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Editorial

In this issue we have, unusually, two book reviews, or to be more accurate, a book review and a chapter review. The more conventional review of *Fetal Alcohol Spectrum Disorders* is by Nia Young, while Chris Williams provides the chapter review. Chris Williams’ review of a chapter in *The Sage Handbook of Special Education* is from the perspective of an Early Years Practitioner in Wales and gives pause for thought. Chris's review highlights both the critical role of the early years practitioner in identifying learners with SEN, and the barriers which currently exist in his context to ensuring that identification leads to appropriate provision. Just as importantly, Chris highlights the gap between what is regarded as international best practice, and reality on the ground in Wales (and probably in the other three countries of the UK). We need to be aware of such gaps if provision is to be improved. It remains to be seen whether the new legislation in process in England, and proposed for Wales, will help to close this gap.

Clare Chalaye and Dawn Male’s report on research they have been conducting into the Engagement Profile and Scale, which was one of the major things to come out of the CLDD project, also gives pause for thought. One of the major contributions that any assessment instrument can make is to enable us to be as sure as is humanly possible that when we describe a child’s strengths and needs in the same words we mean the same thing. This is particularly important for learners with the most complex needs, since knowing as accurately as possible where to start is at least one of the keys to enabling them to make progress. I hope that Chalaye and Male’s article will act as a reminder that establishing that we can agree about where a child is now is the first step both to helping them make progress, and demonstrating that they are doing so. Sandy Turner and Joanna Ciuksz address a related issue in their piece about demonstrating progress using the *Routes for Learning* materials. It would be interesting to know if they have been able to use the strength of their network to address the issue of reliable baseline assessment.

Nicola Vann is refreshingly honest about the lack of objective evidence for the benefits of hydrotherapy, and the need for more research giving solid evidence of its effectiveness if it is to be made more easily accessible. The need for research evidence to underpin the methods which are used every day with children and young people with SLD/PMLD, and for that evidence to be easily accessible to practitioners is a theme which runs through this issue, and which is also relevant to Sue Marshall’s article about the MOVE curriculum, as implemented in one school.

Dawn Male also contributes her usual review of a piece of recent research. For this issue, she has chosen an article by Daisy Loyd about ascertaining the views of pupils with ASD. The piece is interesting because it includes some innovative ways of eliciting the views of pupils with a range of disabilities in response to the same questions, which could easily be adapted for pupils with SLD/ PMLD.

The final article in this issue is by David and Tracy Creighton, who share with us the experience of the death of a child from their perspective as parents. As Fliss has written in her introduction to this piece, this article is a response to a discussion on the SLD Forum about both support for schools, and how schools can support parents when a child dies. Tracy and David’s article is both moving and useful. It helpfully breaks into what is still often a taboo area, in which we all say nothing for fear of saying the wrong thing. Another very different account of the impact of the death of a child, this time from a researcher’s perspective, can be found in the article *Catherine’s Legacy* by Mary Kellett. Readers may also be pleased to hear that Erica Brown has agreed to contribute an article on bereavement in the not too distant future.

Other future plans are for an article on places which you can visit with a group of learners with SLD/PMLD (again inspired by a strand on the SLD Forum), and a new piece by Keith Park. There is always space for articles by practitioners who want to share, as Sandy and Joanna have done, about what their school, or professional learning community is achieving, and especially for articles which help build the evidence base on effective teaching for learners with SLD and PMLD.

Reference

Kellett, M (2005) *Catherine’s legacy: Social communication development for individuals with profound learning difficulties and fragile life expectancies* *British Journal of Special Education* 32 (3), 116–121

Jean Ware
Editor
An evaluation of the Complex Learning Difficulties and Disabilities Engagement Profile and Scale as a measure of engagement for children and young people with profound and multiple learning difficulties

Clare Chalaye and Dawn Male

Introduction
This article describes a study which aimed to evaluate the use of the Complex Learning Difficulties and Disabilities (CLDD) Engagement Profile and Scale (EPS) (SSAT, 2010) with children with CLDD, including those with profound and multiple learning difficulties (PMLD). The rationale for the study was that, as the tools are easily accessible and can be used by a variety of staff working with children/young people with CLDD and/or PMLD, those who use these tools should be able to do so with the confidence that they are a reliable measure of pupil engagement.

The CLDD project
The CLDD project was initially launched in 2009 in England and Wales (SSAT, 2010), funded by the Special Schools and Academies Trust (SSAT). This inquiry-based approach aimed to increase the engagement for learning of children and young people with CLDD, who they described as having: ‘... conditions that co-exist; these conditions overlap and interlock creating a complex profile... Children and young people with CLDD present with a range of issues and combination of layered needs e.g. mental health, relationships, behavioural, physical, medical sensory, communication and cognitive... Their attainments may be inconsistent, presenting an atypical or uneven profile. In the school setting learners may be working at any educational level, including the National Curriculum and P scales.’ (SSAT, 2011a, p 2)

This definition encompasses pupils with PMLD, the chosen group for this study.

The project was piloted, mainly in English and Welsh special schools from September 2009; subsequently, a free online tool-kit called ‘Engagement for Learning Resource Framework’ (SSAT, 2010) was produced. This included:
- briefing packs to support professionals and families regarding pedagogies for children with a range of specific complex conditions;
- the Enquiry Framework for Learning (IFL), a tool designed to support multi-disciplinary professionals and families in establishing personalised pedagogies for children (SSAT, 2010);
- the Engagement Profile and Scale (EPS).

The Engagement Profile and Scale
Engagement for learning lies at the heart of these tools. The CLDD project defines engagement as ‘... a journey which connects a child and their environment... to enable learning and achievement’.

‘The CLDD project defines engagement as “...a journey which connects a child and their environment... to enable learning and achievement”.’
‘Training with the tools is available…, but as these tools are freely available to practitioners, many who use the tools will have received no training.’

The study
The aims of the study and the questions asked

As previously stated, the aim of the study was to evaluate the use of the EPS with children with CLDD, including those with PMLD. The question asked was: Is the EPS a reliable measure of engagement for children and young people with CLDD, including those with PMLD?

Reliability is the extent to which a tool gives consistent results, when used repeatedly (Robson, 2011). In this case, if reliable the EPS should yield similar results for the same child across the sample. The study design aimed to maintain conditions across sample groups as much as possible to reduce extraneous variables, enabling a true measure of reliability to be achieved.

It was speculated that, if the EPS is a reliable measure of the engagement of children and young people with CLDD, including PMLD, then there should be no differences in engagement scores recorded by staff for the same child according to factors such as familiarity/unfamiliarity with the child/young person; levels of training; experience of working with children/young people with special educational needs (SEN) generally and PMLD specifically; professional role (eg teacher or TA).

Table 1: Engagement indicator definitions

<table>
<thead>
<tr>
<th>Engagement indicator</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness</td>
<td>Shows response, consciousness, acknowledgement or recognition</td>
</tr>
<tr>
<td>Curiosity</td>
<td>The need, thirst or desire to explore, know about, learn or make a connection with</td>
</tr>
<tr>
<td>Investigation</td>
<td>Actively trying to find out more within or about an activity or experience</td>
</tr>
<tr>
<td>Discovery</td>
<td>‘Light bulb moment’: a new or repeated action or experience (planned or by chance) that causes realisation, surprise or excitement etc.</td>
</tr>
<tr>
<td>Anticipation</td>
<td>Shows expectancy or prediction as a result of previous knowledge, experience or skill</td>
</tr>
<tr>
<td>Persistence</td>
<td>‘Sticking with it’: continued effort (may be in short bursts), perseverance, determination, refusing to give up or let go</td>
</tr>
<tr>
<td>Initiation</td>
<td>A self-directed request, movement or indication, however small, which can be considered to express an intention, want or need</td>
</tr>
</tbody>
</table>

Each engagement indicator is rated and scored from 0–4, with 0=no focus; 1=low and minimal levels – emerging/fleeting; 2=partly sustained; 3=mostly sustained; 4=fully sustained. These scores are then summed to yield a total engagement score. Qualitative comment can be added in response to the question: What happened/what didn’t happen and why?

The EPS is promoted for use by teachers and teaching assistants (TAs) who will have varying degrees of knowledge of their pupils, according to factors such as the length of time the pupil has attended the school or the time that the teacher/TA has worked with them. Training with the tools is available through the SSAT, but as these tools are freely available to practitioners, many who use the tools will have received no training.

Personalisation of learning was the sole aim of the CLDD project and the EPS and, although the instructions for use suggest the benefits of consultation with people ‘who know the student well’ to support interpretation of behaviour (SSAT, 2011a, p 1), it does not specify prior knowledge of the child as being necessary to use the tools accurately.
With this in mind, the following sub-questions were explored:

- Are there differences between observations made by staff who are familiar or unfamiliar with the child they are observing?
- Are there differences between observations made by staff working in the same and different schools from the child they are observing?
- Do staff who have or have not received training with the CLDD tools score their observations differently?
- Are differences demonstrated between observations made by staff who are experienced or inexperienced in working with children/young people with (a) SEN, or (b) PMLD?
- Are there differences between observations made by teachers and TAs?

### The contexts

The study was carried out in two schools. School 1 is a large special school (215 on roll) in Greater London, based on two sites. The main site caters for 160 pupils aged 4–19 years with S/PMLD, many with complex autism. The smaller site caters for 55 pupils on the autism spectrum aged 4–11 years. School 2 is a special school (68 on roll) based also in Greater London, for pupils aged 2–16 years, who have a wide range of physical disabilities and complex health needs, many with learning disabilities, including PMLD.

### The participants in the study

#### The children

There were two child participants in this study: John and Charlotte. Both children have profound and multiple learning difficulties. John attends School 1, Charlotte attends School 2. Both children are eight years old and both have been assessed by their class teacher as working at P-level 3(i). Challenges to John’s learning include visual impairment and epilepsy. Challenges to Charlotte’s learning include hydrocephalus, cerebral palsy, epilepsy, hearing and visual impairments.

### The adults

A total of 50 members of staff participated in the study: 29 from School 1 and 21 from School 2. From School 1 there were 13 teachers and 16 TAs; 28 of these were female. From School 2 there were four teachers and 17 TAs; 18 of these were female. Staff age was recorded in five age bands (from 18 to 60+ years) with a mean (average) age of 30–39 years in School 1 and 40–49 years in School 2. Standard deviations (sd) (ie how the measurements for the groups were spread out from the average) were 1.20 in both cases.

The number of staff with experience of working with children/young people with SEN at School 1 was 15; of these, 10 had experience of working with children/young people with PMLD. At School 2, 14 had experience of working with children/young people with SEN, 12 of them with children/young people with PMLD.

At School 1 staff from both sites were invited to take part in the study via a whole school email, through announcements at staff briefings or following messages over the intercom system. Staff at School 2 were asked to take part by their head teacher, who was keen for them to become more familiar with using the EPS.

