Responding to the Mental Health Needs of Young People with Profound and Multiple Learning Disabilities and Autistic Spectrum Disorders: Issues & Challenges

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Abstract

Teachers in residential special schools often work with young people who experience some of the greatest obstacles to learning. In particular, young people with profound and multiple learning difficulties (PMLD) and those with autistic spectrum disorders (ASD) require expert teaching and management by professionals who have a detailed understanding of the individuality of these young people. The identification of mental health difficulties in young people with PMLD or ASD is often confused by the challenge of interpreting behaviours which become associated with a 'condition' rather than a manifestation of a mental health problem. This paper describes research which investigated professional understanding of and responses to mental health needs in young people with PMLD or ASD in a group of residential special schools. It is suggested that there remains a lack of understanding of the complex relationship between individual learning needs and mental health difficulties and that this is an obstacle to effective management and remediation. The development of greater cohesion across professional services, and with families, is perceived as an essential factor in enabling improved provision in this area.

Key words: mental health, profound and multiple learning disabilities, autistic spectrum disorders

Introduction

Research into the prevalence of mental health difficulties experienced by both adults and children with severe or complex learning disabilities indicates higher than normal rates in this population (Holland & Koot, 1998; Emerson & Hatton, 2007). An investigation reported by Whitaker and Read (2006) confirmed that the incidence of psychiatric disorders in children with intellectual disabilities was higher than that in their peers with mild or no intellectual disabilities and that current levels of understanding of the interface between mental health and learning disability are somewhat tenuous. Clarification of this relationship may be important if services for this population are to be effectively delivered. However, there remain many obstacles to determining both the extent and nature of the difficulties experienced by children and young people. Not least, the challenges of applying standardised measures or instruments to children who may have limitations of comprehension or difficulties with communication, even when using augmentative approaches, brings into question the reliability of data in this area (Emerson, 2005; Kaptein, et al 2008). Whilst an appreciation of mental health and its management by professionals from across the caring professions has increased considerably in recent years, there remains a significant level of confusion and misunderstanding in respect of the mental health needs of children described as having profound and multiple learning disabilities (PMLD) and those with autistic spectrum disorders (ASD).

The identification of mental health difficulties in young people with learning disabilities is often confused by challenges of interpreting behaviours which become associated with a 'condition' rather than a manifestation of a mental health problem (Carpenter, 2004; Davies & Hogg, 2004). Reporting research conducted in the Netherlands, Kaptein et al. (2008) using the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) recorded problems with behaviour, emotions and relationships in 61% of children with learning disabilities compared to 9.8% of a matched population without learning disabilities. Ghaziuddin et al. (1998) suggested that the incidence of mental health difficulties experienced by persons with Asperger Syndrome could be as high as 65%. Bradley et al (2004) report higher risk of mental health disturbances amongst individuals with autism and severe intellectual disabilities, identifying anxiety, mood swings and sleep stereotypes as particular areas of vulnerability. In addition, Hutton et al. (2008), in a follow-up study of 135 individuals with an autistic spectrum disorder to identify new-onset psychiatric disorders, indicate that the most common difficulties experienced were affective, including a mix of anxiety and depression, and that 'a key diagnostic issue concerns their recognition' (p.382). In a further study, Muris et al., (1998) found significant indicators of high anxiety in 84.1% of children with autistic spectrum disorders. However, other writers (Howlin, 1997; Prelock, et al. 2003) have emphasised the need to exercise caution when making such interpretations because of the recognised difficulties which individuals on the autistic spectrum have in respect of communicating emotions and abstract ideas. Regarding individuals with PMLD, the literature reports that mental health difficulties, for this minority population, are often overlooked (Gratsa et al., 2007; Sheehy & Nind, 2005; Carpenter, 2004; Davies & Hogg, 2004). One of the issues is the lack of appropriate diagnostic tools to more accurately diagnose mental health difficulties. In addition, associated complex health needs prevalent in this group, can often mask mental health problems (Davies & Hogg, 2004). Carpenter, (2004) describes another perspective, where 'physical state can impact upon emotional well-being' when giving evidence from the mother of an adolescent young woman with PMLD. Her daughter's change in personality was at first attributed and disregarded by doctors as resulting from hormonal changes associated with puberty. Only when a dramatic weight loss presented were further investigations undertaken, finding a dislocated hip. The prolonged effect of constant pain had changed her mood and impacted considerably on her emotional well-being.

