

Depression in Young People with Learning Disabilities: Identification and Accessing Support

A Scoping Exercise

**Sharon Daniels
for the Judith Trust
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Professional advice:

Dr Sarah H Bernard MD, MB, ChB, FRCPsych, DRCOG

Consultant Psychiatrist with the Child and Adult Mental Health of
Learning Disabilities Team at the South London and Maudsley NHS
Foundation Trust.

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Literature review

Depressive disorders are increasingly recognised as one of the greatest causes of distress, and most common mental health problems, in people with learning disabilities (Sikabofori and Anupama, 2012). While around 6% of the mainstream population experiences depression in any one year (NHS), studies suggest that up to 20% of people with learning disabilities will experience depression (Sikabofori and Anupama, 2012). The WHO further suggests that up to 23% of people with 2 or more chronic physical conditions will experience depression (NHS Website).

Mental ill-health is a major issue in children and young people, with estimates suggesting that 10% of young people have a diagnosable mental health problem (ONS 2004), rising to up to a possible 40% for young people with learning disabilities (FPLD, 2002). Hassiotis and Turk's (2012) recent study claims that many young people with learning disabilities may have mental health problems which are unidentified and therefore untreated, and yet which impact on their daily living. The prevalence of depression in mainstream post-pubertal adolescents is estimated at 3% (Clinical Knowledge Summaries, 2009). There are no epidemiological studies addressing the prevalence of depression in young people with learning disabilities. Given the high prevalence of mental ill-health in this age range, and the high rates of depression in the overall learning disabled population cited, this is an area where there is a need for further research.

When one considers the aetiology of depression, it is evident that people with learning disabilities are at an increased risk. There may be biological or genetic factors related to those which caused the learning disability; some conditions are associated with an increased risk of mental illness (Emerson and Hatton, 2007).

Psychosocial factors are a logical area in which people with learning disabilities are more likely to be affected, but which is not extensively researched (Sikabofori and Anupama, 2012). Emerson and Hatton (2007) state that children with both diagnoses of both learning disabilities and mental ill-health experience higher rates of poverty, adverse life events, maternal mental ill-health, familial unemployment, all of which are known triggers for depression as well as other mental health problems. They estimate that 20-33% of the increased risk of mental illness in young people with learning disabilities can be attributed to the impact of social disadvantage, along with several adverse life events experienced frequently by children with a learning disability (ibid).

It is also important to consider cognitive factors where, once again, there is evidence that people with learning disabilities are at an increased risk. Emerson and Hatton (2007) recognise that difficulties in problem solving associated with some conditions contribute to increasing the likelihood of mental ill health; Zigler (2002, in Alim, 2012) similarly notes increased dependency on others for decision-making. Young

people with learning disabilities are more likely to have negative perceptions of the self, their environment and the future (Sikabofori and Anupama, 2012). Children with learning disabilities are both less optimistic about success when faced with new challenges and find less satisfaction in problem solving (Zigler, 2002 in Alim, 2012). Many studies have demonstrated that people with learning disabilities are more likely to experience negative self-esteem (LaBarbera, 2008). In turn, low-self esteem is a predictor for depression and related disorders such as anti-social behaviour, eating disorders and suicidal thoughts (Erol and Orth, 2011).

Transition planning should start at age 14, with a formal move between social services at age 18, and having to leave school by 19. Raghavan (2010) identifies the transition period, from child-centred to adult-centred services, as a time of particular vulnerability to mental ill-health. He attributes this to a variety of factors including a lack of opportunities to realise aspirations and a loss of social networks as people leave school. For those with more complex needs, the chances of securing paid employment, participating in community and social life or even have a chance to voice their wishes can be limited (ibid).

Young people with mild-moderate learning disability and depression, themselves attribute their depression to similar factors. They cite their physical/medical conditions, stressful life events, social isolation, and factors related to transition to adulthood such as social comparison and planning for the future, as causes of their distress (Stalker et al 2011).

The FPLD (2009) recognises that young people with learning disabilities not only experience higher risk of mental ill-health but also poorer access to appropriate services where symptoms arise. Carers, both familial and paid, may not identify symptoms as those of mental ill-health and therefore not ask for appropriate support. An NASS (2007) study identified a lack of understanding of mental ill health, and a lack of confidence in identifying mental health needs, in students with learning disabilities.