The British Psychological Society (BPS) Code of Human Research Ethics (BPS, 2010) and Code of Ethics and Conduct (BPS, 2009) were adhered to throughout this study.

### Procedure

#### How data were collected

The main data collection method was observation by all participating staff of video footage of John and Charlotte. John and Charlotte were filmed by the first author whilst working with their class teacher and TA. Both children were given activities that they engage in highly, as recommended in the EPS guidelines (SSAT, 2010). John worked one-to-one with his teacher, who encouraged him to engage with an activity centre. He was seated in his class chair, within easy reach of the activity centre, with his teacher in front of him. When Charlotte was filmed the room was darkened but lit with coloured lights and music was playing. She was seated in her wheelchair which had a tray attached to the front. In the video Charlotte moves her hands in a shallow tray with water and shells in it. She is encouraged to maintain engagement by her TA.
A pilot study was conducted prior to the main study; only minor amendments were required.

All staff viewed the video footage of John and Charlotte on two occasions and recorded their observations on the EPS. There are two different versions of the EPS (SSAT, 2010), one for pupils in mainstream schools and one for pupils in SEN/Early Years provision. The latter was used in this study, with minor amendments. Two minutes elapsed between the first and second showing to facilitate note taking, with a further eight minutes being given to complete the EPS. Staff were encouraged to refer to the engagement definitions as they completed the EPS.

**Scoring**

As indicated above, the EPS is scored from 0–4 for seven engagement indicators: 0–28 in total. Only the total scores were used for comparison purposes in this study.

**Data analysis**

The scores from the EPS for the seven engagement areas were totalled for each child and comparisons were made between these, taking into account different staff characteristics, using independent samples t-tests; these are tests which assess whether the means of two groups are statistically different from each other. A result is considered ‘significant’ because it has been predicted as unlikely to have happened by chance alone. Typically, levels of significance are set at 5% (ie a 1 in 20 probability that it is a chance result). If 1% probability has been set (ie a 1 in a 100 chance that it is a chance result) the results may be described as being ‘highly significant’.

For the sake of brevity, only quantitative data yielded by the EPS will be reported and discussed in this article.

**Results**

Table 2 shows John and Charlotte’s total EPS scores recorded by all staff participants.

<table>
<thead>
<tr>
<th>Child</th>
<th>Mean</th>
<th>Lowest</th>
<th>Highest</th>
<th>Range</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>John</td>
<td>17.40</td>
<td>8</td>
<td>27</td>
<td>19</td>
<td>4.00</td>
</tr>
<tr>
<td>Charlotte</td>
<td>15.50</td>
<td>4</td>
<td>24</td>
<td>20</td>
<td>5.05</td>
</tr>
</tbody>
</table>

It will be noted that there is considerable variation in the range of total EPS scores awarded to John and Charlotte (the lowest total score for John being eight and the highest 27; the lowest total score for Charlotte being four and the highest 24).

Remaining results will be presented to correspond with the research questions.

- Are there differences between observations made by staff who are familiar or unfamiliar with the child they are observing?

| Table 3: Total EPS scores according to familiarity/unfamiliarity with child |
|-----------------------------|--------|-----------------|-----|
| Child | Know child | Number of staff | Mean | sd  |
| John  | Yes       | 16             | 16.40| 5.70|
| No    | 34        |                | 17.90| 4.70|
| Charlotte | Yes | 20             | 13.10| 3.60|
| No    | 30        |                | 17.10| 3.50|

John’s mean total EPS score from staff who knew him was lower than from those who did not know him; however, the difference was not significant. Charlotte’s mean total score from staff who knew her was lower than from staff who did not know her; this difference was highly significant.

- Are there differences between observations made by staff working in the same and different schools from the child they are observing?

| Table 4: Total EPS scores according to school location |
|-----------------------------------------------|--------|-----------------|-----|
| Child | School | Number of staff | Mean | sd  |
| John  | School 1 | 29             | 17.60| 5.50|
| School 2 | 21        |                | 17.20| 4.40|
| Charlotte | School 1 | 29             | 17.10| 3.60|
| School 2 | 21        |                | 13.20| 3.50|

A pilot study was conducted prior to the main study; only minor amendments were required.
There were highly significant differences in mean total EPS scores awarded to Charlotte by staff who knew her compared with staff who did not.

John’s mean total score from staff with SEN experience was marginally higher than from those without SEN experience. This difference was not significant. Charlotte’s mean total score from staff with SEN experience was lower than from those without SEN experience; again, this difference was not significant.

For John, the mean total score from staff with PMLD experience was higher than from those without PMLD experience. This difference was significant. For Charlotte, the mean total score from staff with PMLD experience was lower than from those without PMLD experience. This difference was not significant.

Are there differences between observations made by teachers and TAs?

John’s mean total score from teachers was the same as from TAs; there was therefore no significant difference. The mean total score for Charlotte from teachers was higher than from TAs but this difference was not significant.

Summary of findings, discussion and conclusions

Results from the data analysis indicate the following:

- There were wide variations in total EPS scores awarded to John and Charlotte by all staff.
- There were highly significant differences in mean total EPS scores awarded to Charlotte by staff who knew her compared with staff who did not know her.
- There were highly significant differences in mean total EPS scores awarded to Charlotte by staff according to school location.
- There were significant differences in mean total EPS scores awarded to John by staff who did, and did not, have experience of working with children/young people with PMLD.

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Table 5: Total EPS scores according to training received

<table>
<thead>
<tr>
<th>Child</th>
<th>Training</th>
<th>Number of staff</th>
<th>Mean</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>John</td>
<td>Yes</td>
<td>26</td>
<td>16.70</td>
<td>4.10</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>24</td>
<td>17.20</td>
<td>5.20</td>
</tr>
<tr>
<td>Charlotte</td>
<td>Yes</td>
<td>26</td>
<td>14.80</td>
<td>3.60</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>24</td>
<td>16.30</td>
<td>4.30</td>
</tr>
</tbody>
</table>

John’s mean total score from staff with training was lower than from staff without training; however, this was not a significant difference. Charlotte’s mean total score from staff with training was also lower than from those with training but, again, this was not significant.

- Are differences demonstrated between observations made by staff who are experienced or inexperienced in working with children/young people with (a) SEN, or (b) PMLD?

Table 6: Total EPS scores according experience of SEN and PMLD

<table>
<thead>
<tr>
<th>Child</th>
<th>Experience</th>
<th>Number of staff</th>
<th>Mean</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>John</td>
<td>With SEN</td>
<td>29</td>
<td>17.70</td>
<td>5.90</td>
</tr>
<tr>
<td></td>
<td>Without SEN</td>
<td>21</td>
<td>17.00</td>
<td>3.70</td>
</tr>
<tr>
<td></td>
<td>With PMLD</td>
<td>22</td>
<td>19.07</td>
<td>1.20</td>
</tr>
<tr>
<td></td>
<td>Without PMLD</td>
<td>28</td>
<td>16.10</td>
<td>4.50</td>
</tr>
<tr>
<td>Charlotte</td>
<td>With SEN</td>
<td>29</td>
<td>14.80</td>
<td>4.09</td>
</tr>
<tr>
<td></td>
<td>Without SEN</td>
<td>21</td>
<td>16.30</td>
<td>3.80</td>
</tr>
<tr>
<td></td>
<td>With PMLD</td>
<td>22</td>
<td>14.70</td>
<td>4.30</td>
</tr>
<tr>
<td></td>
<td>Without PMLD</td>
<td>28</td>
<td>16.00</td>
<td>3.80</td>
</tr>
</tbody>
</table>
In addition, it was only the total EPS scores awarded to John by teachers and TAs where there was complete agreement; in all other cases, although not statistically significant, differences in scoring were noted. In general, the overall conclusion which could be reached is one of inconsistency in terms of reliability of inter-rater scoring of the EPS and, therefore, the indications are that the EPS is not a reliable measure of John or Charlotte’s engagement, at least in the areas identified above.

Perhaps interestingly, although there was a trend for staff who had received training in the use of the EPS to return somewhat lower total EPS scores for both children, there were no significant differences according to whether or not training in the use of the EPS had been received.

Carpenter et al (2011) maintain that the EPS allows ‘…educators to quantify and track the student’s progress numerically in terms of engagement’ (p 35); this requires trustworthy initial ratings, in order to ascertain baseline engagement and equally trustworthy subsequent ratings in order to assess progress. However, as noted above, the current findings suggest that the use of the EPS as a means of quantifying and tracking a pupil’s progress, according to inter-rater reliability, would be questionable.

This study has focused on inter-rater reliability (ie agreement in scoring among raters); but what of intra-rater reliability (ie agreement of repetitions of ratings by a single rater)? By way of exploration of this question the adult participant in the pilot study was asked to rate John and Charlotte’s engagement using the EPS with a four-month period between ratings. It could be anticipated that, as the same video was viewed on both occasions, the scores returned by the single rater on the second occasion of observation would be the same as the scores returned on the first occasion of observation. The initial scores returned by the rater were 13 and 15 for John and Charlotte respectively, and 11 for both children upon second scoring. The rater was a very knowledgeable practitioner, with considerable experience of working in a special school and of using the EPS. She had also received training in the use of the EPS and was familiar with both children – as such, it would be reasonable to anticipate that her ratings over time would be reliable; as noted, however, reliability (trustworthiness) of scoring in this case is perhaps questionable. Clearly, this exercise was by way of exploration only and, therefore, no generalisations can be made but the indications are for the need for further research in relation to both inter- and intra-rater reliability in relation to the use of the EPS.

Concluding comments

The CLDD project achieved much, from establishing the Engagement for Learning Resource Framework (SSAT, 2011), to gaining national press coverage which raised public awareness of the very existence of children/young people with CLDD (Kyffin, 2011). The tools are easily accessible, free for families and practitioners, endorse multi-disciplinary team working, promote an inquiry-based approach to learning and encourage regular, structured observations leading to in-depth recording of pupils’ actions. The CLDD executive summary (SSAT, 2010) recommends that ‘…schools look to consider the introduction of the Specialist Schools and Academies Trust’s Engagement Profile and Scale to aid and enrich student engagement in learning’ (p 4). From the findings yielded by the present study, which call into question the reliability of the tools as a quantitative measure, it would appear that, as noted above, further research is required before the decision to implement these tools in every school is made. In the concluding section of the Executive Summary of Findings from the CLDD project (SSAT, 2011b) a suggestion for future research was for ‘…a more wide-ranging and formal evaluation of the CLDD Engagement for Learning resources in their final form, subject to in-depth evaluation and feedback from users’ (p 22). We concur with this.

Clare Chalaye is deputy head teacher in a special school in south east London and has recently completed an MSc at the Institute of Education, University of London in Special and Inclusive Education. She is now embarking on doctoral studies at the Institute of Education, researching into dignity and respect for pupils with PMLD.

