy of specialist support services
- line management of specialist support services
- multi-professional co-ordination.

**Adequacy of specialist support services**

Almost one third of head teachers commented on perceived inadequacy of specialist support services in terms of hours of input received; comments such as ‘never enough’, ‘totally inadequate’ and ‘we need more’ were common. Comments relating to perceived inadequacy of particular specialist support services included:

- ‘School nurse is urgently needed’
- ‘Social services very lacking’
- ‘Educational psychologists seem to have evaporated’

One head teacher commented on the perceived collapse of health authority input resulting in publicity campaigns, including newspaper coverage.

Comments relating to the implications of perceived inadequacies included:

- ‘School responds to emergencies, plus there’s no ongoing work with pupils’
- ‘A number of children have had to wait to come into school as we have been unable to meet their medical needs’

**Line management of support services**

Eight head teachers commented specifically on difficulties in relation to line management of specialist support services, for example:

- ‘Difficulty of working with NHS staff and not being their line managers’
- ‘Difficulties occur as they are not funded and therefore line managed by the school’

Some head teachers had addressed this problem by either buying in the services they needed or by supplementing those provided by the LA or health authority; others expressed a wish for greater financial autonomy in relation to funding for specialist support services:

- ‘funding should be delegated to schools so that head teachers can ensure quality of provision’

**Multi-professional co-ordination**

Seven head teachers reported that they were trying to establish improved services for families and pupils via better co-ordination of supporting services. It was considered by head teachers that the boundaries between services and teams led to fragmentation. This was then exacerbated by perceived lack of knowledge by specialist providers who were ‘visiting’ educational settings:

- ‘Poorly co-ordinated across PCT, no ‘joined-up’ service for the pupils or school’
- ‘High turn-over with new health authority staff having little knowledge of the educational setting’

However, a minority of head teachers (n=3) stated that they were endeavouring to try and solve this issue by establishing improved links with visiting professionals and made comments such as:

- ‘Currently looking to establish better links, we hope to build a multi-disciplinary team’
In cases where this had happened, head teachers reported that their schools were becoming centres for a range of specialist support services for their school and the wider community.

**School challenges**

Head teachers were asked to list three challenges that they felt would affect their schools over the next few years. On analysis of these responses (\( n = 352 \); possible responses = 167 \( \times 3 = 501 \)) the largest number (34%) related to perceived widening of the ability range of pupils to be catered for (e.g. ranging from moderate learning difficulties to profound and multiple learning difficulties). Perceived difficulties associated with multi-disciplinary working and perceived inadequacies in terms of level / usefulness of specialist support services featured in a minority (5%) of these qualitative responses.

‘**Considerable variation in the number of hours of specialist support received was reported, which ranged from no input to full-time support.’**

**Summary**

In this study we sought to establish the level of specialist support services received by schools for children with SLD and head teachers’ perceptions of the value of these services. The study was conducted in the context of an increasing number of children attending SLD schools with more severe and/or complex needs.

Considerable variation in the number of hours of specialist support received was reported, which ranged from no input to full-time support. Positive associations were found between the number of pupils identified with different categories of special educational needs and the hours of support provided by specialist services, with pupils identified as having more severe and/or complex needs receiving higher levels of specialist support. In terms of usefulness, the highest rating was accorded to the careers service. Relatively high levels of usefulness were also accorded to specialist advisory teachers and clinical psychologists. Conversely, in the region of a quarter of head teachers rated social workers, physiotherapists and educational psychologists as being ‘of no use’. Particular areas of concern for some head teachers were the adequacy of the level of service provision, the quality of some services, line management of specialist providers and multi-professional co-ordination.

**Discussion and conclusions**

It would appear from our survey that a proportion of head teachers do not place high value on many of the services provided. One possible explanation for this is that these professionals are perceived as not to be providing actual ‘hands on’ and/or practical support to classroom teachers, perhaps because of a lack of time and/or being diverted from what schools perceive their real support needs to be; for example, in our study educational psychologists were perceived by some head teachers to be spending a disproportionate amount of their time on the ‘Statementing’ process. Another possible explanation is that, in some instances, these professionals are not experts in the field of children and young people with more severe and/or complex needs and hence the quality of their support is perceived by head teachers to be inadequate. In addition, as noted in the qualitative comments, the input from some specialist services (e.g. educational psychologists) was deemed inadequate in terms of the number of hours of input.

In terms of the careers service, the high value placed on it by head teachers may be partly due to their role in the Transition Plan which is part of the Annual Review for students at 14 years of age (see Code of Practice, 2001). The careers service, often via Connexions, provides personal advisors to support schools in addressing the specific needs of students by providing a collaborative and holistic approach to the transition to adult life; it may be that many schools lack in-house expertise in this area and thus place a high value on the ‘outside’ specialist support received.

Since the implementation of Local Management of Schools (LMS), head teachers have become accustomed to having significant control over resources, including the deployment of staff. It may be that in the future head teachers will need to take greater responsibility for the employment of those staff who provide additional specialist support to their pupils. Individual schools are unlikely to be provided with sufficient funds in order to employ the staff required to provide all the specialist support services required; however, this may be increasingly possible with the development of federations and local children’s trusts. In the present study a third of head teachers, who reported on the funding of the school nurse, stated that they were jointly funding the post with the local primary care trust (PCT). Greater involvement in the employment, and funding, of staff who provide these services will offer schools the opportunity to be involved in the line management of support service staff which may address the challenge of perceived lack of overall responsibility for service delivery, adequacy of service level provision, competency of staff and of difficulties in multi-professional collaboration; this challenge is not
new and has been discussed at length by, among others, Lacey (2001) and Glenny and Roaf (2008). Clearly, our findings suggest that there is an on-going need to address these challenges.

Many of the services referred to are delivered by staff who work for PCTs, part of the National Health Service (NHS). Many PCTs have undergone significant changes in the past few years including a reduction in their number. In addition, some PCTs have changed the way that they are organised by joining with other parts of the NHS e.g. joining with acute services to form community foundation trusts. Some PCTs now cover the same geographical areas as LAs and by cooperating with them, in some instances pooling budgets, try to provide a more seamless service to children. The current coalition Government has recently presented the health and social care bill 2011 which suggests abolishing PCTs and the transfer of their commissioning role to general practitioners. According to anecdotal evidence (e.g. as reported to the first author, a serving head teacher) these changes, along with savings that LAs have been required to make as a result of the 2011 spending review, have affected the level of service offered in some schools. Some schools, for example, have identified a reduction in the level of OT, physiotherapy and speech and language therapy that they receive. These schools have also highlighted a reduction in services provided by their LAs with many of the services transferred to a ‘buy back’ service i.e. schools having to purchase the service using their budgets. Some schools have reported that they still receive a core offer but that they have been unable to ‘buy back’ services to ensure that they continue to receive the same level of support.

As we noted elsewhere (Male and Rayner, 2007; 2009) the indications are that special schools will continue to be required to meet the needs of an increasingly complex and diverse pupil population. The apparent increase in children identified with PMLD and degenerative and/or life limiting conditions, for example, will lead to the need for more support from PCTs via increasing therapy input. Without this support, many of the children may be unable to access the curriculum and participate in extracurricular activities. In addition, on a day-to-day basis these schools are likely to need greater support from nurses, with some schools needing a team of nurses rather than a nurse who is simply present for medicals. The increase in children identified with ASD and showing challenging behaviour may also lead to a need for greater support from educational and clinical psychologists. This support will need to be for the school and family so that a consistent approach to behaviour management, and social interaction, can be established. All of this additional input may result in a return to a more ‘medical model’ and significant adjustment in the way that disability is perceived in special schools. It is hoped that the adjustments that have occurred in society over the past few decades will continue to allow schools to maintain an emphasis on education. Greater multi-professional collaboration may in fact allow the ‘medical model’ and ‘social model’ of disability (see Oliver, 1990) to work alongside each other or to begin to merge and create a model that is of greater benefit to all of the pupils and schools. In order to do this schools will need to ensure that they maintain their education emphasis and do not become what could be satellites of the PCT.