Individuals may struggle to express their feelings adequately (Stalker et al, 2011), or may describe their feelings as “‘grouchy’, ‘bored’, ‘having no fun’ or ‘empty’” (McCarthy, 2010, p. 66) rather than sad. Diagnosis may be reliant more on external symptoms such as lethargy, loss of appetite, disrupted sleep patterns or reduced concentration span, and particularly withdrawal, rather than expression of feelings, especially as verbal skills decrease (McCarthy, 2010). These symptoms could readily be attributed to other common conditions associated with learning disabilities, such as epilepsy, and hence depression may be overlooked. Concern may be raised not where the patterns of these features vary from the norm, but where they vary from what is usual for that individual. This is dependent on consistent support and accurate recording, and changes can be easily missed where carers and settings change regularly.

Similarly, behavioural symptoms of depression may be interpreted as challenging behaviour or distress if a child cannot express their feelings (FPDL, 2009); once again

the symptoms are attributed to the learning disability rather than to depression. Anger is a common feature of depression in young people with learning disability and depression (McCarthy, 2010). Raghavan (2012) notes that many people with challenging behaviour may have undiagnosed mental health needs, and that distinguishing causes for behaviours is itself challenging. Alim (2012) asserts that people with learning disabilities “may react to trauma through disturbed behaviours that may be regarded as the psychological symptoms of depression or anxiety” (p.168).

This phenomenon is known as ‘diagnostic over-shadowing’; symptoms may be considered to be inherent to their learning disability and other conditions not investigated. This occurs due to the “erroneous assumption that mental disorder and ID are mutually exclusive categories rather than ones that overlap” (Raghavan, 2012, p.10). There may also be a concern not to attach another ‘label’ to the child which may further stigmatise them (FPLD, 2009). Even when they do attend the GP with concerns, the GP may also attribute symptoms to the learning disability rather than raise concerns about mental illness, again leading to a lack of appropriate referral. Thus diagnostic over-shadowing occurs both with carers and with medical professionals.

The importance of working with the language and abilities of the individual is central to diagnostics to effective use of talking therapies (Dagnan, 2012). Stalker et al (2011) found people that young adults (aged 18-26) with mild-moderate learning disabilities could talk about their depression with appropriate support and expressed it in a variety of ways. Verbally they used medical terms and spoke about bodily sensations, their feelings and emotions and expressing fears. Verbal interaction was often augmented through the use of photographs and other visual and technological aids. Individuals were supported in bespoke ways to meet their particular needs in order to facilitate this expression. Much was also expressed through behaviours such as pacing, over-eating, aggression/self-harm and lethargy; all behaviours which have a higher prevalence in people with learning disabilities and may not be identified as symptoms of depression. All the participants in the study had diagnoses of depression/anxiety, and were receiving treatments, and it may be their verbal expression of their feelings was shaped by this; people without the diagnosis may not be able to express themselves in such a way in order to gain a diagnosis.

Feelings such as anger or low self-esteem may exhibit themselves through self-injurious behaviour, or suicidal behaviours; for some with more severe learning disabilities the ability to plan and carry out these thoughts can be compromised (Bernard, 2009); the lack of overt behavioural expression serves to mask the feelings the individual may be experiencing. McCarthy (2010) notes that “it is very difficult to diagnose depression in young people with significant communication problems” (p. 67). Diagnosis becomes harder as communication skills decrease.

Depression affects about twice as many adolescent males as females (Clinical Knowledge Summaries, 2009). Goleman (1990) notes that rates of depression in pre-teens are similar for boys and girls but, as teens go through puberty, girls are

more prone to depression, and that body image is an important factor in this. He also notes that the behaviour of depressed teens varies by gender, with girls gaining more social support and boys internalising their feelings more. In considering the long-term outcomes for teens with depression, Dimantopoulou et al. (2011) examined co-occurring depression and delinquency and found higher rates in girls, but worse long-term outcomes for boys, although such differences cannot be presumed to apply to people with learning disabilities too. While this study will not investigate individuals, recommendations for any future research must include exploration of gender differences in young people with learning disabilities, including prevalence rates, behaviours and outcomes.

Similarly one must also consider race in relation to depression. Olsen and Goddard (1996) note that while some studies show increased rates of depression in black adolescents, others show no significant difference; there is no racially segregated data for adolescents with learning disabilities. Their research demonstrates that neither race nor socio-economic status are determinants of risk, rather it is family processes such as cohesion and conflict which affect outcomes. In turn, they quote studies which demonstrate lower cohesion and increased conflict in black families, which in turn could increase rates of depression. In studies of the wider population, there is evidence that race and gender influence the prevalence and form of depression. Riolo et al (2005) showed higher rates in Whites than in African Americans and Mexican Americans; the opposite pattern was found for dysthymic disorder and also note that race/ethnicity, gender, and education are related to the prevalence of dysthymic disorder. In consideration of the experiences of those with disabilities, Parmelee et al (2012) show that gender and race can be predictors of depression in people with osteoarthritis, with levels of pain and disability affecting different racial and gender groups in different ways.