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


SSAT (2011b) Complex Learning Difficulties and Disabilities Research project: developing meaningful pathways to learning Executive Summary Wolverhampton: SSAT


Wolverhampton: SSAT

References
“To sum up Sally, she lived life with the attitude “I was told I can’t but I can and I did”.”

Who was Sally?
On 1 May 2012 our world changed forever when we had to say a final goodbye to our beautiful daughter Sally. Sally had a rare chromosome disorder like her older brother Joshua. In addition Sally had many complex health issues; she aspirated on liquids, was gastro fed, she had severe reflux, lung damage, poor oxygen saturation levels requiring night time oxygen therapy and required three-monthly IV antibiotics. Sally spent many weeks and months over her life in hospital with pneumonia and other severe infections. Sally nearly lost the battle a number of times but always pulled through.

To sum up Sally, she lived life with the attitude ‘I was told I can’t but I can and I did’. Sally had severe mental development delay which meant she had no language and lived for the moment like a one-year-old. She had a huge zest for life and everyone she met instantly fell in love with her smile and personality. Sally didn’t let her disabilities and health problems stop her doing anything; from going to the cinema, kayaking, sledding, driving a JCB or just playing in a ball pool with her friends and brother. Sally had a fantastic relationship with her brother and they would grab each other in affection. In hospital she would go to the nurses’ station to watch the world go by and get her feet massaged.

Sally needed 24x7 care due to her lack of a sense of danger, health problems and ability to play with and ‘trash’ anything. Sally was always the favourite of her various carers, with many staying in touch following her death.

Cuddles after a special day at Chester zoo
Sally left a massive impression in her short 12-year life; touching many lives and showing people you should enjoy what you have and love everything.

What is it like to lose a child?
Losing a child is a million times harder than you can imagine. Immediately after Sally died we were in a bubble and extremely sensitive to the world around us. Everything that was said and the smallest of actions meant something to us. We became annoyed at people for the silliest of things, extremely grateful for the smallest of help and generally were in a heightened state of alert. We could get upset at anything that reminded us of what we had shared with Sally as the happy memories and the immediacy of our loss exploded in emotion.
Our world had been turned upside down and the simplest task took every little bit of energy. Even sorting out photographs for the funeral took two days and deciding on the order of service many days. It was an exhausting time and our bodies felt like they had been hit by a dozen buses, all battered and bruised. We stopped sleeping as Sally was in our thoughts every minute of the day and night. We felt sick all the time so couldn’t face food and we generally stopped caring about ourselves. Our world stopped and we thought we would never feel happy again. Our bodies and brains stopped functioning properly with our short-term memory vanishing and it took many months to start a slow recovery. Even a simple decision took effort and it felt like our brains were made of treacle and didn’t want to work. In summary we were in absolute shock.

People’s reaction to the loss
How people reacted to us when Sally died can be easily put into two camps: total sympathy, or total blanking out and avoiding us. We now fully understand both reactions, but due to our heightened sensitivity we probably didn’t fully appreciate this at the time.

As a parent I wanted to talk about Sally to everyone and tell them all about her and what had happened. I didn’t want to hear other people’s experience of grief or how their loved ones had died. They meant well but my world was all about Sally. Their well-meaning help wasn’t going to take away my pain and loss.

Just after Sally had died we had to go through the details of her death with everyone we met. This was extremely hard and ignited the emotions at the moment of her death, often leaving us in tears and emotionally drained. These were conflicting actions as we wanted to talk to people but knew it was exhausting. Having friends tell other people helped enormously as it took the pressure away from us. It also helped other people by not having to confront us as we understood they were terrified about talking to us. What do you say to a parent who has just lost their child? This was a double-edged sword as you would eventually have to face them and say what? As parents we were telling dozens of people about Sally’s death so had to face the awkward conversation many times, whereas other people only had to face it once. The message here is don’t put off the initial conversation, and then just be there for the family. Other parents were constantly relating our loss to their own

children and were in shock and horror about what we were going through. After a few dozen conversations we did go into autopilot mode as it was a means of protecting our emotion and stopped the constant, spontaneous tears. We were aware people were going out of their way to avoid us, suddenly leaving a room when we arrived, crossing the road, not going to events we might be attending and generally trying to avoid eye contact.

What is an acceptable reaction?
If you only take one message away having read this article, that should be: don’t ignore the grieving family as they really don’t want to be isolated and abandoned. They want to talk about their child with everyone who had the pleasure of spending time with him or her. Every snippet of experience, or little stories about them, are so important – as a parent, you have a thirst to know everything about your child when they were away from you.

What did people say to us and what felt right for us? There was no point in asking us how we were feeling as it was pretty obvious our world had just collapsed. What did work was people coming up and saying ‘I remember when Sally did this with me…’, ‘when Sally made this squeal or laughed…’ We continue to cherish these little snippets of things we were made aware of at a time when Sally was either at school or on a trip with someone else.

Initially a hug meant a thousand words and just told us people cared for us. A hug helped people to express their own emotion and provided support and comfort. Immediately after Sally had died we left the hospital at midnight and went to a hospice Sally had used during her life. Staff just gave us a hug and didn’t need to say anything. They shared the emotion and we just knew they were walking this journey with us. This is a lasting positive memory and the individuals involved will always be special to us. Sally then arrived shortly after and was placed in the Rainbow room where we could say goodbye in a familiar environment.

How should schools react?
We were very fortunate that Sally went to two very good schools that reacted in the most ideal way possible. Unfortunately Sally’s secondary school has experienced a number of deaths due to the nature of having severely disabled children, but that means they have experience in dealing with the loss of a child.
Both schools immediately contacted us and staff came to visit Sally at the hospice before the funeral. This meant so much to us. Sally was a very popular girl at school with some classmates being with her since they started school many years ago. They were going through shock themselves, trying to understand where ‘their Sally’ had gone and why she wasn’t coming back. Equally, many staff had spent years caring for Sally and sharing the emotions of supporting a medically complex child with us, so Sally’s death was traumatic for many people.

To help Sally’s classmates the schools worked with her friends and produced a memory board with each child drawing or writing their thoughts. These boards were displayed at the funeral and kept by us to remind us of all the good friends Sally had at school. The memory boards mean so much to us as they are the link to Sally from all her ‘boys’ at school.

Following Sally’s death we had the challenge of explaining to her brother why she was no longer coming out of hospital. He was used to Sally vanishing for a few days whilst in hospital but she always came out. Joshua also has severe learning difficulty, but fortunately not the health problems of Sally, so when people started telling him Sally was ‘in heaven’ he became very confused. Sally was suddenly taken out of his life and he was then told by some people she had gone to heaven. His reaction was ‘Josh, no heaven’. He is unable to differentiate between heaven and Tesco. This concept was very confusing for him so we kept it simple and honest and told him ‘Sally has died and won’t be coming home’. It appears very blunt but he needed the truth rather than introducing a concept that he wasn’t able to associate with. This point is probably more important in a multi-faith school where children could have opposing stories of what happens when you die. Keeping it simple and avoiding religious terms leaves this responsibility to the parents. Within the classroom the children needed to be told Sally had died and was no longer coming back, without the teachers’ religious beliefs influencing their message. It was very difficult but a consistent message needed to be maintained, since the children were in a state of high emotion and the world became very confusing.

In the weeks following Sally’s death her class friends created memory boxes and had group discussions talking about their feelings towards Sally and any emotions they were going through. Asking the children how they wanted to remember their friend made them part of the process.

After a hard day playing with my brother on the beach
The schools also came up with long-term memories. Sally’s primary school purchased a water feature which reflected Sally’s enjoyment of water play. Her secondary school held a ‘Mischievous Day’ (mischief being one of Sally’s main traits), when anything could happen, including having Christmas dinner in July and a snow machine. Teachers wore their clothes inside out; there were circus skills and a visit from a ‘bug man’. Children wore boxes on their heads and let off balloons at the end of the day whilst saying a few words about Sally. We were invited to take part, with Joshua also being encouraged to talk about Sally. Some of Sally’s friends wanted to talk to us and talk about Sally, which was nice for all of us. The teachers talked to us about what they had done with Sally and produced pieces of her work along with photographs we had never seen before.

Parents do want the school to remember their child and, in addition to the above, the secondary school created a memory garden where we were invited to plant a tree with her friends.

Family fun time with a bit of adrenalin thrown in!

All these acts showed the children it was OK to talk about someone who has died, to talk about the good times with their friend and to show emotion. We felt that this was especially important for boys, as society does tend to encourage suppression of emotion in boys.

To conclude, the main points we want to share are:

- Communicate. Don’t shy away from talking to the parents, however difficult you feel it is, as you can’t avoid them forever. Talk about the positives and share memories.
- Please talk about the child with family, friends and class friends as this allows the emotions to come to the surface.
- Create a memory board for the funeral, put together by their class friends.
- Hold some special event to remember the child and invite the family.
- Grief takes time and everyone reacts in their own way, so don’t get upset if you don’t get the reaction you expect.

Sally’s parents Tracy and David Creighton are fully involved in the special needs community and are parents of Sally’s brother Joshua, who also has a rare chromosome disorder which manifests itself as a severe learning disability. Both are founding members of the ABC Family group, a special needs support group, www.ABCFamilyGroup.com, which provides a regular weekend play session for young children along with an evening youth group for the older children. Tracy works as a Senior Teaching Assistant in a local special needs primary school specialising in the education of children with PMLD, and David is the head of an IT Department. Both Tracy and David have provided their children with a full and rich life with regular trips out and holidays. They believe in living life to the full with no limits on what children with special needs can do. They have often been seen pushing beach wheelchairs, climbing hills with off-road wheelchairs, caravanning, and making regular trips to the theatre, museums and local restaurants with their children.

Tracy and David can be contacted at info@abcfamilygroup.com

‘All these acts showed the children it was OK to talk about someone who has died, to talk about the good times with their friend and to show emotion.’
Introduction

Even within our schools that provide for pupils working at pre-national curriculum levels, teachers who work with pupils with profound and multiple learning difficulties can often feel isolated, lacking the professional support of practitioners who understand the daily challenges of teaching such a specialised curriculum and population. This article describes how a group of teachers from a county special school network have established and embedded outstanding collaborative practice that has had long-term benefits for both the teachers and the pupils with profound and multiple learning difficulties within their schools.