Concluding comments

We suggest that the findings reported here have implications for the level and quality of specialist support needed now and in the future for children and young people attending special schools and the way in which these schools and the specialist support services work together to meet the needs of children and young people with increasingly complex needs.

We hope that the findings from the study will contribute to the provision of guidance to schools and policy makers regarding the provision of specialist support services which will enable schools and PCTs to provide high-quality, ‘joined-up’ services and support for children and young people with more severe and/or complex needs and their families.

Matthew Rayner has over 20 years’ experience of working with children with learning difficulties and is now Head teacher at Stephen Hawking School in East London, a school for primary aged pupils with profound and multiple learning difficulties. Many of the children have additional physical or sensory impairments. His current interests are how supporting services and school self-evaluation can support curriculum development for children with profound learning difficulties.

Dawn Male is a Senior Lecturer in Psychology and Special and Inclusive Education at the Institute of Education, University of London.

‘It is hoped that the adjustments that have occurred in society over the past few decades will continue to allow schools to maintain an emphasis on education.’
References


Emerson, E and Harton, C (2008) Estimating the current need/demand for support for people with learning disabilities in England Centre for Disability Research (CeDR), Lancaster University

Evans, P and Ware, J (1987) Special care provision: education of children with profound and multiple learning difficulties Windsor: NFER-Nelson


Introduction

In my work with children who have profound and multiple learning disabilities (PMLD), I have been developing a model of ‘listening and responding to people who do not use words to communicate’ (Goodwin, 2008; see Figure 1), in order to establish a process for eliciting their views. A model of how we can involve children in the services they use is important to provide a framework that supports practitioners to include and involve children who are excluded from potentially empowering processes. The model supports practitioners to conceptualise a process of observation, reflection and interpretation and has been utilised in contexts such as play, advocacy, residential and education. In this article, I discuss the principles and theoretical framework which provide the basis for the listening and responding model and explore possibilities for enabling children with PMLD to have increased choice and control.

Listen to the person and those who know the person

Consultation approaches with children with learning disabilities increasingly use total communication methods in order to ensure as far as possible that meaning is understood by the child and the caregiver. However, many PMLD children who communicate pre-intentionally may not have been listened to due to perceived issues of their capacity and the validity and ethicality of such approaches.

Pre-intentional communication is described by Grove et al (2000) as behaviour that is not intended to have a communicative response (e.g., yawns, head turns, grimacing). On the other hand, intentional communication has function for the person in that they are ‘sending a planned message in order to intentionally gain a response from others’ (Whittle et al, 2007, p 11). However, it is suggested by Bradley (in Lacey, 1998) that communication is not dependent on intentionality as communication and shared understanding takes place without intentional communication. Therefore the careful and sensitive interpretation of children’s pre-intentional communication raises the possibility of enabling us to listen and respond to children with PMLD. Alluding to this point, a factsheet produced by Mencap (1998) suggests that children with PMLD may not be able to inform us of their views or indeed communicate their views directly. However, observing how a child responds to both positive and negative experiences is potentially a valid method for ascertaining their views. Nonetheless, opportunities for ascertaining the views of children who communicate pre-intentionally may be difficult to achieve unless it is perceived as a multi-dimensional process that involves others (Clarke, 2005).

The support of others who can sensitively listen to the child is important in eliciting the child’s views. People who know and love the child and independent advocates can be extremely valuable in gaining different perspectives. The question of who is best to consult with the child is reliant on the person who will faithfully represent the child’s view. With whoever undertakes this role, potential limitations exist from professional bias, inference, personal values and attitudes, (Ware, 2004) and the possibility of overestimation (McConkey cited by Porter, 2001). Sigafoos. 1999 (cited by Bradshaw, 2001) additionally suggests that much communication with PMLD children is pre-empted or constructed rather than interpreted, which leads to the possibilities of practitioners potentially misinterpreting children’s views or experiences. However:

‘… the choice of the facilitator will largely depend on individual factors, for example who knows the person best, who the person is most comfortable with and who would faithfully ‘write with their hearts’. (Sanderson 1998b, p 167)

Look

Careful observation of the person is extremely valuable in eliciting potential views. Longitudinal perspectives are particularly useful to capture reactions and gauge communication as they ensure consistency of meaning in response to specific contexts. Observations can be facilitated during different interactions and periods of time and in different environments for a specific
the SLD experience

DICE
Disability Inclusion Community Education

Listening and Responding to people who do not communicate using words

- Listen to the person and those who know the person
- Look
- Join and be with
- Involve and do with

- Document

- Reflect and interpret experiences and journey

- Develop ideas that respond to what we have learnt about what people want

- Put into action lessons learnt from working with and listening to people

disabilityinclusiondice@fsmail.net

This poster uses Meyer Johnson PCS symbols
Copyright D.I.C.E (2008)
purpose or remain unstructured. Observation can support decision making about preferences, however we may not be able to successfully interpret all observations and this method needs to be used with caution as the conclusions often cannot be confirmed by the child.

Children with PMLD can be difficult to observe as much of their communication may be subtle and idiosyncratic. Edwards (2008), helpfully notes physiological factors to look out for including rate and depth of breathing, levels of energy, movements, posture and skin tone and recommends mirroring the person to draw possible conclusions as to what the person may be feeling. This can assist in the interpretation of unintentional communications. Rich (undated) suggests that adults observe and sensitively listen and attune themselves through routines in which they continually ‘interpret in order to respond in the best possible way’ (p 5). Such attunements may lead to increased child responsiveness. Observation can also support understanding of a child’s preferences and importantly support practitioners to respond to children’s intrinsic motivations so that interactions are increasingly child-centred (Goodwin and Edwards, 2012).

Facilitating observation as a method of listening to children is a contentious subject and raises ethical issues. Observation is increasingly being used, particularly through the mosaic approach which offers a multi-dimensional method of listening and responding (Clarke, 1996). In using observation, we should remember consent issues and there is a need for children to have privacy no matter how limited this may be for issues and there is a need for children to have observation, we should remember consent participatory research. These approaches may offer very little opportunity to hear PMLD participants, such as emancipatory and participatory agendas that actively involve perspective. Observations are being increasingly sideline in favour of more participatory agendas that actively involve participants, such as emancipatory and participatory research. These approaches may offer very little opportunity to hear PMLD children unless their significant others are part of the research process.

Join and be with and involve and do with

Listening should be process orientated as children with PMLD live, learn and explore within the moment. For children with PMLD, communicating feelings and thoughts and reflecting on their experiences is cognitively and communicatively complex. To convey and recall events firstly requires a person to understand the context, and to have a memory of their experience of an item, event, experience or situation and secondly an intentional method to communicate their thought. Failing this, the caregiver needs to have the ability to understand and successfully interpret their communication. In asking questions a way to say yes and no is important, but may not yet be developed, so other considerations such as indication of refusal, consent, dissent, distress or happiness can be used as a means to elicit potential views.