Improving access to psychological therapies (IAPT, 2009 in Raghavan, 2012) identifies key barriers that people with learning disabilities face in accessing psychological therapies; professionals' lack of confidence in working with people with learning disability, professionals' concerns about their ability to build a therapeutic relationship with a person with learning disability and professionals consider that psychological therapies would be better used on people with greater cognitive abilities (IAPT, 2009). There are few studies which evaluate the impact of Guided Self Help (Chaplin and Hardy, 2012), Psychodynamic Therapies (Alin, 2012) or CBT (Dagnan, 2012). NICE Guidelines (2005) state that no young person should receive medication for depression without being offered psychological intervention, and therefore professionals need to ensure talking therapies are adapted to meet the needs of those with learning disabilities. Additionally, NICE (2005) recommends that co-morbid diagnoses are assessed and managed with the depression. More work is needed to understand how these approaches can work for people with learning disabilities. However, the obvious challenges that exist in accessing mainstream therapies serves to highlight the need to prevention and early identification and intervention for people with learning disabilities.

The WHO estimates that by 2020 depression will be the leading contributor to the burden of disease in the developed world (NHS Website). Depression affects a person's ability to function on a day-to-day basis, including their ability to live independently in the community and work; this impacts on the cost of care provision, as well as considering the social and emotional impact on the individual and their family and carers. Depression in young people tends to be chronic and recurrent (McCarthy, 2010). People with learning disabilities and mental health needs "face severe inequalities in provision of mental health services" (Raghavan, 2012 p. 10), despite the fact that Valuing People suggests that the "NSF for Mental Health is applicable to people with ID (intellectual disability) of working age" (ibid). Young people with learning disabilities may be at a higher risk of depression, it may be harder to identify and intervention options may be reduced. It is therefore essential that there is a better understanding of depression in young people with learning disabilities in order that proactive measures can be taken to prevent it and to ensure early identification and provide early intervention where it occurs.

Aims and Objectives

The aim of this Scoping Exercise was to

1. make recommendations to the Judith Trust Board as to the need for further research within the area of depression in young people with learning disabilities. As the literature review demonstrates, depression in young people with learning disabilities is under-researched and not fully understood. There are many facets which warrant further exploration.
2. to examine the understanding and experiences of professionals working with young adults with learning disabilities, in the area of depression.
3. review of the current academic literature, legislation and good practice guidance and examples, to gain a wider understanding of the situation with regards to depression in young people with learning disabilities.

Methodology

A survey was compiled which comprised 4 areas:

- Understanding of possible signs and symptoms of depression, and that these are often features of other learning disability-related conditions
- Knowledge of what action to take if concerned about depression in young people with learning disabilities
- Working relationships with mental health professionals
- Training on mental health in learning disability

The survey was disseminated to 3 groups of people:

- Teachers and Learning Support Assistants (LSAs) in mainstream schools, where there are pupils with learning disabilities
- Teachers and Learning Support Assistants in special needs schools
- Staff in Children with Disability Teams (CDTs)

Schools and CDTs were chosen both through personal contacts and through mailing lists. An e-mail was sent to each service briefly outlining the project, with the project information leaflet (Appendix 1) attached. The e-mail contained a link to the survey. The survey was also posted on Facebook and Twitter, which led to other organisations also linking the survey to their websites. A 3 week period was allowed for completion of the survey. During this period, reminders were sent and the survey was regularly publicised on Facebook and Twitter.

The remit of this project did not include consulting with people with learning disabilities, their carers or families, nor with CAMHS. However, one parent and one CAMHS Clinical Psychologist contacted the project officer. Informal discussions were held with these people, which are included in the project (see Appendices 2 and 3).

Analysis of the data was carried out via Survey Monkey.

Results

Respondents

20 people responded to the survey. The respondents came from a wide variety of backgrounds. Figure 1 indicates the type of service, with most coming from special schools, many of which were residential. Responses in the 'other' category included summer camp worker, third sector organisation, parent/carer, Social Worker Case Manager Children with Special Health Needs, community support and Positive Behaviour Support team. 89.5% of respondents were female.