The problems associated with the assessment and definition of mental health difficulties in these populations of young people are clear (Sheehy & Nind, 2005; Gratsa et al., 2006; Scholte et al., 2008). It is therefore not surprising that teachers and support staff working in special schools, the majority of whom have had little or no training in the identification and management of mental health problems, may be both confused and frustrated when attempting to provide appropriate support for their young people.

The provision of appropriate levels of support for addressing mental health in schools is, to some extent, dependent upon the establishment of a clearer picture of the mental health needs of young people. National initiatives, such as the introduction of the Social and Emotional Aspects of Learning (SEAL) (Department for Education and Skills, 2005) materials into schools provide an indication that there is recognition of the need to address mental health in young people on the part of national government. However, whilst this resource has found favour with teachers and others working in mainstream schools, those

working with young people with complex special educational needs report that they are largely inadequate in terms of this population.

The Research Study

This paper reports research conducted into the mental health needs of young people in independent residential special schools in England and discusses issues of identification, interpretation and professional intervention in relation to a complex school population. It focuses in particular upon young people with PMLD and/or ASD. Whilst the needs of these young people are distinct, there are areas of over-lap when considering issues and challenges related to mental health; in particular, barriers to communication resulting in reliance upon observed changes in behaviour in order to detect a possible mental health need. This research focuses upon the complex issues and challenges identified by professionals involved with these young people when attempting to identify, and respond to, mental health needs. In order to enable respondent school staff to be able to consider issues with consistency of understanding, terminology and working definitions were clarified at the outset of the research. We defined mental health as:

> A positive sense of well-being which enables an individual to be able to function in society and meet the demands of everyday life. People in good mental health have the ability to recover effectively from illness, change or misfortune.

On the basis of this, we defined mental health problems in the following way:

> The term "mental health problems" is used to describe levels of emotional, psychological or psychiatric distress that present significant challenges for the young person, their families and those who support them. This may cover a range of problems from relatively mild emotional disorders such as anxiety (which can become very serious) and mild depression to serious psychiatric disorders (e.g. psychosis).   (National Association of Independent Schools and Non-Maintained Special Schools, 2007)

The research described in this paper was designed to investigate both the prevalence of mental health difficulties in young people including those with PMLD or ASD attending residential special schools in England and to identify the challenges faced by staff in addressing pupil needs in this area. The work was commissioned by a national charitable organisation (National Association of Independent Schools & Non-Maintained Special Schools (NASS). This followed concerns expressed by school staff with regards to a perceived increase in mental health related difficulties experienced by young people in their schools. Similar concerns were expressed with regards to a lack of professional preparation for provision of appropriate levels of support. At the outset of the project it was apparent to the researchers that the information available with regards to the extent of the difficulties experienced by young people was largely anecdotal and that this alone would be insufficient to facilitate an appropriate level of response.

Methods

An initial postal questionnaire survey, sent to 124 residential special schools was used to interrogate staff understanding of mental health issues, the extent of difficulties experienced by young people in the schools, the levels of service provision from other professional agencies and the preparedness of in-school staff for management of the challenges faced. Whilst the survey sample could not be said to be representative of all special schools or other providers for young people with PMLD or ASD, it was purposive in identifying a population with complex needs from which data could be extrapolated which would be illustrative of both the nature of mental health challenges faced by young people and their teachers and the procedures adopted in their management. The questionnaire made use of both fixed choice questions requiring a response on a Likert scale indicating perceptions related to services provided, speed of response and in-school provision and open ended questions seeking exemplars of practice and personal interpretations of the efficacy of school based interventions. Responses were received from 48 schools; of these respondents, 33% of schools catered for young people with ASD and 8% for PMLD. Data were coded and analysed and used to formulate further questions for use in interviews with key staff in the schools. A total of 43 follow-up one-to-one interviews using a semi-structured narrative approach (Elliott, 2005) were conducted with teachers and other professionals including psychologists, therapists and care staff. These interviews were designed to enable respondents to provide exemplars with regards to both experiences and the practices commonly deployed in schools. All interviews were conducted and audio recorded by members of the research team who had experience of working in special schools. The use of a cross sectional index and retrieval grid (Gillham, 2005) enabled interview data to be used for identification of key issues and points for discussion. The collation of responses from transcription allowed the researchers to attribute inductive codes to segments of text in order to extract both common themes which might allow for generalisation and exceptional experiences which could assist in the provision of exemplars of innovative practice (Miles & Huberman, 1994).