The experience of being engaged with a child can provoke further questions about who the child is and what is important to them. Intensive interaction can facilitate opportunities for us to join with the child. The process of mirroring, in particular, enables us to enter into their world and experiences and may help us to understand what is important to them (Hewett et al, 2001). Through mirroring behaviours that may even seem weird or abhorrent, the child may become more understood. Such attunement is vital to ensuring that the child recognises that they have a ‘voice’ and efforts to enable contingent responding enables them to see that they can contribute to the world around them.

Money et al (1999) describe a shadowing technique which could be used to gain understanding of how a child with PMLD experiences the world by entering into their perspective. This multi dimensional listening challenges positivistic epistemology and leans towards ‘a rendering of what [being a child with PMLD] might be like’ (James, 1996, p 315 cited by Warming in Clarke, 1995). Although it is questionable how realistically we can enter into the experience of a child with PMLD when most of us have not experienced the child’s substantial impairment, difficulties in learning and experience of a disabling environment, such endeavours can be useful in ensuring emphatic and child centred responses.

Making choices can be very difficult for children with PMLD. They may require repeated opportunities to carefully explore the items, and support to develop their memory in order to formulate a preference. We also need to observe the child’s response closely in order to document accurately how they are expressing their preference. People with PMLD are reliant on our skills in documenting and interpreting their expressions, but this choice may not automatically represent a view (Ware, 2004). However, it is important to continue to offer choices, seek views and experiences as much as possible and closely work with the person as:

‘Observation is increasingly being used, particularly through the mosaic approach which offers a multi-dimensional method of listening and responding (Clarke, 1996).’
the SLD experience

‘… it is the start of a continuum that leads ultimately to being able to initiate communication, though many (PMLD) children may never achieve this level; and it is also an important part of treating young people in a respectful and inclusive way.’ (Goodwin and Edwards, 2009).

Documentation
The use of documentation is wide ranging. Traditional methods of documentation rely on photographs and annotated passages describing the context of the photo. With the advent of digital photography, more innovative and participative methods that use photos and videos to make a multi-media profile have been utilised. Other documentary methods such as life stories using objects or pictures to represent life events, bag books, memory boxes or life quilts which involves sewn images to create documentary pieces (Hewitt, 2006) enable engaging options for involving children. Creative processes such as shared story-telling, interactive drama and movement, use of technology such as big macks, objects of reference additionally have potential benefit in eliciting views of children with PMLD but require further investigation to ensure validity.

Documentation provides us with a snapshot of experiences or moments. Rinaldi (in Clarke et al, 2005) describe documentation as a process of ‘visible listening’ and the ‘construction of traces’ (p 23) that make the experience seen, enables interpretations to be re-interpreted and subjective meanings become inter-subjective (involving many reflections) or participative. Therefore, documentation processes should ideally be pursued with children as ‘co documenters’ (Clarke, 2005) and should be made accessible so that they have a means to check or revisit experiences or what others say or feel about the experience. How to make the process meaningful and accessible to children with PMLD and the practicalities of sharing in a transparent manner is practically challenging. Working with children who have profound cognitive delay and possibility of additional sensory impairment may benefit from innovative methods such as video where they may be able to re-enter the moment or use of other stimulus such as objects of reference, so long as the person can ascribe meaning to the representation. Other possibilities exist through sharing documentary processes with practitioners and parents as proxies (Jenkinson, undated). Person-centred planning tools have aided documentation of what is important to the person. Such methods have been described as letting:

‘… the style of communication receive recognition, grow into a unique record of personal development … giving a voice and letting others know how you wish to be treated.’ (FPLD 2000, p 26 in Smith, 2001)

For children with PMLD who may find participating in documenting difficult, the process at least offers a means for others to view the person with possible new eyes and for meanings to become shared through further reflection and interpretation. Documentation can be used as a tool for them to communicate about themselves and for us to listen, respond and share important messages (Driscoll et al in Clarke et al, 2005). Capturing children’s experiences faithfully, through a documentary, reflective and interpretive process requires honesty and clarity about the processes that have been used.

Reflect and interpret experiences and journey
In order for children with PMLD to have the quality of life they deserve, serious attempts should be made to reflect and interpret their communication. Although best guess (Sanderson, 1997) is sometimes used, this may be not enough as carers and friends will have different meanings and interpretations of what it means when a child responds in a certain way; indeed a framework that establishes interpretations may be needed. A reflection group may be a way of facilitating this, or for some it could be a circle of friends.

Different perspectives, from professionals and carers may exist within a reflection group.

Porter et al (2001) refers to the importance of reflecting on practice so that:

‘… staff are open to interpretations and views of others, and encouraged to question their own opinions and the evidence for these’. (p 13)

Within the reflection period, Porter suggests that validity of communication with regard to intentionality should be checked. Checking and revisiting situations, potentially through the use of video is needed in order to ensure that their potential view is interpreted effectively and a strong process of establishing the person’s communication is required in order to effectively safeguard children with PMLD from misinterpretations. Porter (2001) refers to a process of validating communication through asking key questions e.g. about how the person communicates, communication of likes / dislikes, comprehension of situations and how certain
the interpretations are. The questions shape discussions in a systematic way and avoid the danger of not

‘... sensitizing ourselves to the range of responses which an individual makes and when we do not check to see that our interpretations are accurate and continue to have the same meaning.’ (Porter 2001, p 16)

Whilst Grove et al (2000) refers to a process of interpreting communicative behaviours in response to decision making and Petry et al (2006) refers to the importance of recording how we are aware the person is showing pleasure or displeasure.

The eight domains of the watching brief (VTA, 2008) for facilitating non-instructed advocacy are useful to support reflection on the person’s life. The framework asks useful questions to determine whether basic rights are being met. As suggested in Goodwin (2002), it may also be useful to utilise frameworks of person centred planning to develop questions about the person and what is important to them through tools such as essential lifestyle planning (Smull & Burke, 1989).

It may always be the case that it is difficult to elicit their potential views due to very idiosyncratic communication (Bradley in Lacey, 1998). That does not mean we ignore the possibility of interpreting meaning from their personal experience even if this involves using a panel or a circle around the child to rate and assist in interpreting body language and emotions. The experience of parents and carers who have lived and worked with individuals for many years, and will talk about their knowledge and understanding of the people they care for would undoubtedly benefit the process. A process of triangulation between an independent observer who can offer objectivity and observers who know the youngster and his context (Petry et al, 2006) may support the process of validation.

**Develop ideas that respond to what we have learnt about what people want**

Person-centred planning processes of PATH (Pearpoint, Forest, O’Brien) and Maps (Snow, Pearpoint & Forest), support the person and those who know and love the person to plan towards reaching the person’s desired goal. Developing ideas is best done with people closest to the child, such as in a circle of friends. Jay (Undated) comments on the value of a PMLD child having a circle of friends to dream with and support the person to reach their goals, especially people who are ‘tuned in’ to how the person uniquely communicates. It is useful to have a facilitator who can objectively ensure that the friends seek to understand the person’s perspective and, critically, ensure that the child with PMLD remains the focus of the circle and any actions that may ensue.

Ideally, a level of agreement and consensus about how to interpret the communication of the person with PMLD is what a circle should be aiming for. However, disparity of view may equal diversity and conversely this could provide additional interpretations. In the case of non-consensus of interpretation the technique used in essential lifestyle planning where it is stated ‘what we don’t know and what we need to find out’ in the form of an action plan may be useful. Grove et al (2000) importantly reminds us that ‘we should not be afraid of admitting that we are not sure of what someone wants’ (p 8) and this needs to be remembered in order to ensure the authenticity of listening and responding approaches.