Recent collaboration

Over recent years the network has changed its emphasis with a stronger purpose to build knowledge, skills and quality collaboration within the network itself. With this re-launch has arisen a new name, SPAN, which stands for SLD, PMLD and Autistic Network. Action research has become prominent, with the research co-ordinators group becoming a catalyst to promote and embed teacher-led enquiry in their own schools. Focus groups are encouraged to continue to research and test new ideas ensuring any discoveries are shared with colleagues through the network. Project questions, research tools and project results have become increasingly relevant and reliable with the help of a recent two-year programme of support led by Barry Carpenter. The research model, ‘The accessible research cycle’ has become the mainstay literature on the bookshelf of every research co-ordinator in the network (Jones, Whitehouse and Egerton, 2012). This has led to a new enthusiasm to embed research findings into practice and to ensure these are shared with others. A few of the more topical areas currently being researched include the impact of sensory diets on pupil engagement, the impact of iPad use on pupil progress and the effect of low birth weight and prematurity on long-term development. Focus groups use findings from the research to ensure practical measures are introduced and impact embedded. For example the iPad/ICT focus group may identify and share useful educational apps for use in class, while the sensory integration group may share knowledge of appropriate equipment to use and how to use it within a specified sensory diet.

The PMLD focus group

Unlike the other focus groups that are formulated for a specific time period the PMLD focus group has had a long-term shelf life and continues to play a major role.
within the SPAN network. Over the last ten years we have observed a continuing increase in the PMLD population in our schools and are often presented with children who would be considered to be in the new category of complex learning difficulty and disability (CLDD) and who are described by the Specialist Schools and Academies Trust as presenting a ‘pedagogical challenge’ (Carpenter, 2010). Traditional skills-based learning can be an effective tool for a learner with severe learning difficulties, but for children with higher-level cognitive needs this instructional approach has little impact on learning. A process-based model, advocated by research practitioners such as Hewett and Nind (1998) and Imray and Hinchcliffe (2012), provides a more holistic ideal where the student is placed at the centre of their learning and the pace and direction of the teaching is guided by the learner. This approach followed by many PMLD teachers in the SPAN network may seem simple to an observer but as practitioners presents us with many challenges, not least the need to provide a personalised curriculum for each child based on a deep knowledge of the student’s strengths, barriers and motivations. The PMLD focus group have become successful collaborative practitioners because they ensure the needs of their learners are at the centre of their group philosophy. Each member comes willing to engage with others and share equipment, research and strategies that have been successful. They are equally willing to share frustrations and barriers to learning and it is in searching for solutions to these that the group have produced some of their most effective shared approaches. In seeking to move from a largely standardised curriculum to a profoundly personalised one, the teachers within the network have used the PMLD focus group as a place to draw on advice and support from colleagues as they seek to engage in methodologies that have a real effect on the learning and quality of life of our unusual learners.

A PMLD focus group case study

Despite the efforts of many talented teachers and the pressure for pupil performance standardisation exerted by Ofsted, it is still not unusual for the parents of children with PMLD to question why a school is ‘wasting’ their child’s time teaching to P levels instead of addressing the things they feel make a difference to their child’s life (Aird, 2014). Many teachers within the focus group have asked this same question, especially when whole school progress and public decisions about the quality of provision are based purely on standardised hierarchical assessments that often bear no resemblance to the actual progress made by PMLD learners. We have all felt the pressure to teach a target that will move a child up to the next level rather than a skill that is emerging or motivating and therefore would be more readily achievable.

During a meeting on the topic of assessment and demonstrating progress for PMLD learners, Clifton Hill, one of the schools in the network, shared an Excel spreadsheet they had produced designed to demonstrate quantitative progress of students through the more scattered Routes for Learning Pathway (Welsh Assembly Government, 2006; see part (a) of Figure 1). The individual document for each pupil indicates a visual baseline and resulting progress showing how many of the 43 milestones have been achieved, and also the quality of each skill based on 5 sub-divided levels of attainment (beginning with an emerging skill where the student has encountered and responded through an observable behaviour up to a confirmed skill where the behaviour has been observed in a variety of contexts and with different people; see part (b) of Figure 1). The document has several clear advantages: (i) it is easy to complete; (ii) it automatically tallies a numerical and percentage score indicating quantitative progress through the assessment tool; (iii) it shows clearly the pattern of student progress (that whilst linear progress is not the norm that progress is most definitely being made).

Other schools in the network using the routes for learning assessment introduced the spreadsheet to their schools thereby multiplying its effectiveness to other teachers and PMLD learners. Evaluation discussions within the group outlined the relief of identifying emerging targets and matching workable teaching strategies whilst also having a tool to demonstrate the effectiveness of the teaching and learning taking place to any external inspection system.

In line with the original network aim this document has also been shared further afield with special schools up and down the country via the SLD forum, following a discussion on the forum regarding the difficulties encountered by teachers attempting to use the national P levels to demonstrate progress for PMLD learners (sld-forum@lists.education.gov.uk).

‘The group... have become successful collaborative practitioners because they ensure the needs of their learners are at the centre of their group philosophy.’
Figure 1: Middle school assessment profile

(a) Name ...............................................................
Baseline March 2013 35.8%
Cum % to date 52.1%

Instructions
- Enter student’s name, baseline month and year above
- Select date in cell when completed next level using list
- If date entered in error use delete key
or select correct date from drop down list

(b) Key to grades - E = encountered, En = engaged, G = gaining skills & understanding, M = mastered, C = confirmed

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Figure 1: Middle school assessment profile
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<td>Initiates actions to achieve desired result (exerting autonomy in a variety of contexts)</td>
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<td>Early problem solving – tries new strategies when old one fails</td>
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<td>Expresses preferences for items not present via symbolic means</td>
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<td>Shares attention</td>
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<td>Deliberately gains the attention of another person to satisfy a need</td>
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<td>21</td>
<td>Modifies action when repeating action does not work</td>
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<td>22</td>
<td>Communicates choice to attentive adult</td>
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<td>Selects from two or more items</td>
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<td>Does two different actions in sequence to get a reward</td>
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<td>Object permanence</td>
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<td>Initiates a social game</td>
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<td>Attracts attention</td>
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<td>28</td>
<td>Repeats an action when the first attempt was unsuccessful</td>
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**The SLD Experience**

*Summer 2014*
**Conclusion**

Well-organised, collaborative networks with a joint working ethos and aims can empower individual teachers and schools to share effective practice and research contributing to continuing professional development and improving provision for special needs learners. This is particularly true for pupils of teachers with PMLD who require a more specialised and distinctive approach. Collaborative practice in this instance can relieve feelings of professional isolation and engender joint practice that motivates and assists teachers to discover and utilise the most effective teaching, learning and assessment strategies for this unique pupil group.

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‘Well-organised, collaborative networks with a joint working ethos and aims can empower individual teachers and schools to share effective practice and research.’

**Sandy Turner** is Assistant Head Teacher at Clifton Hill School, Caterham. She has been teaching pupils with special needs for 26 years and is an advocate of personalised learning approaches. She aims to influence children to reach their potential by supporting teachers and classroom assistants to focus on effective learning strategies.

**Joanna Ciuksza** is a class teacher at Brooklands School, Reigate and works with a group of learners all of whom have profound and multiple learning difficulties. She aims to ensure that the children achieve their full potential and that they have a challenging, inclusive, relevant and fun education.

*If you would like more information about developing collaborative practice or any of the research topics or models mentioned in this article then contact:*

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Hydrotherapy: the benefits and challenges of current practice

Nicola Vann

What is hydrotherapy?
‘Aquatic therapy’ is a water-based therapy used by physiotherapists and occupational therapists which can be used to treat a wide variety of conditions. It is a useful therapy for treating children and adults with both physical and learning difficulties and has been utilised for many years. ‘Hydrotherapy’ has been recorded as far back as the ancient Egyptian, Persian and Roman civilizations as a treatment for sickness. Historically, it differs from aquatic therapy as it refers to a medical treatment rather than a physical therapy. However, in the present day the terms aquatic therapy and hydrotherapy have become interchangeable for the exercise-based water therapy that physiotherapists administer. For the purposes of this article the term hydrotherapy will be used.

The benefits of this therapy for many people with physical and learning disabilities are reported by parents, carers and patients, and therapists with experience in this field know the difference it can make to the quality of life and function in this client group. However, there is a lack of objective evidence in the form of clinical research to support its use. Unfortunately this lack of research has implications in an age where provision of a service is dependent on clinical evidence. For children and adults with physical disabilities such as cerebral palsy, hydrotherapy may be the only form of exercise they can access due to their restrictions in movement or in moving and handling difficulties which are possible to overcome in water. Hydrotherapy is often viewed as ‘a luxury treatment’ and therapists feel forced to prioritise patients whom they feel would benefit most when, in actual fact, the reality is that most children and adults with a disability may reap considerable benefits. The evidence which does exist is positive in supporting the hypothesis that hydrotherapy is an effective therapy. Fragala-Pinkham et al (2010) looked at the outcomes of a 14-week aquatic exercise programme for children with developmental disabilities and found significant improvements in their physical ability, not just in the water, but in their physical activity levels generally. These improvements carried over for more than six months after they had finished the programme.

Why hydrotherapy?
From a young age we learn that things appear less heavy in water. Water supports body weight which, for a person with a physical disability, can allow active movement that is not possible on land. In addition, water offers a resistance to movement which can be utilised to improve muscle strength. Therefore water is an extremely useful medium in which to carry out therapeutic programmes, but why is it so important to have a specialist hydrotherapy pool? Why can treatment not be delivered in public swimming baths if accessing a hydrotherapy pool is difficult? Some may argue that this would be a sensible compromise and for some young people and adults it may be just as appropriate. However, the fact which needs consideration is that the water temperature in a typical hydrotherapy pool is higher than a regular swimming pool, usually between 33°C and 36°C. The warmth of the water relaxes muscles allowing for an increased range of movement which may not be possible to achieve on land. It may also reduce pain, which is particularly beneficial in post-operative patients. Aside from the therapeutic benefits of warmer water there are general health implications to be considered. This is a client group with reduced mobility and slower movement patterns, and standard pool temperatures can feel extremely cold. Alongside this, many clients with neurological impairment have circulatory problems which may be exacerbated by cold water. If you were to put a person with sensory integration difficulties into cold water this may also be a problem and any potential therapeutic gains could be lost.

“Hydrotherapy” has been recorded as far back as the ancient Egyptian, Persian and Roman civilizations as a treatment for sickness.”
Hydrotherapy is not just important for clients with disabilities; it also has its place in the early stages of rehabilitation following orthopaedic surgery (Trees and Moss, 2013). Health spas advocate it for its generic health benefits such as detoxification, increasing metabolic rate and digestion, improving skin and muscle tone and boosting the immune system (for more information, see www.hydrotherapy.org.uk). These benefits are also important to all who access hydrotherapy and these health benefits are not gained in a regular swimming pool with uncomfortably low temperatures.

**Difficulties with accessing hydrotherapy**

One current difficulty in accessing hydrotherapy is the lack of available hydrotherapy pools. Special schools tend to have a pool on-site which can be accessed during term time by pupils at the school and some community groups may also have access to these pools. However, during school holidays the majority of these pools are closed and this limits availability and continuity in hydrotherapy.