The extraction of key issues from the data provided an opportunity for the researchers to interrogate these in relation to the literature and also formed the basis for further discussion with professionals working in the sample schools. In this paper a number of the key issues are discussed making use of the both the qualitative data gained through interviews and the quantitative detail obtained from the questionnaire.

Research of this nature clearly deals with issues of a sensitive nature. The researchers adhered to an ethical code, approved through university research committee procedures, which ensured the anonymity of research respondents and confirmed the right of individuals to withdraw from any aspect of the investigation. Informed consent was sought and obtained from all participants.

Key Issues and Challenges

A number of key issues emerged from the research, indicating shared areas of concern amongst professionals working with young people with PMLD or ASD. Firstly, respondents indicated anxiety and confusion in distinguishing between features of a diagnosed disorder or learning disability and mental health problems. Identification of potential mental health problems was highlighted as a major challenge when working with these young people. Secondly, issues were

highlighted in relation to responding to mental health needs; whilst interventions and strategies were identified by teachers and other professionals, these were often reactionary and not always informed by an understanding of complex needs. However, some examples of good practice were observed in relation to maintaining emotional well-being, which may be important in preventing future mental health problems. Finally, issues related to the involvement of others when identifying mental health problems or needs were also noted; these concerned the involvement of external agencies and of parents and carers. Each of these issues will be discussed here in turn but should be regarded as complex parts of a more general pattern of confusion and lack of strategy in dealing effectively with mental health matters as a whole.

Identification and Interpretation of Mental Health Needs

Several respondents indicated a lack of confidence in identifying possible mental health problems in young people with complex disabilities. Whilst expressing confidence in understanding and identifying characteristics associated with diagnosed conditions and disorders, many reported concerns when considering mental health problems. Lack of training in identifying mental health problems was reported by many respondents. Whilst staff had experience of working with individuals with PMLD or ASD, few had had the opportunity to access appropriate training in order to i) distinguish between recognised characteristics of a diagnosed disorder or learning disability and possible mental health problems, ii) learn about appropriate ways of responding to individual needs when a mental health problem arose.

> 'We struggled to put together a working definition to use… when it is part of their impairment and when it is clearly a mental health issue, there are obviously overlaps.'   Head of Care

> 'because the children are so complex and have some many issues going on, how could you say 'oh that is his autistic behaviour or no that is mental health'   Head of Junior Department

> 'children who would come under the PMLD umbrella, it is very difficult then to tell whether that comes under mental health, whether it comes under frustration because of communication issues, whether it comes under something completely different.' Director of Learner Services

Communication barriers were identified as particular challenges, with staff often relying upon observed changes in behaviours in order to identify a possible mental health concern. Behaviours were often viewed as a form of communication and behaviour indicators were therefore central to identifying a need beyond that which was usual for the individual. For example, when asked what kind of indicators staff would look for that would trigger concerns about mental health problems the following response is typical of many respondents:

> 'the majority of students have no verbal language their main means of communication is through their behaviour so changes in behaviour or a particular behaviour being much more evident…''' Head Teacher

Behaviours that were uncharacteristic and atypical for the individual young people were reported as particular indicators of problems and alerted staff to

taking action of some description. However, respondents indicated that changes in behaviour were often difficult to interpret and assess, particularly where individuals were coping with emotional stress as part of their diagnosed difficulties, as is particularly the case for individuals with ASD. Lack of effective communication was associated with an inability to express feelings and emotions which may lead to mental health needs.