**Put into action lessons learnt from working with and listening to people.**

To ensure that services respond to children’s views we need to ensure that evidence is collated with honesty, clarity and reflection on the process through clearly documented evidence. Questions of validity continue to exist, which increases the need to build up evidence through transparent processes that clearly document meaning and promote understanding of the child and their perceived views and preferences. To ensure a positive outcome, action-orientated processes such as Solution Circles will support the circle of friends or supporters to advocate and represent children with PMLD.

At a personal level, listening and responding to children with PMLD may support development of daily routines and interactions that better meet needs and take into account their wishes and preferences.‘

‘At a personal level, listening and responding to children with PMLD may support development of daily routines and interactions that better meet needs and take into account their wishes and preferences.’
Conclusion
This article has argued that our shared experiences and daily interactions should be recorded as they often present answers, challenges and further questions which, guided through a process of documentation, interpretation and reflection enable us to listen and respond to the children in a child-centred fashion. It seems helpful to combine careful interaction and observation of the person, involving the people who know the child best, and to be open to the range of potential interpretations.

Documentation, interpretation and reflection of experiences and daily interactions that we have with children lead to our continued understanding of who the person is, what is important to them and preferences they have which can be utilised to support people to build meaning and further understanding of the experiences of children with PMLD and potential views.

The listening and responding cycle helps to enable their voice, and through a supportive process that can develop a representation of a person’s needs and wishes. The accuracy of this representation continues to be a questionable issue and it is the responsibility of those caring for the children to constantly check and revise their conclusions and to be open to the possibility of misrepresentation, but none-the-less continued listening and responding has an important role to play in ensuring that the child is involved in their lives as much as they can be and respected as a unique person.

Clearly to enable consultation to be truly effective and to complete the listening and responding cycle it requires that the messages from children be shared and taken seriously by practitioners and decision makers who should attempt to respond to messages that people have. That is another challenge!

‘Documentation, interpretation and reflection of experiences and daily interactions that we have with children lead to our continued understanding of who the person is, what is important to them and preferences they have …’

Martin Goodwin has more than 17 years’ experience in a range of capacities including play and leisure as well as education, participation and advocacy, working with children, young people and adults with learning disabilities including ASD, SLD and PMLD. Martin has specialised in approaches to improve interaction, communication and participation of people with learning disabilities. He is a qualified teacher in post-compulsory education (QTLS) and a children’s rights advocate.

References
Bradshaw, J (2001) Communication Partnerships with People with Profound and Multiple Learning Disabilities Tizard Learning Disability Review 6, (2)
Goodwin, M, Miller, J, Seddon, A, Percival, V, Smith, C (2002) What do we as a service need to take into account in order to effectively facilitate the involvement of people who use alternative methods of communication in consultation? Unpublished
Jenkinson, S Art of Documentation: Moonbeams Creativity with young children and families Moonbeam
Voices through Advocacy (VTA) (2008) _When communication gets tough_ London: Voices through Advocacy, Scope


Ware, J (2003) _Creating a responsive environment – for people with profound and multiple learning difficulties_ London: David Fulton Publishers


Spiritual, moral, social and cultural development (SMSC) at Abbey Court School

John Bosley

Introduction

At the last Ofsted inspection in July 2010 pupils’ spiritual, moral, social and cultural development (SMSC) was judged to be outstanding at Abbey Court School. In the revised Ofsted Framework (2012) there is a renewed emphasis on the inspection of spiritual, moral, social and cultural development which impacts on many of the other judgements, including a school’s capacity to improve. To make progress the school needs to move beyond outstanding!

The evidence for SMSC across the school is very good and through discussion the leadership team developed an idea that would allow this to be encapsulated so that it could be successfully shared with new staff, visitors to the school and with other schools. It would also be useful for staff training, for moderating pupil progress and for base lining expectation for pupils.

The idea of an SMSC Exemplar was born!

Abbey Court considers that the promotion of pupils’ SMSC is of high importance and an SMSC exemplar file, where there are clear definitions provided for each of the four SMSC areas along with information about overall planning, delivery, monitoring and evaluation would support this. The exemplar would also contain examples of photographs and accompanying text on activities which have been undertaken with individual pupils to promote their personal development which are related to P levels and National Curriculum levels.

The exemplar sets the scene by identifying the nature of need at Abbey Court, an SLD school:

This was important to set the context for the exemplar and the exemplar then identifies at what levels these pupils are working within the P levels and National Curriculum.

What is SMSC? The exemplar attempts to define this and subsequent pages look in detail at each element of SMSC: defining each one; and explaining how we plan, deliver and evaluate the specific element to enable pupils to develop all or some identified characteristics.

The document is then divided into key stages in order to

- demonstrate the different ways in which the needs of pupils working from P1.1 to
early National Curriculum Levels are met at Abbey Court School

- combine information from a variety of documents to give a comprehensive summary of how pupils at Abbey Court are monitored and supported in the teaching and learning of SMSC.

Each key stage section of the exemplar (the examples are from Foundation/Key Stage 1) then focuses on three pupils who represent 3 particular cohorts: Profound and Multiple Learning Difficulties (PMLD); Severe Learning Difficulties (SLD) and those pupils who are functioning near to Moderate Learning Difficulty (MLD) ability levels: the High Achievers in our context.

The exemplar identifies the level the pupils are working at and the type of learning that they are engaged in with pertinence to SMSC.

**Conclusion ... suggestions for development**

A recent external review of SMSC at Abbey Court school carried out by a recently retired HMI commented that:

‘The school considers that the promotion of pupils’ spiritual, moral, social and cultural development is of high importance and this is evident in some of its documentation, for example, the ... SMSC exemplar file, where there are clear definitions provided for each of the four SMSC areas along with information about overall planning, delivery, monitoring and evaluation. The file also contains examples of photographs and accompanying text on activities which have been undertaken with individual pupils to promote their personal development which are related to P levels and National Curriculum levels’.

At Abbey Court we see the provision for SMSC as very much to do with our climate, ethos and values and we place a high value on the quality of respectful and caring relationships not only between staff and pupils but amongst pupils. Our exemplar has enabled us to capture some of this. It enables us to endeavour to share and explain it and to continue to grow and nurture what should be at the heart of a school.

John Bosley is Deputy at Abbey Court Community Special School, an Outstanding school in Medway. He has been teaching in SLD schools for nearly 30 years and Deputy at Abbey Court for half of those (and he’s still smiling!).

‘At Abbey Court we see the provision for SMSC as very much to do with our climate, ethos and values and we place a high value on the quality of respectful and caring relationships not only between staff and pupils but amongst pupils.’
Developing children services to improve the quality of life for children and young people with severe learning difficulties

Mark Fox

Introduction
Every Child Matters (DfES 2004) provided a policy imperative for re-thinking the needs of all pupils – including those with severe learning difficulties. The major focus of Every Child Matters (ECM) was at a strategic level through ensuring the links between the various agencies and policies rather than addressing the individual needs of the child (see DfCFS, 2009). This imperative has now been addressed by the Children and Families Bill which aims to transform the special educational needs (SEN) system in a number of ways. It aims to raise the aspirations of young people and put them, and their parents, explicitly at the centre of decision making. It also aims to give them greater choice and control over the support they receive so they can make a successful transition to adult life. For children and young people with severe learning difficulties such aims around choice, control, aspirations and adult independence are all central to the concept of Quality of Life (QoL). This paper highlights strategies available to services to actually make a difference for the individual child and young person.

Over the last 20 or so years the concept of Quality of Life has been increasingly used in working with adults with disabilities (see BILD, 1997, Rapley, 2003, Cummins, 2005). However it is only recently that it has been used in work with children and young people with learning difficulties (Turnbull et al, 2003). Quality of Life can be defined as:

‘General feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential.’ (Schalock et al, 2002, p 9)

Quality of Life focuses, for children and young people with severe learning difficulties, on their ability to make self-determined choices and to participate in society. Underpinning this is the need to ensure that pupils with SLD are given a voice and a choice about the services that they receive.