An increasing number of private gyms have hydrotherapy pools on-site as hydrotherapy can be beneficial not just for people with a neurological disability but, as stated earlier, for people undergoing rehabilitation from orthopaedic surgery and sports injuries. These can often be hired out by the general public; however, this may be at a cost that is unrealistic to meet on a regular basis. Another setback is that they do not tend to have the hoisting and changing facilities that would be necessary for a large proportion of this client group.

Many hospital hydrotherapy pools have unfortunately had to close in the last few years due to lack of funding to maintain running and repairs, leading to many people being unable to access a hydrotherapy pool who would have been able to do so previously. You only have to type ‘hydrotherapy pool closure’ into a search engine to see article after article about yet another hydrotherapy pool which has had to close down. Another difficulty with the provision of hydrotherapy is the number of staff that are required in order to ensure safety. Some therapists run groups with parents in the pool handling their own child in order to increase the population size able to access this service.

**Conclusion**

In conclusion, experience and understanding of the therapeutic properties of water tell us that hydrotherapy would be beneficial to many people with varying degrees of disability. However, much of the evidence is purely subjective and in order for NHS guidelines to change to advocate hydrotherapy, more clinical research is needed. The research that has been undertaken suggests there may be long-term benefits for children with disabilities undergoing regular hydrotherapy programmes and that regular hydrotherapy may reduce the need for surgical intervention and speed up recovery times. These examples suggest that there could be both health and financial benefits from making hydrotherapy more accessible.

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‘The research... suggests there may be long-term benefits for children with disabilities undergoing regular hydrotherapy programmes...’
Nicola Vann is a Paediatric Physiotherapist working at Neurological Physiotherapy in Stockport, and Park Lane School in Macclesfield. She qualified at Keele University in 2002 and has a specialist interest in cerebral palsy. She can be contacted at info@neurologicalphysiotherapy.co.uk

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www.halliwick.org.uk/downloads/HASTInfoLeaflet05.pdf

www.hydrotherapy.org.uk
MOVE Partnership at Wyvern Academy

Sue Marshall, with support from Dianne Rickard and Nigel Carter

Introduction to MOVE
The MOVE Partnership is a small UK-based charity aiming to provide severely disabled children with the opportunity for independent movement.

MOVE is an innovative programme that combines expertise from therapy and education with the personal knowledge and wishes of the individual and their family. It aims to effectively teach functional skills to children and adults with physical disabilities and complex needs. The increased movement and function allows greater access to learning and independence, promoting equality and inclusion.

The MOVE Programme was originally written for children in special schools, many of whom had profound and multiple disabilities, but now is available to children in Early Years settings, mainstream schools and adult services. The programme reaches far and wide and is used in many countries throughout the world.

MOVE was developed in the mid-1980s by a special education teacher in California who felt that the current education system was not meeting the needs of children and young people with complex needs. Non-ambulant children were leaving education with fewer skills than they entered with, so she set about identifying the challenges which were standing in the way of continued physical development for this group of young people. Time constraints, rate of learning and difficulty generalising skills were generally felt to be obstacles to skill acquisition. She went on to develop the MOVE Programme which addresses these difficulties and advocates teaching through routine activities with regular opportunities for meaningful practice in varied situations. The benefits are clear to see: increased mobility and function has a huge impact on the lives of our children and young people. The impact is life-changing, not only for the individual but for the family, carers and society as a whole.

Since then, many studies have shown the benefits of MOVE and research supports all the underlying principles of the MOVE Programme.

Initially set up in the UK as The Prince of Wales’ Advisory Group on Disability, The Disability Partnership, as it was originally known, became MOVE Europe (an independent charity) in June 1997, concentrating on developing the MOVE Programme in Europe. In 2012 The MOVE Partnership was formed, reflecting its wider remit and uptake of the MOVE Programme.

MOVE provides a framework for cross-agency collaboration; it integrates teaching, therapy, care and nursing skills to gain maximum effect in working with the young person and their family towards their personal goals. MOVE is a systematic approach where participants practise motor skills whilst engaged in everyday activities.

The MOVE Programme is composed of six stages:
- assessment
- goal setting
- task analysis
- measurement of prompts
- reduction of prompts
- teaching the skills

MOVE Partnership at Wyvern Academy

Introduction
Wyvern Academy is a purpose-built school for children and young people aged between 3 and 19 years with severe and complex learning needs, including autism, physical disabilities and medical needs. All of the children and young people attending Wyvern Academy have a statement of special educational needs. Wyvern Academy is a Centre of Excellence for the MOVE programme and is the only school within the region to deliver the programme. Wyvern Academy is committed to the MOVE Programme; the school has an effective MOVE team and this team consists of a MOVE Coordinator, two MOVE trainers and 32 MOVE practitioners. The MOVE Programme is delivered across the school from early years through to our young people...
in the sixth form. MOVE is at the heart of our organisation and as such is always on the agenda at transition meetings, person centred reviews, parents’ evenings and other multi-agency meetings. The MOVE Programme is fully integrated into the ethos of Wyvern Academy; MOVE goals are included in lesson plans and written into the child or young person’s IEP. Each participant on the programme has individualised goals. Each goal is linked to a practical activity and critical skill and the development of such skills is built into the participant’s daily routine.

**MOVE Centre**

Wyvern Academy is a designated MOVE centre where some of the children and young people begin their journey, acquiring new skills necessary to achieve their personal goals. Here they can practise in a quiet environment before using their newly-acquired skills functionally throughout the day. To aid the teaching of functional mobility skills, the centre has specific equipment such as slopes, variable height steps and even a mechanical therapy horse.

**Assessment**

An initial assessment will involve the child’s parents/carers, the child or young person entering the programme, their class teacher and teaching assistant, the MOVE coordinator, their physiotherapist and, if necessary, their paediatric consultant. During the assessment the child or young person is given every opportunity to be involved and contribute to the process. Appropriate resources and communication systems are provided to support equal opportunities and inclusion.

Parents, carers and families as a whole often feel that they work in isolation; they do not have a team around them to support new interventions and programmes and are lacking in training, confidence and equipment. However, through the MOVE Programme the child and family feel empowered and take ownership of the programme supported by a collaborative team and creating greater potential for progress and achievement. Natural opportunities for practise occur at the start and end of the day, such as getting up and out of bed, transfers, standing, washing, dressing and eating.

**Access to learning**

Children and young people with a physical disability are unable to access their learning in the same way as an able-bodied child; a child with a physical disability is more reliant on someone facilitating their movement and providing opportunities for learning. A child with movement can initiate their own interest; they can choose to lean forward and reach for their snack or drink, they can stand and reach for something on a shelf or walk across the room to get a book, making choices to meet their own needs and desires.

**Goal activities**

Goal activities are designed to be meaningful and motivate. They must have a purpose and outcome such as taking the register to the office, while being supported in a prompted walker. Another goal activity might be to stand and clean your teeth or transfer from a wheelchair onto a conventional chair for lunch. Goal activities promote health, function and sociability; they also develop communication, inclusion and independence. Movement and change of position is essential for good health, minimising the potential for fixed contractures, chest infections, digestive problems and pressure sores.

**Opportunities to practise the skill**

It is essential that skills are practised throughout the day and within a variety of contexts, including school, home and respite care. For children and young people with significant physical disabilities learning a new critical skill can be a huge challenge; for example, the skill of holding the head in an upright position long enough to make eye contact with someone, or being able to move while sitting so that an object can be reached and explored. When the participant is fluent in the skill it is then generalised into a variety of situations and environments, within the local community and into the wider society.

**Therapy services**

The support and guidance provided by the therapy service is invaluable to the professional development of staff and the physical and postural development of our children and young people. We work in close partnership with the therapists ensuring that the needs of the children are met.

**Wheelchair service**

The academy supports and facilitates regular wheelchair clinics; our involvement in this process allows us to make recommendations with regard to the design and flexibility of the wheelchair. Our input is essential
in supporting the delivery of the MOVE Programme, particularly when needing to adjust or remove prompts during the teaching and acquisition stage. A wheelchair prompt could be a head rest, chest support, lap strap, or foot straps. Having the flexibility to adjust or remove such prompts provides opportunity for teaching.

**Manual handling**
Wyvern Academy has a Manual Handling Advisor providing the necessary training for all staff. Manual handling supports the safe delivery of the MOVE Programme and enhances good practice, ensuring that health and safety is at the centre of all movement. Manual handling risk assessments are completed for all activities; outlining the task, individual capabilities, operational movement and environmental hazards. Approved manual handling resources are also beneficial in supporting the acquisition of skills.

**Cognition and learning**
Wyvern Academy has embraced the MOVE Programme and embedded its principles into effective and inclusive teaching practice. MOVE has enhanced our teaching and learning; our approach is now more holistic and centres on the theory that movement is an essential prerequisite for learning. Wyvern is currently monitoring the children and young people on the programme with regard to cognition and learning, demonstrating the correlation between increased mobility, access to learning and achievement. Children and young people on the programme appear more actively engaged and more motivated to learn. With movement there is equality of opportunity and a sense of achievement.

**Case study**
**Mitchel, 13 (attends Wyvern Academy)**
Mitchel is 13 years old and has cerebral palsy. Mitchel is a very sociable young person. He enjoys watching football, going on holiday, eating out and playing in the garden with his sister. The cerebral palsy has affected function and control within his arms and legs, ultimately inhibiting the ability to stand and walk. Before he started on the MOVE Programme 18 months ago, Mitchel was unable to stand, apart from in his standing frame, and his family had no specific plan on how to achieve their goal of helping him to walk. He would spend the majority of his time sitting in his powered wheelchair which, amongst other things, caused him some constipation and digestion issues.

At the beginning, Mitchel lacked motivation and self-belief; he was reluctant to challenge himself and push the boundaries.

Once Mitchel started on MOVE it was identified that his opportunities to stand must be increased in order for him to gain the strength and confidence in his legs that would help him towards his goal of walking. To begin to achieve this, a fully supportive walker was provided and opportunities for him to use it were built into his daily routine, for example, walking down to the kitchen to see what was for lunch. Photo 1 shows that Mitchel has developed his standing and walking skills in a prompted walker. He began with small steps and short distances but now is able to take himself to the front office and down to the hall for assembly.

Mitchel’s family noticed that just by being active in an upright position, even for short periods, his digestion and constipation improved. Also, as he was being encouraged to be more active and use his legs more, his frustration levels dropped and his muscles began to develop some strength. Over time and with regular access to the walker, Mitchel’s range of movement within his legs and feet improved, providing a much stronger platform for standing and walking.

Little by little and with lots of hard work and determination Mitchel’s confidence and capability grew to the extent that he could take over a hundred steps in his walker. Mitchel developed a confident approach to his walking; building confidence and momentum to the point where he sometimes appeared to be
running. Mitchel then began taking his walker outside in the playground and on one occasion he became over confident and almost ended up in the hedge, much to Mitchel’s amusement. As would be expected, this has greatly improved his self-esteem and sense of achievement; he is proud of his ability to stand and walk.