> 'I could see the emotional stress she was experiencing… and we knew she could even tell herself, she didn't know what was happening but she knew there was something not right herself… she could be fine one minute and the next minute very aggressive or destructive or physically harming herself, and then an hour later she would be happy and fine.'   Senior Teaching Assistant

> 'We have children whose behaviour we feel is a reflection of their feelings about the fact that they don't have a lot of family contact… the behaviour they present when other children are having visitors indicates that actually they have a problem… does that come under mental health? It is unpicking where is the behaviour, where is the mental health? …if somebody is suffering from jealousy to the degree that they feel that they need to reach out and hurt somebody to express themselves, is that us failing them in terms of their communication or is it that they actually need help and support that you might get if you were able bodied… if you had those sorts of problems (jealousy) you would probably be receiving some form of counselling but you don't when you have got PMLD.'
> Team Leader, Care

In addition to observing atypical behaviours, some identified particular triggers for the development of mental health needs, including puberty and cycles associated with change and transitions.

> "We might see a period of depression and then perhaps not…You can put it down to cycles… from after the six weeks holidays from about October we could see the child going down and then about February time she would pick up again…"
> Senior Teaching Assistant

Transitions are frequently stressful for young people with PMLD or ASD and this may explain their lack of ability sometimes to 'meet the demands of everyday life' or to 'recover effectively from illness, change or misfortune'.   (National Association of Independent Schools and Non-Maintained Special Schools, 2007)

Despite concerns and anxieties regarding identifying mental health problems, some respondents indicated a systematic approach to observing and assessing changes in behaviour. Examples included daily behaviour records, video evidence, monitoring of observations and changes, contact with parents and care staff and a collaborative effort to monitor individuals in order to trigger actions and interventions where appropriate. The following excerpt reflects many of the responses regarding observing and monitoring change:

> '…if there is something which we haven't seen before, we let everyone know that this has happened. We have either verbal (or) we have documentation that goes out once a week… in their recording folders we would add a sheet 'if you see this can you let

us know'. We will try and get… some video evidence so then we know what we are looking at.'   Head of Junior Department

However, whilst staff reported some systematic approaches in attempting to discern mental health problems, the challenges inherent when young people have PMLD or ASD should not be under-estimated. Despite systematic observations it can still be 'difficult to be certain' (Hutton et al., 2008) and indeed the respondents' perceptions indicate deep uncertainty in this area.

Responses to Mental Health Needs: Interventions and Practice

Although many challenges were identified as key concerns for staff working with young people, nevertheless a range of positive approaches and interventions was identified by respondents. Expertise was evident in schools as respondents identified strategies commonly used with individuals with PMLD or ASD. These strategies frequently focused upon enabling communication and included the use of visual structure, visual mind-maps and flow charts, feelings thermometers/wheels to express emotions, personal tutorials and email communication.

> 'Finding a way to communicate so that the children can relay to you what their anxieties are if possible. We can do that through exploring using visual mind maps and using other visual methods and feelings thermometers and feelings wheels…gauging really how a person is feeling by them being able to indicate that through some method.' Head of Speech and Language therapy

Some schools saw the promotion of emotional well-being as integral to the curriculum and many indicated that they addressed emotional well-being within the Personal Social and Health Education (PSHE) curriculum. Others adapted curriculum materials developed for use in mainstream settings, for example SEAL materials and the use of 'Zippy's Friends' (Partnership for Children, 2003), which were used to enable individuals to self-reflect and to understand emotions and feelings. Adaptation of strategies and resources to meet individual needs was a common theme with respondents emphasising the need to personalise interventions and resources, for example,

> '…they all need adaptation and personalisation… whether this is applied to resources and materials in this area or other areas of teaching I think there is a lazy tendency to want off the shelf resources… which we than apply unthinkingly to individuals… which I think is a danger, so I think at best what you should try to build up is a bank of useful resources and materials that we have used with particular children.'   Director of Children's Services

Some interventions were aimed at addressing anxiety, stress and behaviour and included the use of therapeutic approaches such as music therapy, relaxation and self-calming techniques. Other strategies focused upon developing social skills through the use of Social Stories (Gray, 1998; Howley and Arnold, 2005) and social skills groups. Schools commonly used strategies to promote well-being and some were pro-active in pre-empting anxieties which may arise at times of change, for example:

> ''…his family were expecting a new baby and we knew this young man would not be able to express how he felt about what was going

> on… we put in social stories to try and explain what was going to go on, what the impact might be upon him, how he might feel about it…'   Consultant Psychologist