The concept of Quality of Life broadens the five Every Child Matters areas into eight which specifically focus on the issues for people with learning difficulties. The Quality of Life Areas are:

- Physical well-being
- Emotional well-being
- Self determination
- Interpersonal relationships
- Social inclusion
- Personal development
- Material well-being
- Rights and privacy

Quality of Life takes a broad perspective on what society should be aiming for with pupils with SLD. Educational progress (which is seen as part of personal development) is only part of one of these areas. Quality of Life is usually measured by developing an understanding of what the pupil thinks is of value (qualitative) and then measuring this by some more objective criteria (quantitative). Central therefore to developing Quality of Life is developing ways of understanding what children and young people with SLD think is of value – this means giving children a ‘voice’. Quality of Life reinforces the view that children and young people with SLD are able to make self-determined choices and to participate in society through social inclusion.

The process
Four half-day workshops were run in a large rural Local Authority for the four Multidisciplinary Teams in the Children Service. These workshops focussed on how to
improve the Quality of Life for children with learning difficulties and disabilities.

At the end of each workshop participants were given a brief questionnaire to complete. The primary question was ‘How can I give children with Learning Difficulties and Disabilities a voice on their Quality of Life?’ Questionnaires were returned from 165 participants who gave a wealth of valuable ideas on how a Children Service could jointly work on developing the Quality of Life for children with learning difficulties.

The participants’ ideas were initially coded and then divided into four core themes:

1. Establishing a communication system with the child
2. Establishing a positive relationship with parents
3. Developing a formal system to give a voice to the child
4. Developing the role of professionals in Children Services

Each of these themes are outlined below and illustrated by quotes from the participants.

1. Establishing a communication system with the child: If you can breathe you can give your views

Participants identified that there are a range of reasons why children may have very limited communication including their age, their learning difficulties, or other factors such as a physical disability which means that they cannot speak.

Time needs to be spent with the child to develop a positive and trusting relationship.

- Ensure there is sufficient time ... to get to know the child and vice versa in order that the child has confidence/relationship with this person

From this there develops an initial understanding of the child through observation and interpretation:

- Use close observation in a variety of situations to inform and build ‘picture’ of views.

From this there develops an understanding of possible communication systems that a child may need:

- More use of Communication Passports to demonstrate child’s ability to communicate

Once a communication system is established it is important to use it to understand the child’s feelings and their views on a regular basis:

- Listen to them – scaffold their views/answers. Explain things to them
- Can’t just seek answers to our questions – child may want to communicate something not covered by our questions.
- Make sure that I ask on each visit the child’s views/feeling on school – all aspects learning social etc.
- Use rating scales – likes/dislikes re all topics linked to young person
- Use an indicator where they are at the moment? What would have to happen to move up the scale? Then disseminate this to the people involved

Finally these views need to be acted upon otherwise all that the child learns is that their voice is not heard:

- Are we prepared to accept choices made after they are offered – resourcing issues?
- Trying to ensure that the young person’s views are carried out

2. Establishing a positive relationship with parents: Nurture the nurturer

Children with severe learning difficulties live in families. Practitioners need to develop good relationships with parents, carers and other adults who are involved with the child on a regular basis:

- Empathy for parents
- Continue liaising with parents as appropriate so that they feel they are listened to and supported

Part of that good relationship is working with parents’ expectations:

- Clarify what procedures/resources are available for the family
- Explain the rights that families have (eg, appeals’ meeting to discuss statements)
- Developing a general overall openness/overview to service users as to what we can offer … rather than the perpetual view that we are the ‘opposition’ and people have to ‘fight’ for what they want/expect.
- Have access to services and facilities that they want and expect rather than have to get them to ‘fit’ what is available. (What we have on offer in terms of education is often
not what families want and expect as their ‘entitlement’.

It was also recognised that there may be a difference between the child and the parents’ views and that the parents’ views may be influenced by their own Quality of Life:

- To be aware that sometimes parents will voice what they think is best for their child but not always what the child wants.
- By trying always when I work with children to ascertain their views in whichever way I can – backed up by observations/triangulation – so that I can be aware of parental views which may sometimes be at odds with the child’s welfare.

Parents were recognised as central to developing the child’s ability to make choices

- Encouraging parents/adults to give child choices
- Provide opportunities to enable the child to make choices
- Help families to look at how they can increase choice and their (child’s) voice in everyday life

3. Developing a formal system to give a voice to the child: Ensure that child’s hopes and dreams are holistic from their view

Participants identified improvements that could be made in the various formal systems that Local Authorities have in place for hearing the voice of the child. The first of these was ensuring that the formal reviews addressed Quality of Life issues:

- Revisiting Annual Review paperwork to consider the Quality of Life issues not just educational element
- Measuring progress other than academic e.g. personal and social development
- Making documentation accessible to children of all ages/special school children in preschool, primary and secondary

Specifically the LA used a ‘My Views’ form which could be developed:

- Changing wording/format of My Views to take into account age of child i.e., pre-school, primary, secondary
- Use photographs to show what child enjoys
- Ensure that child’s hopes and dreams are holistic from their view and not just from an academic point (filled in by school)

- Gain views on different activities for annual reviews by using happy/sad faces and plot views on scale

The My Views form could be used in different ways

- Look at changing/improving the wording in accompanying letter sent to parents/schools with My Views
- At pre-school level send My Views to both parents and pre-school in order to obtain wider views
- Share My Views with all agencies
- Discuss the ‘My Views’ document for Annual Reviews with the pupil and try to widen it to Quality of Life concerns

In addition participants identified a number of other situations where obtaining Quality of Life views would improve their service:

- By asking Quality of Life questions when I carry out initial assessments at CAMHS – the Quality of Life areas would provide a useful framework for identifying needs
- Collect Young Persons’ views (of Quality of Life) before going to SEN Tribunals
- There is a SDQ (Strength and Difficulties Questionnaire) re LAC’s emotional well being … The questionnaire is not child friendly … without this information being collated/collated appropriately the necessary services/support will not be identified

As well as developing the My Views Questionnaire participants identified a number of ways that the child could have a greater voice in their own Quality of Life:

- Person Centered Planning – involving them in their assessment and all aspects of their lives and choices they can make
- Focus on obtaining child’s views at transition times
- Ensure that good practice that is taking place in schools e.g., children producing personal passports and PowerPoint presentations so that their voices are heard can feed into the statutory process and impact more holistically
- Involve them in developing their own programmes
- Involving children in target setting

Participants also identified a range of wider forums where children’s voices needed to be heard:
Social networks for children with disabilities essential for Quality of Life
Give child opportunity to attend clubs after school
Involve young people in developing services
Involve Young People in the Youth Parliament and the Youth Council
Awareness of forum for pupils with disabilities eg, Widening Horizons

4. Developing the role of professionals in Children Services: A lifelong perspective when making decisions about service for child

Participants identified ways of working that would improve children with learning difficulties’ Quality of Life. They identified that the prime role of practitioners in Children Services was to support the child:

- Key worker to get to know child well
- Be child’s advocate where possible
- Child’s views more important than professionals’
- Promotion of professional practice being person centred

In order for this to happen participants highlighted the support that would be required from managers:

- Build in expectations from managers that team members will take time to seek and record the views of children and young people
- I need to have time within my programme to do thorough effective consultation work with parents and children – instead of my time being allocated to a school

However participants realised that the child can only be supported in a context:

- Focus on needs of the child and the family—not just concentrating on educational attainment
- Focus on reduction of stress of those supporting children
- By continuing to support Early Years setting to develop strategies within their groups to help children express their views – so that every child has a voice

They identified the need for development opportunities for staff (and parents):

- Show real examples of good practice of improving communication of gaining pupils’ views
- Communication toolkits for everyone including free training not just for professionals but for parents
- Cascade to practitioners the ‘Small Voices, Powerful messages’ training – to empower adults to give children a voice
- Training for SENCOs in looking at Quality of Life not just academic attainments

This then leads to how professionals have to work together across agencies:

- Communication by professionals so that child’s voice is heard by all
- More inter-agency work – sharing more information
- Knowledge of other agencies and what they can do
- Hold joint reviews with education and social care
- Refer to appropriate services who can help in areas where SEN has no remit
- Support colleagues in their work

Conclusions
The participants in these workshops identified a wide range of ideas that would promote the Quality of Life for children and young people with severe learning difficulties. Quality of Life promotes the importance of pupils being empowered to be able to communicate their needs, make choices and stresses the importance of the family context. Such a focus reinforces the importance of the different agencies including Health, Social Care, Housing and Voluntary Services, working effectively together.

The diversity of ideas from these workshops highlights the opportunities there are for change in Children Services. The Children and Families Bill will provide a legislative framework for change. However it will only make a difference if the experiences of practitioners working in this area are listened to and acted upon. In the same way as we need to listen to the voice of the child, so policy makers need to listen to the views of practitioners about what will make a difference to the Quality of Life of children and young people with severe learning difficulties.

‘Quality of Life promotes the importance of pupils being empowered to be able to communicate their needs, make choices and stresses the importance of the family context.’

Mark Fox has worked as an Educational Psychologist for over 30 years. He is presently...
Programme Director for the training programme for Educational and Child Psychologists at the University of East London. Previously he was Head of the Advisory Assessment Service at SCOPE.

References


Department for Children Families and Schools (2009) Revised ECM Outcome Framework London: DfCFS


Materials review

Cerys Jones

Materials reviewed:
My Face Emotional Literacy Discussion Cards
Problem Solving Discussion Cards
Tell Me a Story – All About You Cards
Tell Me a Story – All About the World Around You Cards

The materials were given to several colleagues within school who work with pupils at key stages three and four. They were asked to identify an individual pupil or small group of pupils within their class with whom they could deliver sessions using the cards. The pupils within the task groups present needs that include autism, emotional and behavioural needs and attention deficit needs. The pupils in all the groups require significant support with reading, writing and thinking skills. Some find oracy and vocal communication a challenge.

The cards in their presentation boxes were warmly welcomed by the majority of pupils within the task groups as something interesting to be using. Staff members working with the pupils noted that this generated initial interest in them wanting to engage with the activities. The illustrations on the ‘All about the world around you’ cards were regarded as inappropriate for the age of the learners at secondary level due to the ‘cartoonish’ look used. Real photographs would have been preferred. The problem solving cards and ‘My Face’ cards were accepted as more suitable for the teenage learners. At both key stages, these cards were deemed to be age appropriate in terms of both their appearance and content.

Staff members found that it was easy to use the materials in a flexible way to ensure that all learners could participate fully in the tasks. The pictures in the ‘My face’ emotional literacy were regarded as ‘fun’ and the pupils liked the fact that they were colourful. The expressions prompted role play which led to productive group discussion. At key stage three, the ‘Tell me a story’ cards were used in a variety of ways; pupils of lower ability were asked to answer questions about what was on the picture cards while more able pupils created their own stories. At both key stages, these cards were deemed to be age appropriate in terms of both their appearance and content.

Stage three using the problem solving discussion cards would have preferred to have had pictures against the feelings words to help them understand what they meant although pupils with a higher ability were able to identify and use the key words within their discussions independently. At key stage four, pupils who were often reluctant to take part in speaking and listening activities showed an interest in wanting to be involved. Pupils at key stage four particularly found that they could relate to the problems stated on the cards and, because the scenarios were short, pupils found it easy to recall them as they discussed them together.

Overall, staff members did think that the materials were a little bit on the expensive side; in some instances it was suggested that without the presentation box, they could have been a little bit more economical. The problem solving cards especially were regarded as expensive considering that some adaptations may have to be made to the layout and presentation of information on the cards for less able pupils. However, the ‘Tell me a story cards’ were considered to be of reasonable value as there were a variety of ways in which they could be used.

Staff members stated that they would be interested in using the materials again as part of their literacy and PSE lessons in order to promote thinking skills and social use of language. It was also suggested that the cards could be used for developing creative writing and drama based activities. Across both key stages, it was noted that the pupils found the activities motivational and pupils were eager to participate. The cards were identified as a useful tool for encouraging the development of communication skills.

Materials reviewed are all obtainable from Small World
www.smlworld.co.uk

My face emotional literacy discussion cards 20 cards depicting emotions plus CD-ROM: £24.00
Tell me a story about the world around you 40 cards: £19.99
Social and emotional problem solving discussion cards: £29.95
Tell me a story about you 40 cards: £19.99

Cerys Jones is a Class Teacher at Ysgol Maes Hyfryd Specialist School, Flint
Dawn Male

The importance of storytelling as a means of transferring knowledge, entertaining, and providing a social context in which people can come together and share a common activity is well established and documented (Grove & Park, 2001). In recent years storytelling has been extended to use with people with profound and multiple learning difficulties (PMLD), with an emphasis being placed on sensory experiences and social interaction. Drawing on an earlier study conducted by Watson, Lambe and Hogg (2002), which aimed to facilitate the acquisition of a range of cognitive, social and motor curriculum objectives by people with PMLD via multi-sensory storytelling, Hannah Young, Maggi Fenwick, Loretto Lamb and James Hogg describe a study in which multi-sensory storytelling was used as an aid to assisting children and young people with PMLD (described in this study as individuals with profound intellectual and multiple disabilities – PIMD) to cope with sensitive issues in their lives.

The study was conducted by PAMIS, an organisation and unit which is based at the University of Dundee which undertakes research into PIMD as well as providing a family support service across Scotland, working collaboratively with the White Top Research Unit, a specialist intellectual disability centre.

The participants were eight young people with PMID from across Scotland, ranging in age from 4–19 years; five were male and three were female. All participants were described as having limited communication skills and were non-verbal; all had physical disabilities but had sufficient motor ability to come into contact with the story objects, sometimes with support. Two participants had a visual impairment and two were registered blind.

The participants’ stories (names changed) and the aims of them were:

<table>
<thead>
<tr>
<th>Participant and story</th>
<th>Aim of story</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Brain has seizures’</td>
<td>reduce fear of seizures</td>
</tr>
<tr>
<td>‘Clare is growing up’</td>
<td>prepare for adolescence and increase touch tolerance</td>
</tr>
<tr>
<td>‘Fraser is growing up’</td>
<td>develop understanding of puberty and masturbation</td>
</tr>
<tr>
<td>‘Joseph’s dentist visit’</td>
<td>reduce anxiety around instruments used at dentist</td>
</tr>
<tr>
<td>‘Martin’s wee turn’</td>
<td>reduce fear of seizures</td>
</tr>
<tr>
<td>‘Rebecca’s toilet time’</td>
<td>use toilet in absence of adult</td>
</tr>
<tr>
<td>‘Sarah has her periods’</td>
<td>develop understanding of period pain</td>
</tr>
<tr>
<td>‘William’s bath time’</td>
<td>develop turn-taking</td>
</tr>
</tbody>
</table>

The multi-sensory stories were developed through collaboration between the parents, the teacher (or other professional), and the PAMIS Sensitive Stories Project Officer. For some stories, a specialist was involved (eg a community dentist advised on ‘Joseph’s dentist visit’). The authors report that the development of the story lines took a number of months, requiring agreement by the development team, and involving numerous draftings of the story lines, consideration of the sensory stimuli to be used and some testing of the stimuli to find the most suitable one for the individual.