How have things changed for Mitchel? He loves to challenge himself, setting new goals, exploring how far he can walk and what activities he can achieve in the walker. In hydrotherapy Mitchel has made fantastic progress. He is more confident, more coordinated and much stronger; with flotation aids he is able to kick his legs and swim across the pool. He practises standing and walking and will plunge his head under the water. His new-found confidence has led to a lovely story: last summer. Mitchel was standing in the garden in his walker supposedly using a hosepipe to water the flowers, but instead he sprayed his family, including the dog. ‘We wouldn’t usually allow him to use the hosepipe in case he got the controls of the powered wheelchair wet – but getting a walker wet isn’t too bad so we let him have a go – our mistake!’ How often can this group of children be mischievous?

Mitchel has achieved a great deal since starting the MOVE Programme, not only in his physical ability but in his attitude to life. He is more willing to try; he will challenge himself and he is determined to live his life to the full. Mitchel now has access to a trike and enjoys riding it within school and outside in the playground. Mitchel is very excited about this and extremely motivated. Access to a trike provides lots of opportunities with regard to exercise, outdoor environment, social interaction and sensory experiences and even more independence. Photo 3 shows Mitchel practising riding a trike in the school hall.

‘Mitchel is happy that he has choices now rather than just sitting in his chair.’

Mitchel on his trike

One of Mitchel’s goals was to ride a trike with his sister in the garden. Mitchel is now able to ride from one end of the school to the other and also enjoys riding around the campus. The trike has further developed his strength and muscle tone, supporting mobility and independence.

Sue Marshall works at Wyvern Academy (MOVE Centre of Excellence) as the Health, Safety and Manual Handling Advisor and MOVE Coordinator. She began work at Wyvern Academy in 1992 and has worked across all ages and abilities, delivering a variety of programmes and interventions. She has a special interest in supporting children and young people with profound and multiple learning disabilities; working to develop their movement, their access to learning and their health and independence. Sue completed a post-registration course in Moving and Handling at Southampton University in July 2002. In March 2010 she trained as a Move Practitioner and then in November 2012 qualified as a MOVE Trainer.

Sue Marshall can be contacted by email at smarshall@wyvern.dorset.sch.uk

Dianne Rickard and Nigel Carter are respectively Director and Chief Executive of MOVE

Mitchel in the hydrotherapy pool

Photo 2 shows Mitchel in the hydrotherapy pool, where he is encouraged to propel himself through the water and stand at the steps. Practising standing is crucial to his next goal; he wants to be able to stand long enough to transfer from his wheelchair onto a fairground ride.

His new-found mobility is helping him to explore and enjoy his surroundings and also gives him access to a variety of activities. This has of course made changes to his home life. Mitchel’s mum, Tina, commented, ‘We have made our home and garden more accessible. Mitchel is happy that he has choices now rather than just sitting in his chair. He uses his walker mainly at school, but has it at home for holidays, which is really nice for him.’
Review

_Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives_
Edited by Barry Carpenter, Carolyn Blackburn and Jo Egerton (2013)

Routledge £34.99 360 pages
(Also available as an e-book)

‘Articulating fundamental knowledge, cutting edge initiatives and emerging trends in FASDs, this book provides an evidence base that will enable services to identify and respond to the need for action on FASDs.’

This quote from the blurb represents the book’s contents well. While awareness of FASDs is increasing, there is still little discussion of the impact of alcohol use by pregnant mothers in society beyond the recommendation that they should not drink. Given that this message has patently not ended the use of alcohol by expectant mothers, work to support children with FASDs and their parents is still essential.

This book brings together writings from a range of well-known authors and professionals within this field, which are carefully divided into easy-to-follow sections. Each section is aimed at one of the book’s two main audiences: families and professionals. For families, following a broad overview of what FASDs are and a description of current drinking behaviours among women in the UK, this book goes on to present useful information concerning the impact of FASDs on parenting and education for children and young people. In these areas, one of the book’s strengths is the attention to children’s developing needs across the age range from birth to adulthood. For professionals, the book offers inter-disciplinary perspectives ranging from medicine to criminology, neuropsychology and social care. This is augmented by a section considering international perspectives on FASDs.

For practitioners, this book gives an excellent perspective on the difficulties faced by children with FASDs both in terms of their general development and specifically in education. One of the strengths of the book is that its focus is evenly distributed across the lifespan with particular attention paid to issues of transition to adulthood and independence. This recognises the importance of beginning support early in order to give young people the skills to develop into adulthood and clearly outlines the kinds of milestones set for children with FASDs that might be useful for practitioners. The book also considers the wide range of practitioners who work with children and young people with FASDs, giving a clear insight into the roles of individual professionals and agencies in supporting these children.

As a lecturer, I would encourage undergraduate students to use the wide range of useful texts in this book in exploring ideas related to the impact of substance abuse and working with children with FASDs. In particular, the section concerning international perspectives clearly highlights the differences in prevalence of FASDs in different areas as well as the policies employed to combat this. However, the nations chosen are not as diverse as they might be and the focus is predominantly on the ‘Western World’ and developed countries. I was hopeful this section would focus more on differences in cultural attitudes towards alcohol, FASDs and drinking during pregnancy, which would have been an interesting aspect to consider in discussing the diverse needs of children with FASDs and their families.

The book is written in a style which is aimed more at practitioners than families. The academic tone could be discouraging to families looking for friendly support and guidance. The emphasis is on general rather than personal issues on the whole, although at least one chapter is written from the point of view of parents and describes their experiences of caring for children with FASDs. While parents looking for initial information concerning FASDs may well find this chapter is a very useful comparison point for their own experiences, I wouldn’t recommend the book as a tool for supporting families. However, for people who are searching for a deeper understanding of the professional and political issues concerning FASDs, this book gives a comprehensive overview.

Nia Young is a lecturer on the BA Childhood Studies at Bangor University.
**Review**

*Teaching and Learning in the Early Years*

Susan Fowler, Michaelene Ostrosky and Tweety J. Yates (2014)

Chapter 36 in *The Sage Handbook of Special Education*

ISBN: 0781446210536

Two volume set (1041 pages):

SAGE £260 (Also available as an e-book)

This article reviews Chapter 36 from *The Sage Handbook of Special Education* (2014) by Fowler, Ostrosky and Yates. This chapter concerns the inclusion, teaching and learning of children in the early years. This review will highlight examples of overlapping and divergent theory and practice between the picture given in the chapter and Welsh schools, taken from my recent experience as an early years teacher, and will raise questions about the future of early years inclusion in Wales. How well does this chapter represent real life in Welsh schools?

It is clear from reading this chapter that the authors have attempted to weld together common movements within education to create an international consensus on the inclusive movement and special educational needs (SEN) in early years education. However, while some seeds have been sown in Wales, the authors’ portrait of SEN service provision is not quite a reality in Wales as yet. Indeed, as a Welsh practitioner, it is not very clear how we fit into this picture of inclusion within the early years. The authors make reference to the ‘UK’ SEN Code of Practice, showing limited understanding of the devolved powers in the UK in terms of SEN legislation. Readers are also unable to clarify their meaning of a UK SEN Code of Practice, as the web link the authors provide appears to be broken.

The authors discuss generally accepted views of early years education that have a lot of relevance to Welsh teachers, such as the significant role of play in developing language, as well as the appreciation that the goal of early years education should be to develop confidence and a love of learning. Likewise, child-initiated learning is one of the cornerstones of the Foundation Phase in Wales and it is interesting to see this topic discussed in relation to developing inclusion for SEN pupils. The authors also mention the crucial role of observations for assessment in the early years, ensuring observations are conducted in multiple settings to ensure reliability. This is particularly relevant to practitioners as Wales has yet to introduce a national strategy for assessment within the early years. The omission of the role of teaching assistants (TAs) in early years education is a little confusing considering the great shift of the last decade towards using TAs as a strategy to include pupils within mainstream schools.

The authors take a great deal of time to emphasise family services strategies within SEN provision which have great relevance to some early years professionals within Wales. An example of this would be the Flying Start programme in Wales. Flying Start has been operational throughout all local authorities in Wales since 2007–8 and aims to be a complete family service with effective communication between Flying Start health visitors and child care providers, whilst also providing parenting support for parents and early language development (Morris and Willis, 2013). However, whilst this is a good example of Wales moving into family-oriented approaches within early years services, their role is to support families within socially deprived areas and therefore would not cover all children with SEN in early years provision in Wales. Despite this, a final report to the Welsh Assembly by Morris and Willis (2013) on the impact of the Flying Start programme in Wales, argues that this shared approach has led to more effective referral of young children, including services within Flying Start and outside agencies, such as the Speech and Language Therapy service and the Behaviour Support service. It could be inferred that this is the kind of approach the Welsh Government is currently committed to.

Similarly, the emphasis on child services working as a team is very consistent with how Wales intends to develop SEN policy in the future. The Welsh Government (2012) has outlined its intentions for a multi-disciplinary approach that involves a full partnership between education, health and social services. As such Wales hopes to achieve a more person-centred perspective, covering children and young adults from 0–25 years, with families deciding the SEN provision they would like to prioritise (Welsh Government, 2012). However, while the response to these proposals has been mostly positive in Wales, there is only a loose commitment to have draft legislation prepared before the end of
the current Welsh Assembly term (Welsh Government, 2013) with the consequence that the development of ‘joined up’ multi-disciplinary practice in Wales has still some way to go.

However, contrary to the authors’ somewhat optimistic view of engaging with SEN services in the early years, my personal experience has always been slightly different. Unless SEN services are engaged through the family doctor at the request of the parents, it seems unlikely that services can be accessed through the school until the child reaches the age of five. For many children with birthdays later in the school year, this means that services are unlikely to be accessed until they have left the early years and are in year one. Whilst working as a teacher in a nursery setting, I had concerns that a four-year-old girl was missing opportunities to engage effectively with adults and peers in class due to her unclear speech. However, I was informed that there was nothing I could do to get speech and language support for the pupil other than to recommend a speech support centre to the child’s parents. The recommendation was not taken up and the child did not access support.

It should also be noted that early years staff are often the first professionals to have regular contact with these very young children and indeed there are instances when even more obvious signs of need have not been identified by parents or health visitors previously in the child’s life. I was surprised to find such a scenario when a young boy started in my reception class with very clear signs of Autistic Spectrum Disorder (ASD). Even more surprising was that the nursery the child had attended the previous year had failed to identify the child’s needs. Indeed, it sometimes seems irrelevant for early years professionals to be trained in the identification of SEN since they are unable to do anything about it in school until the child is older.

In conclusion, due to the enormity of the task the authors have attempted, the chapter is perhaps overly simplified and at times, excessively optimistic about current practices internationally. For me, as an early years teacher in Wales, the authors’ work represents where Wales is hopefully heading, but is in no way an indication of our current practices. For now, all early years teachers can do is monitor their pupils, discuss their concerns with parents and then wait, frustrated, until the child turns five.