Overall, respondents indicated that interventions were developed according to individual needs. Many schools allocated key workers for young people, sometimes assigned on a one-to-one basis, offering personal tutorial systems for support for individuals. A range of interventions and strategies were described, with the majority of these focusing primarily upon promoting emotional well-being and addressing behaviour triggers. However, whilst professionals in schools may be familiar with the use of interventions or their associated resources, they appear to lack a foundation of knowledge with regards to the causal factors or interpretations of mental health which these are attempting to address. In such situations, the delivery of an intervention may prove less than effective and in some instances provides no more than a superficial approach to tackling a major problem. Indeed it has been suggested that if the management of young people's mental health in schools is to be sustained, it is essential that staff charged with the responsibility for managing vulnerable individuals develop professional skills and understanding beyond those usually associated with their own discipline (Han & Weiss, 2005).

Involvement of Others: External Agencies and Parents

The involvement of others, specifically external agencies and parents, was identified by many as a key issue when identifying and responding to mental health problems. Many schools reported the use of internal processes first, in order to respond to individual needs and to promote well-being. Staff often worked with professionals from other disciplines within school, particularly supporting therapies.

A number of issues and challenges emerged in relation to the involvement of external agencies, ranging from lack of availability, limited expertise in PMLD or ASD, delays in referral routes and variation in response rates. Many respondents indicated that involvement of external agencies was difficult due to lack of knowledge of the individual. This was further complicated by the idiosyncratic communication modes and responses of these young people.

The challenges identified were often complex due to confusion when children were placed in schools outside their home local authority; this led to difficulties identifying 'who should do what', issues involving Child and Adolescent Mental Health Services (CAMHS) teams and problems identifying a named person for referral.

> 'It is not always easy to find a named person to make the referral to, so you can spend quite a lot of time finding out who is the person I should be referring to. In fact is some areas, they don't have anybody that you can refer to.'   Head of Speech and Language Therapy

Involvement of parents was also indicated as an issue by some schools. This involvement was regarded as important and many reported regular communication with parents. However, some indicated that parents may be wary of any mental health diagnosis and may withhold their concerns. Respondents reported that some parents themselves also experienced mental health difficulties.

> 'It is also persuading the parents to come on board… that can be a real problem because they don't want to recognise that actually there may be something else that it is wrong with their young person on top of everything else that they have got to deal with.'
> Team Leader

Conclusion and Recommendations

It is apparent from the findings of this research that the schools involved were effective in devising and personalising approaches for the management and promotion of well-being in young people with PMLD or ASD. This is an area in which many staff expressed confidence and is supported by a range of accessible resources. This level of confidence is less apparent with regards to situations where individuals are experiencing additional mental health difficulties. The complexity of PMLD or ASD is such that it is not possible to provide a generalised response and it is necessary to establish collaborative processes and procedures which are focused upon the specific needs of individuals. This is often difficult to achieve either because of difficulties in accessing professionals from across a range of disciplines, or because of a lack of understanding of PMLD of ASD on the part of otherwise expert professionals.

In order to address these challenges it is important to recognise that whilst many of the individual professionals who work in these schools have expertise and competences essential for the management of these young people, no individual has a monopoly on understanding this complex problem. It is therefore essential that the significant pool of expertise which resides amongst professionals and families is brought together in a more cohesive whole if improvements in response to mental health issues are to be achieved more effectively. This requires a strategic approach to developing professional dialogues and partnerships between all concerned parties, based upon mutual respect and recognition of the skills and knowledge of all participants in the process. Such a move will require an acknowledgment of the expertise which exists within families and the ability of young people to recognise and express their own needs, albeit in often unconventional manners. This is likely to require the provision of training which involves professionals from all disciplines and recognises the contribution which families can make to promote greater understanding of the needs of individual young people.

It is no longer acceptable to assume that mental health difficulties are 'simply part of a condition or learning disability'. Attention needs to be drawn to the professional responsibilities which all colleagues share in ensuring a more holistic view of the needs of individuals in their charge. Only when this is achieved are appropriate responses likely to become embedded in practice when working with this complex population. It is evident from this study that some schools are beginning to evaluate the effectiveness of specific interventions designed to support the emotional well-being of young people with PMLD or ASD. Further research which concentrates upon understanding the efficacy of these interventions should be welcomed and could inform changes in practice for the benefits of these young people.

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