The final agreed stories were presented in a cardboard box, in which objects were attached to A3 size pages. The stories included an average of eight sentences (one sentence per page) and all stories involved multiple sensory ‘experiences’ (eg symbols and/or objects) which reflected the sensory capacities of the individual.

Storytelling was undertaken by either the mother (five participants) or a professional (two teachers and one occupational therapist). Stories were rehearsed by the story teller to a non participant prior to the first presentation of the story. Each story was read a minimum of eight times by the same story teller either in school, nursery or, in one case, at home. Participants’ behaviour during storytelling was observed and video recordings were conducted.
during sessions 1, 4 and 8. The video recordings were coded by the project officer. Behaviours fell into two categories:

- **Engagement with story:** three main behaviours in this category were ‘looks at page’; ‘head orientation to page’; ‘touches object’

- **Social engagement:** three main behaviours in this category were ‘looks at storyteller’; ‘eye gaze’; ‘head orientation to story teller’

Semi-structured interviews were conducted with parents and professionals at the end of the project in order to ascertain their views regarding the experience of the use of multi-sensory storytelling and how effective they felt this had been in helping the child or young person to deal with a sensitive issue.

Overall, the authors report positive changes for seven of the eight participants. Only one participant (Martin) showed no increased engagement either with the story or the story teller. However, the authors speculate that illness during the course of the study could have contributed to the apparent lack of positive changes in Martin in relation to storytelling.

Analysis of the behavioural data indicated the following: increases from session 1 to session 3 in duration of looking at page or head orientation to the page in six of the eight participants (Brian, Sarah, Fraser, Joseph, Rebecca, William) although this was only a consistent trend for Brian and Sarah. Joseph, Rebecca and William all showed an increase in touching the objects between sessions 1 and 3. Martin showed a decrease in touching from session 1 to session 3. Of the six participants who showed an increase in looking at the page or head orientation, three (Brian, Sarah and Joseph) showed a concomitant reduction in looking at the storyteller. One participant (Martin) showed a reduction on all measurements including looking at storyteller and eye gaze. Clare’s head orientation to the page is reported to have remained relatively consistent overall while touching objects and head orientation to the story teller increased. Duration of looking at the storyteller and eye gaze increased in Fraser’s case while Rebecca’s attention to the story teller in session 3 reverted almost to the session 1 level but her duration in eye gaze was reported to have consistently increased to the level of looking at the story teller.

The authors conclude by discussing the specific multi-sensory storytelling factors which they consider to have led to the positive outcomes, these were:

- the activity of storytelling provided a single context in which the adult and child or young person could jointly focus on a sensitive issue
- the potential of multi-sensory storytelling to personalise stories that focus on a specific issue identified by parents and/or professionals, linked to a real life situation
- the stories themselves could exemplify both a sensitive issue and a positive resolution
- repeated readings provided opportunity to increase the understanding of the story by the child or young person and how it related to their own experiences
- the nature of storytelling is inherently enjoyable for the child or young person, thereby making the likelihood of his or her motivation to engage with the story more probable

Finally, the authors discuss some of the methodological and procedural issues and
challenges inherent in conducting research in the field of PMID and, more specifically, in relation to the present study, including the issue of proxy reporting (ie parents/teachers/carers reporting on behalf of the child or young person) and the challenge of determining the nature of understanding in the individual with PMID. They also suggest some methodological improvements for future studies, including more refined interviewing with observations rooted explicitly in example of behaviours that indicate improved coping with sensitive issues by the child or young person and expanding and refining the behaviours observed, particularly in relation to affective responses. Despite the challenges, however, they conclude that:

“The consistency of the present results … indicates that the continued development of multi-sensory storytelling has an important role to play in supporting people with PMID, their parents and the professional staff who care for and educate them.” (p.141)

It would be good to see parents and professionals being actively involved in the further development of multi-sensory storytelling. Here is a suggestion: what about some pilot projects in schools and other settings, with dissemination of the outcomes via this journal? A series of single-participant studies across the UK would add significantly to the knowledge base: any takers?

Dawn Male is a Senior Lecturer in Psychology and Special and Inclusive Education at the Institute of Education, University of London. E-mail: Dawn.Male@ioe.ac.uk

References
Young, H, Fenwick, M, Lambe, L and Hogg, J (2011) Multi-sensory storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues: a multiple research methods analysis of engagement and outcomes European Journal of Special Needs Education 26, (2), 127-142
Books and Resources

Celebrating Success – Inclusion for individuals with Down’s syndrome across mainstream education settings

The celebrating success series brings to life the DSA Education Support Packs by using case studies written in the words of teachers, assistants and parents. The series is split into four areas of education – Early Years, Primary, Secondary and Further Education/Employment and demonstrates how to implement successful inclusion across each key phase of education.

In order to make them available to as wide an audience as possible they are available to download free of charge as PDFs from the Downs Syndrome Association website.

www.downs-syndrome.org.uk

The Reading and Language Intervention for Children with Down Syndrome

The Reading and Language Intervention for Children with Down Syndrome (RLI) is a structured teaching program designed to meet the specific learning needs of children with Down syndrome. The programme provides daily individualised reading instruction that includes the teaching of sight words, letter sounds and phonics in the context of book reading, together with the teaching of vocabulary. An evaluation of RLI suggests that it accelerates progress in key reading skills when compared to ‘teaching as usual’. (See articles section)

The handbook includes two DVDs and a resource CD. It provides detailed guidance, video illustrations, assessment forms and teaching resources to help teachers and teaching assistants implement the program.

Down’s Syndrome Education International
E-mail: info@dseenterprises.org
www.dseinternational.org

R2D2 Inflatable Remote Controlled Switch Adapted Toy

R2D2 has an inflatable super durable body and stands over 65cm in height. A foot pump is included to assist with the inflation and deflation of the body. A remote control handset controls the toy, allowing it to move forwards, backwards, left and right plus 360 degree spins. The remote control handset has been adapted to provide four switch sockets which give access to the four functions (forward, backwards, turn left and turn right). This provides a variety of options for switch control depending on the ability of the user, plus lots of opportunities for interaction and turn taking using switches and the handset buttons which can be used alongside switches. Use any standard 3.5mm switches (not included). Requires 4 x AA batteries and 1 x 9V battery – included.

R2D2 Remote Controlled Inflatable Switch Adapted Toy: £86
www.inclusive.co.uk

New StepPAD

A new, ergonomically designed portable teaching tool and sequencing communication aid that will fit into a purse, pocket or hands. A really useful device for vocational tasks, household chores, personal routines, school schedule, cooking procedures, shopping lists, activity transitions and simple choice making. Press any of the four activity buttons to activate a step by step sequence. Users hear the steps one at a time by pressing the next button. Press play to repeat a step. Review previous steps with the back button. Create up to 8 different activities (4 activities, 2 levels).

Dimensions: 165mm x 50mm x 13mm. 2 x AAA batteries included.