Christopher Williams has been a primary school teacher for six years working within north-east Wales. He is currently employed as an Early Years teacher in Flintshire and is working towards a Master’s in Education Studies at Bangor University.

References
The self-advocacy movement affirms the right of all individuals with learning difficulties and disabilities (LDDs) to enjoy the same basic human rights as their fellow citizens (Mittler, 1996). Core components of self-advocacy include being able to express thoughts and feelings and being able to make choices and take decisions (Further Education Unit, 1990). Accordingly, what has been termed ‘inclusive research’ practices (see Walmsley, 2001; 2004) are increasingly being advocated and ways of ‘hearing the voices’ of children and young people with LDDs are being sought (see, for example, Lewis, 2002; Porter, 2009; Nind and Vinha, 2012; Haigh et al, 2013). However, eliciting the views of individuals with more complex needs, including those on the autism spectrum, can be challenging.

In the paper Gaining views from pupils with autism about their participation in drama classes Daisy Loyd describes how interview approaches were devised to enable pupils with autism to give their views about their participation in drama classes. The approach described formed part of a larger study that aimed to identify outcomes for pupils with autism from participation in drama education and to examine relevant teaching approaches that facilitated these outcomes (Loyd, 2013). The outcomes focused on in the larger study were interaction and communication with other people as well as engagement in make-believe.

The participants were ten pupils aged 16–18 years attending a further education unit within a special school for children and young people with autism spectrum disorders (ASD). Six of the pupils were female and four were male. Four pupils used verbal language as their main mode of communication; four used occasional words but were predominantly non-verbal and two did not use verbal language to communicate.

Pupils were observed over a 34-week period. Interviews with the pupils were carried out during week 17; this gave the researcher (Loyd) time to observe each pupil and see how he/she communicated in a variety of contexts; it also enabled the pupils to become familiar with the researcher. Advice and support was also sought from the pupils’ teachers, the school speech and language therapist and the school psychologist.

Loyd describes the interview approach as ‘multimodal’; this enabled the pupils to access interview questions in different ways and allowed them to respond in their preferred ways. Examples given of the different ways in which the pupils chose to respond were verbally in single words or sentences, or by pointing to symbols or pictures. This multimodal approach allowed all the pupils to be asked the same questions but also incorporated flexibility for the pupils to expand on their answers if they wished.

All interviews were carried out on an individual basis and were conducted in a quiet room in the further education unit. Prior to the interviews the purpose of them was explained to the pupil and he/she was asked by his/her teacher if he/she agreed to be interviewed. In the quiet room the pupil was given a choice of where he/she preferred to sit and was asked if he/she was happy to be video-recorded. All pupils agreed. The process of the interview was explained and the pupil was told he/she could leave the room at any time. A ‘stop’ card was also introduced for the pupil’s use if he/she chose. Pupils were given time to respond to each question and had the option not to respond. The pupil’s response was repeated to the pupil to confirm the answer.

The interview approach had four parts, and there were a total of 16 core questions. For the first part pupils were asked seven questions about their likes and dislikes in school, likes and dislikes in drama and performances and feelings about performances. Widgit symbols that the pupils were familiar with were used (Detheridge et al, 2002) and topics, options and feelings were investigated. Questions were put into a sentence format and three options were offered to complete the sentences. For example, ‘I like...’ with options ‘work experience’, ‘drama’, ‘computer’.

‘Loyd describes how interview approaches were devised to enable pupils with autism to give their views about their participation in drama classes.’
The second part of the interview approach involved five questions using photographs. The pupil was given three photographs of him/herself in drama and asked to describe what was happening and then to choose his/her favourite and least favourite picture from the three options. For example, ‘Tell me what is happening in this picture? Fran is...’ If verbal communication was not the main way of communicating or where prompting was needed, symbols linked to the activity in the photograph were placed near to the photographs for the pupil to choose by pointing. As a way of enhancing trustworthiness of responses some of the questions covered in the first part of the interview were also covered in the second part.

The third part of the interview approach used video. Each pupil was asked to watch a two-minute video of him/herself in drama and was asked what was happening and who he/she was with. Where verbal communicating was not the main way of communicating or where prompting was needed, words and symbols linked to the activity were placed near to the computer for the pupil to choose by pointing. The video was repeated if the pupil wanted to watch it again.

An aspect of the main study was to investigate the influence of social context on the pupils’ perspective-taking abilities. The fourth part of the interview therefore involved two theory-of-mind (ToM) tests (the ‘Sally-Anne’ test, Baron-Cohen et al, 1985 and the ‘Smarties’ test, Perner et al, 1989), comparing pupils’ abilities to recognise themselves and know what others thought about them in drama and performances and in other curricular areas.

The findings indicated that the pupils enjoyed drama: six of the ten pupils identified drama as being the activity they most enjoyed from a list of activities. All pupils could identify what they did in drama and performances, what parts of the sessions they most and least enjoyed and could reflect on performances in which they had been involved. Pupils were also able to describe how they felt about drama sessions and performances: ‘happy’, ‘not nervous, excited’, ‘proud’, ‘psyched up and ready to go’.

In addition, all pupils volunteered to add further information about their participation in drama through extended responses to questions, comments about photographs or video footage and requests to see photographs or video footage again.

Four pupils demonstrated that working with their peers was an important part of drama. Six pupils could talk about the make-believe elements of drama and showed awareness of playing a role:

‘... the customer was having her breakfast and the waiter, which was me, was, well, sleepy, yeah...’

(Ben, showing awareness of playing the role of a waiter)

Some pupils could also show awareness that they were going to perform in front of people and that their performance would have an impact on others:

‘... I made people laugh. They think I’m funny.’

(Clare, describing her performance in Alice in Wonderland)

For two of the pupils their demonstrations of the ability to recognise that their performance could evoke feelings in others contrasted with their findings from the experimental ToM tests. Loyd suggests that, when considered alongside other sources of data gathered during the study, these findings in relation to ToM support the view that experimental tests of ToM may not accurately reflect an individual’s perspective-taking ability in real-world social contexts.

Reflecting on the interview approach, whilst acknowledging that the approach had limitations (eg pupils who had more difficulty communicating verbally required questions to be repeated as well as prompting), Loyd nevertheless considers that the different modes of communication (eg symbols, photographs and video footage) enabled the pupils to participate in all parts of the interview. Pupil responses, she notes, were not dissimilar to those of typical peers. She concludes:

‘This point serves as a reminder for practitioners to not be constrained by the labels that may define their pupils and, instead, be freed to use pupil views to enhance how they can work meaningfully with them.’

This is a very carefully conducted study, of theoretical and practical relevance, which makes a significant contribution to the growing body of research which aims to find...
ways of eliciting the views of ‘hard-to-reach’ individuals. Loyd’s hope is that sharing her experience will be useful for others working in the field: my view is that indeed it will.

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

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Walmsley, J (2001) Normalisation, emancipatory research and learning disability Disability and Society, 16 (2), 187–205

Books and Resources

Grace, J
Sensory Stories for Children and Teens with Special Educational Needs
A Practical Guide

Sensory Stories are short stories of a few lines which are brought to life through a selection of meaningful sensory experiences. For students with PMLD, Sensory Stories can open up new avenues for communication and inclusive learning. For students with SPD and ASD, they offer a fun way of encountering sensory experiences and triggers in a safe, repetitive way, which over time can help to reduce associated anxieties. This accessible guide offers teachers, other professionals working with students with SEN and parents a complete step-by-step guide to creating and using Sensory Stories effectively. Aiming to make Sensory Stories affordable and accessible to schools and parents alike by using everyday items found in the classroom and home, Joanna Grace provides original, ready-to-use Sensory Stories with accompanying lesson plans, games and activities and adaptations for different abilities and diagnoses. Written by an experienced SEN consultant and sensory learning specialist, this is unique and essential reading for teachers, other professionals and parents wishing to introduce the many benefits of multi-sensory storytelling to children in their care.

Available October 2014 £19.99
Jessica Kingsley Publishers
ISBN: 978-1-84905-484-3
Tel: 020 78332307
Email: hello@jkp.com

Chapman, R, Townson, L and Ledger, S (eds) with Docherty, D
Sexuality and Relationships in the Lives of People with Intellectual Disabilities
Standing in My Shoes

Drawing extensively on personal experiences, this important volume looks at sexuality and relationships in the lives of people with intellectual disabilities, painting a genuine picture of the range of sexualities and relationships people want. Honest and reflective, it shows how sexuality has been managed and controlled in different countries. It explores a range of issues such as rights, resilience, protection, sexual oppression and the lack of privacy for those living in care institutions. Co-edited and with contributions by people with intellectual disabilities and allies, this unique book offers an authentic account of the challenges people face and what society needs to do to respect people’s rights. Providing insight into a morally, ethically and legally complex area, this book provides support for teachers concerned with this area, and other professionals working in the field as well as academic researchers and students.

Available October 2014 £25
Jessica Kingsley Publishers
ISBN: 978-1-84905-250-4
Tel: 020 78332307
Email: hello@jkp.com

Franklin, S with Sanderson, H
Personalisation in Practice: Supporting Young People with Disabilities through the Transition to Adulthood

This book demonstrates very clearly how the personalisation of support and services works in practice. The authors describe how Jennie, a young person with autism and learning difficulties, was supported through the transition from school to living independently using simple, evidence-based person centred planning tools. Jennie’s story illustrates the importance of quality person centred reviews, dispels the many myths surrounding Individual Service Funds and personal budgets and demonstrates how families, schools and other agencies can work collaboratively to help young people with disabilities move into adulthood with more choice and control over their lives, and with better life prospects. Practical pointers for readers to apply to their own circumstances are included, and the book contains helpful examples of the key person centred thinking tools. Anyone involved in supporting children and young people with disabilities as they approach adulthood will find this book a useful resource.

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**Free apps designed for people with severe learning difficulties**
A father has developed a selection of free, fun and educational iPad apps, designed especially for his son, who has severe learning difficulties. The apps are now available in the Apple app store for anyone to download, completely free of charge. The apps engage users in activities such as matching pictures, spotting numbers and drawing lines.

Ellis Business Services
http://bit.ly/1gu1Ai7

**Articles**
Arellano, A and Peralta, F

**Self-determination of young children with intellectual disability: understanding parents’ perspectives**

Self-determination is considered to be a basic human right which, to develop, demands contextual opportunities as well as individual competencies. For people with intellectual and developmental disabilities, the family is the natural support environment in the task of increasing control over their own lives. There is little, however, that has been published in Spain on the needs and strengths of families in this regard. This article presents a study carried out in Spain on the knowledge, attitudes and strategies that a sample group of parents (N = 201) have regarding self-determination. An analysis of the data gathered highlights the need for intervention proposals to prepare parents to further their children’s self-determination, through collaborative partnerships and through cognitive restructuring.

British Journal of Special Education 40 (4), 175–181, December 2013
http://bit.ly/1hKhKst
New Cerebra guide on transition

Cerebra, the charity for children with neurological conditions, has just published a new guide for parents and carers on Transition to Adulthood which aims to help parents of young people with disabilities and/or special educational needs manage their child’s transition into adulthood so that the social care, education and health needs of their child are met and sustained throughout this process and into the young person’s adult life.


Nowicki, A E et al
Children’s thoughts on the social exclusion of peers with intellectual or learning disabilities

Previous research has shown that children with intellectual or learning disabilities are at risk for social exclusion by their peers but little is known of children’s views on this topic. In this study, the authors used concept mapping to investigate elementary school children’s thoughts on why they believe their peers with intellectual or learning disabilities are sometimes socially excluded at school. Participants were 49 grade five and six children who attended inclusive classrooms. Interviews were digitally recorded and transcribed. The researchers extracted 49 unique statements from the transcribed data, and then invited participants to sort the statements into meaningful categories.

Sorted data were entered into matrices, which were summed and analysed with multi-dimensional scaling and cluster analysis. A four-cluster solution provided the best conceptual fit for the data. Clusters reflected themes on: (1) the thoughts and actions of other children; (2) differences in learning ability and resource allocation; (3) affect, physical characteristics and schooling; and (4) negative thoughts and behaviours. The overarching reason for social exclusion focused on differences between children with and without disabilities. This study also provided evidence that children are effective, reliable and competent participants in concept mapping. Educational and research implications are discussed.

Journal of Intellectual Disability Research

58 (4), 346–357, April 2014

http://bit.ly/1kv5sUn

Neece, L C

Mindfulness-based stress reduction for parents of young children with developmental delays: implications for parental mental health and child behavior problems

Parents of children with developmental delays (DD) typically report elevated levels of parental stress compared with parents of typically developing children. Children with DD are also at high risk for exhibiting significant behaviour problems. Parental stress has been shown to impact the development of these behaviour problems; however, it is rarely addressed in interventions aimed at reducing child behaviour problems. The current study examined the efficacy of mindfulness-based stress reduction (MBSR) for parents of children with DD by investigating whether this intervention is effective in reducing parenting stress and whether decreases in parenting stress lead to reductions in behaviour problems among children with DD. Forty-six parents of children with DD were randomly assigned to an immediate treatment or wait list control group.

Participants completed questionnaires assessing parental stress and child behaviour problems at intake and at a second assessment, which took place after only the immediate treatment group had received the MBSR. Parents who participated in MBSR reported significantly less stress and depression as well as greater life satisfaction compared with wait list control parents. Regarding child outcomes, children whose parents participated in MBSR were reported to have fewer behaviour problems following the intervention, specifically in the areas of attention problems and ADHD symptomatology.


Events

Under the Sea - An Ocean Extravaganza Adventure for Children of all Ages

22 August, Stamford, Lincolnshire

Using songs from The Little Mermaid, Finding Nemo and Shark Tale children will develop performing skills whilst having lots of fun becoming underwater characters. They will also create an ocean scene using art and craft materials. Children require packed lunch and drinks for all Summer School activities, along with clothing suitable for acting and dance. Children of all abilities are welcome. All ‘Holiday Programmes’ such as this have details under each one as to what the activity entails and when it may or may not suit. They also have a small amount of funding to pay for a learning support assistant to attend sessions with a child if required.

£23
Tel: 01780 762000
www.wildcatstheatreschool.co.uk

‘Go Wild’ Weekend for Deaf Children with Additional Complex Needs

22–24 August, Essex

The National Deaf Children’s Society are offering places to deaf young people with additional needs who would like to take part in their exciting free activity weekend. These events are all about what young people can do and there is a flexible approach to ensure everyone is included and that they enjoy themselves! Activities on the weekend will include cookery, making costumes and pottery all with an animal theme. There will also be a visit from the Animal Man, as well as outdoor games, sensory stories and time for outdoor fun. Staff and volunteers are trained to support young people who use a range of communication methods and who have a variety of care and support needs and will ensure all children are able to participate and enjoy a range of challenging and achievable activities.

Booking form available at www.ndcs.org.uk
The Halliwick Concept Foundation Course
26–29 August, York

The Halliwick Concept is an approach to teaching all people to participate in water activities, to move independently in water, and to swim. It focuses particularly on those with physical and/or learning difficulties.

A certificate of attendance is awarded on completion of the Halliwick Foundation Course. However, to gain a certificate of competence the candidate must complete (after the course) a minimum of 35 hours experience working with swimmers with disabilities and successfully complete an assessment.

£280 for the 4-day course
www.halliwick.org.uk

PWSA UK National Conference 2014 ‘Living with Prader-Willi Syndrome’
13–14 September, Swanwick, Derbyshire

This year’s programme is as follows:

Saturday 13th September:
Programme for Parents/Carers with children aged 0–16 years
Sunday 14th September:
Programme for Parents/Carers with teenagers/adults aged 16+

Event cost: TBC
Tel: 01332365676
www.pwsa.co.uk

Snow White and the Seven Dwarfs Relaxed Performance
2 January 2015, Manchester

Now booking: a pantomime performance at the Manchester Opera House starring Priscilla Presley, aimed at anyone who would benefit from a more relaxed and supportive environment. A relaxed attitude to noise, walking around, leaving the auditorium and reduced special effects and lighting will ensure a more comfortable experience.

Tickets from £10
Tel: 0161 245 6505

Circus Starr
September–November, at 27 different venues around England

Circus Starr is a touring circus troupe boasting world-class, professional artists from across the globe. It was first founded in 1987 to help raise much-needed funds for local charities whilst providing free seats for thousands of disadvantaged, disabled or vulnerable children. Through its unique network of partner charities and local businesses, Circus Starr provides over £1.3 million worth of free tickets to children, their families and community groups throughout the UK every year. Circus Starr aims to increase children’s confidence, sociability and self-esteem.

To receive donated tickets contact Cath Logan.
Tel: 01260 288690
www.circus-starr.org.uk

News

Arsenal becomes first Premier League club to install Changing Places toilet

The Emirates Stadium, home of Premier League football club Arsenal FC, launched the 600th fully accessible Changing Places toilet in April of this year.

Alun Francis, Arsenal’s disability liaison officer, added: ‘We are all incredibly proud to be the first Premier League stadium to install a Changing Places toilet. Arsenal values everyone connected to the Club and we want all visitors to the Emirates Stadium to feel like they belong here and enjoy an equal match day experience without the stress that standard disabled toilets can cause.’

Learning Disability Today
www.learningdisabilitytoday.co.uk

BMA calls for parity in quality of healthcare for people with learning disabilities or mental ill health

The British Medical Association (BMA) has called for urgent action to address the inequalities in healthcare facing people with learning disabilities or mental ill health.

The BMA’s report, Recognising the importance of physical health and intellectual disability — achieving parity of outcomes, calls for a range of measures to address the fact that men with mental health problems die, on average, 20 years earlier than those without; women with mental health problems die 15 years earlier. Similar patterns of premature mortality are seen among adults with a learning disability. Jan Tregelles, chief executive of Mencap, added: ‘It is unacceptable that people with a learning disability die significantly earlier than the general population because of unequal access to healthcare. Too often, physical health needs are not picked up, and signs are not explored or taken seriously, because people only see the “learning disability”. This is despite the fact that people with a learning disability are more likely to have other health issues, such as obesity and respiratory problems’.

Learning Disability Today
www.learningdisabilitytoday.co.uk

Why is it OK for politicians to ignore people with learning disabilities?

Gary Bourlet wants to give people like himself, with learning disabilities, a greater voice and presence so they feature in places other than ‘secret footage on Panorama’, referring to Winterbourne View, where the abuse of patients with learning disabilities was exposed by the BBC in 2011. To this end, he has set up People First England, to encourage adults with learning disabilities, rather than care professionals, to participate in politics and appear on TV and radio discussing stories that affect them.
Charities take over Jewish learning disability-focused website

Learning disabilities charities Langdon and Kisharon have taken over the running of Jweb, a specialist website for people in the Jewish learning disabilities community. Jweb will continue to operate independently, offering a free-to-use, user-friendly portal with forums, events listings, noticeboards and a countrywide directory of Jewish learning disability services.

Learning Disability Today  
http://bit.ly/1eN0th1

Ombudsman calls for fair treatment of children with SEN

Fair treatment for children with Special Educational Needs (SEN) is being called for by the Local Government Ombudsman in a new report. The report SEN: Preparing for the Future urges that children with SEN, and their families, must be treated fairly and receive the support to which they are entitled. It highlights a number of stories where pupils are being unlawfully excluded from school and being denied specialist support.

Local Government Ombudsman  
http://bit.ly/1cJ4x3J

Support to help children with complex health needs overcome the barriers to ‘An Ordinary Life’

The Foundation for People with Learning Disabilities is launching a package of new support materials to raise awareness of the aspirations of children with complex health needs and their families and to highlight the opportunities available to improve their lives. The materials are the result of the charity’s three year project ‘An Ordinary Life’ and include the briefing, Looking for an Ordinary Life, and the booklet Children and Young People with Complex Health Needs – A One-stop Booklet for Families. The briefing has been designed for practitioners, children’s health and social care commissioners and schools and colleges. It aims to inform and raise awareness about the aspirations of this group of children, while the booklet for families aims to offer information and routes to support which will improve the quality of life for children, young people and their families.

www.learningdisabilities.org.uk
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
- report on 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
   Hewett, D (1998) Challenging behaviour is normal in P Lacey and C Ouvry (Eds) People with profound and multiple learning disabilities London: David Fulton

Illustrations, tables, figures and photographs can only be reproduced as black and white and must be submitted separately to the article as high resolution (a file size of at least 1MB) tiff, eps or pdf files (jpegs are also acceptable). Illustrations, tables and figures should be given titles and should be numbered consecutively. Photographs should be accompanied by captions. Permission to reproduce photographs should accompany articles. If you have any queries about how to submit articles then please contact the Editors before preparing your material.

Articles should be submitted to: Dr Jean Ware or Fliss Kyffin
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E-mail: f.k.kyffin@bangor.ac.uk

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

A voice of their own

A toolbox of ideas and information for non-instructed advocacy

Annie Lawton

This toolbox is a place to come for ideas, suggestions or contact details to help you with particular problems you might come across when you are advocating for a person with high support needs. There is no ‘right’ way to do this. The important thing is to collect together a number of different tools and use these in whatever combination ensures your advocacy partner has a voice, is listened to and is taken seriously by others who can bring about change.

This is a revised edition of the toolbox which takes into account major changes in health, social care and advocacy in England since it was first published in 2006.

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ISBN 978 1 905218 31 8 £18.00