New StepPAD: £75
New StepPAD with Go-Talk overlay software: £99
www.inclusive.co.uk

Mansell, J and Beadle-Brown, J

Active Support

Enabling and Empowering People with Intellectual Disabilities

Active Support is a proven model of care that enables and empowers people with intellectual disabilities to participate fully in all aspects of their lives. This evidence-based approach is particularly effective for working with people with more severe disabilities. The authors provide a comprehensive overview of Active Support and how it can be used in practice, based on the theory and research underpinning the methods involved. They describe how to engage people with intellectual disabilities in meaningful activity as active participants, and look at the communication style needed to foster positive relationships between carers and the people they are supporting. Highlighting the main issues for those trying to put Active Support into practice, they explain what is needed on a day-to-day basis to support the implementation, improvement and maintenance of the approach, along with possible solutions for the difficulties they may encounter. Finally, they look at how to integrate Active Support with other person-centred approaches, drawing on examples from various organisations and individual case studies.

The definitive text on Active
Artículos

Bradshaw J

El uso de aplicaciones de comunicación alternativa para el iPad y el iPhone: un resumen de los desarrollos recientes

El propósito de este artículo es proporcionar un resumen de las aplicaciones de comunicación (apps) que se pueden utilizar con dispositivos como el iPad, iPod y iPhone para apoyar argumentación y comunicación alternativa (AAC). Un breve análisis de la investigación sobre el uso de tecnología de alta tecnología en el ámbito de la comunicación facilita una introducción al iPad, iPod y iPhone AAC apps. Estos dispositivos y apps tienen un papel a menudo crucial en el espectro de dispositivos AAC que actúan activamente. Pueden tener algunas ventajas distintas en términos de costo, facilidad de uso y aceptabilidad, pero la investigación continúa para determinar su usabilidad.

Tizard Learning Disability Review 18(1), 31–37, 2013

Burgoine, K, Duff, FJ, Clarke, PJ, Buckley, S, Snowling, MJ y Hulme, C

Eficacia de una intervención de lectura y lenguaje para niños con síndrome de Down: un ensayo controlado aleatorizado

Este estudio evaluó los efectos de una intervención de lenguaje y lectura para niños con síndrome de Down (vea el apartado anterior, “Recursos”). Los auxiliares de enseñanza fueron entrenados para proporcionar una intervención de lectura y lenguaje a niños en sesiones individuales de 40 minutos. Los datos se recopilaron en el diseño de control de lista de espera, en el que el grupo de estudio recibió la intervención de manera inmediata, mientras que el grupo de espera recibió la intervención después de un retardo de 20 semanas. Las pruebas se realizaron a los niños en tres puntos: previa a la intervención, después de 20 semanas de intervención y después de 40 semanas de intervención. Después de 20 semanas de intervención, el grupo de estudio mostró un progreso significativamente mayor que el grupo de espera. Los resultados sugieren que la intervención es efectiva para mejorar los siguientes aspectos: lectura, decodificación, conocimiento fonológico y fusión de fonemas.


Eventos

El BILD Positivo de Comportamiento apoyo internacional investigación y conferencia de práctica 2013: promoviendo enfoques basados en evidencia

8–10 de Mayo
Brighton

El cuarto congreso internacional de investigación y práctica BILD ofrece a académicos, investigadores y profesionales la oportunidad de examinar el data, explorar ideas, compartir la práctica y escuchar a los hablantes destacados. Este congreso internacional de investigación y práctica reunirá pensadores y líderes para compartir sus experticias, revisar la evidencia y presentar los últimos hallazgos en los enfoques positivos de comportamiento para las personas con discapacidades que se presentan en diferentes contextos, que incluyen niños y adultos. Presentaremos diferentes enfoques de implementación, así como perspectivas internacionales.

BILD
Tel: 01562 723010
Severe and Complex Needs Information Day

Inclusive Technology
Tyne and Wear
Tuesday 14 May 2013
Cardiff
Tuesday 11 June 2013
Manchester
Tuesday 2 July 2013

This day focuses on the use of ICT to support the communication, learning and leisure needs of children and young people with severe and complex special needs. Delivered by experienced practitioners, the session will explore how the use of ICT facilitates meaningful and motivating access to the curriculum. This day would be useful for teachers, therapists and support assistants working directly with learners experiencing severe and complex special educational needs.

Inclusive Classrooms – Supporting Struggling Readers and Writers
Inclusive Technology
Tyne and Wear
Wednesday 15 May 2013
Cardiff
Wednesday 12 June 2013
Wednesday 3 July 2013

This day focuses on using ICT to support students with special needs in mainstream settings. This includes looking at providing access to the computer for those pupils who struggle with the keyboard and mouse, including those with Dyspraxia:

- Simple adaptations to the keyboard and mouse.
- Accessibility changes to the operating system and applications.
- Alternatives to keyboards and mice – from large keyboards to eye gaze.
- Software to improve access: word prediction and speech recognition.

Tel 01457 819790
www.inclusive.co.uk/events

Roadshows
Communication Matters
Belfast
Wednesday 1 May 2013
Glasgow
Thursday 9 May 2013
Birmingham
Wednesday 26 June 2013
Bristol
Monday 4 November 2013
Roadshows provide information and offer up-to-date knowledge on the range of AAC equipment and services available in the UK.
Roadshows are free, but places must be booked in advance
www.communicationmatters.org.uk

News

Children and Families Bill introduced into Parliament

The Children and Families Bill has been published by the Department for Education. The Bill includes clauses on special education needs (SEN) which aim to reform the SEN system. The clauses include the duty on local authorities to draw up Education, Health and Care plans and to set out a ‘local offer’ of services available to parents and young people.

http://services.parliament.uk/bills/2012–13/childrenandfamilies.html

Hate Crime
Stop learning disability hate crime helpline launched

Stop Hate UK has launched a new 24 hour helpline service, Stop Learning Disability Hate Crime, in England and Wales. The new service will be funded by the Ministry of Justice Victim and Witness Fund.

Stop Hate UK

New study will research adults with a learning disability and depression

BEAT-IT is a behavioural activation intervention for adults with learning disabilities and depression, which will be run in North Wales, Glasgow and North West England.

KIDS

E-mail: learning@bild.org.uk
www.bild.org.uk/events
Information for contributors

The SLD Experience is a journal for teachers, parents and other professionals working in support of children and young people with severe learning difficulties, including those with profound and multiple learning difficulties and autistic spectrum disorders. The journal is published three times a year (spring, summer and autumn).

The journal aims to:

- disseminate information, review and make critical comment on:
  - government legislation and policies
  - good practice ideas, including those that support and promote inclusion
  - the latest curriculum developments
  - the latest research, with implications for good practice
- provide material of interest to all readers, including teachers and classroom assistants, therapists, psychologists, parents and others working in mainstream and special schools
- provide an advertising service for readers
- provide a forum for readers to express their views and share ideas

Contributors are invited to submit descriptive and/or critical articles as well as articles based on original research.

Specification and style

Articles should normally be between 1,000 and 3,000 words in length, including tables, figures and references. Shorter articles (e.g., 500 words) are also welcomed. References should be cited in the text as follows: Smith (2002); Smith and Jones (2002). If a work has three or more authors use the ‘et al’ form, e.g., Smith et al (2002). The list of references following the text should be in alphabetical order of authors’ names in the following style:

1 Journal articles

2 Books

3 Articles in books

Illustrations, tables and figures should be given titles and should be numbered consecutively. Photographs are welcomed and may be submitted as original prints or as slides. Photographs should be accompanied by captions. Permission to reproduce photographs should accompany articles.

Articles should be submitted to:
Dr Jean Ware
School of Education
Bangor University
Normal Site
Bangor
Gwynedd, LL57 2PZ
E-mail: j.ware@bangor.ac.uk

One hard copy of the article should be submitted, typed double spaced on A4, plus one copy by e-mail.