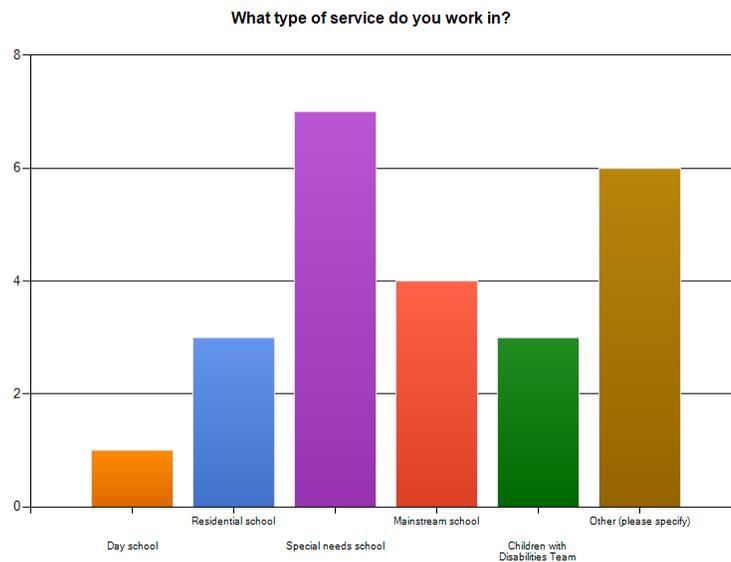


Figure 1.

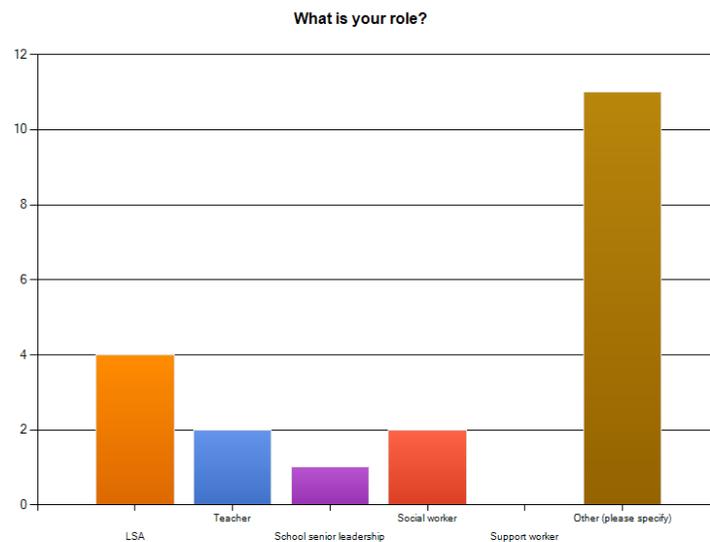


Figure 2.

Figure 2 illustrates the roles of respondents, with 'other' being the most common response and including student, mental health practitioner, psychotherapist, school counsellor, psychiatrist, advocate, transition worker, parent carer, rehab worker, cover supervisor and behaviour specialist.

Training experiences of staff

Training in LD and mental health	Sources	How useful?
66.7%	Professional qualification Vocational qualification External short course	100% very helpful

Table 1

Training in LD and Depression (last 2 years)	Sources	How useful?
80%	Professional qualification Vocational qualification Academic Qualification External short course	100% very helpful

Table 2

Tables 1 and 2 indicate that most respondents have received training on these issues which they found very helpful. No examples were given as to how this had changed their practice.

Experiences of support for young people with suspected depression

Figure 3 shows that all respondents had at some point been concerned that a young person with learning disabilities might be depressed; 87.5% said sometimes and 12.5% said often. 20% felt that the person received the support they needed, with 80% considering that need was 'partly' met (Figure 4).

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Have you ever been concerned that a young person with learning disabilities has had clinical depression (rather than just feeling sad)?

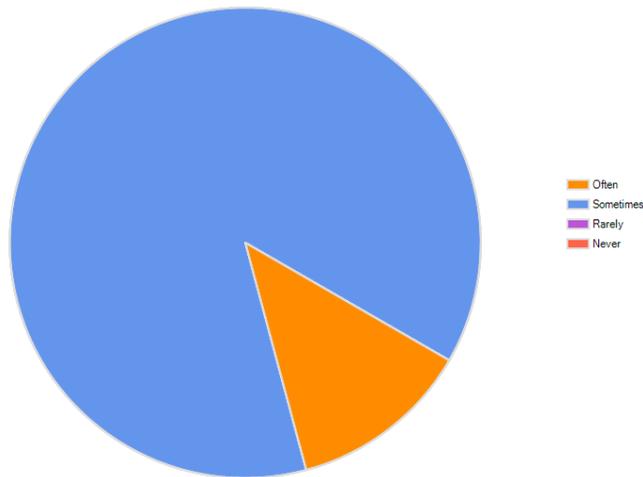


Figure 3

Did you feel the young person/people got the support that they needed?

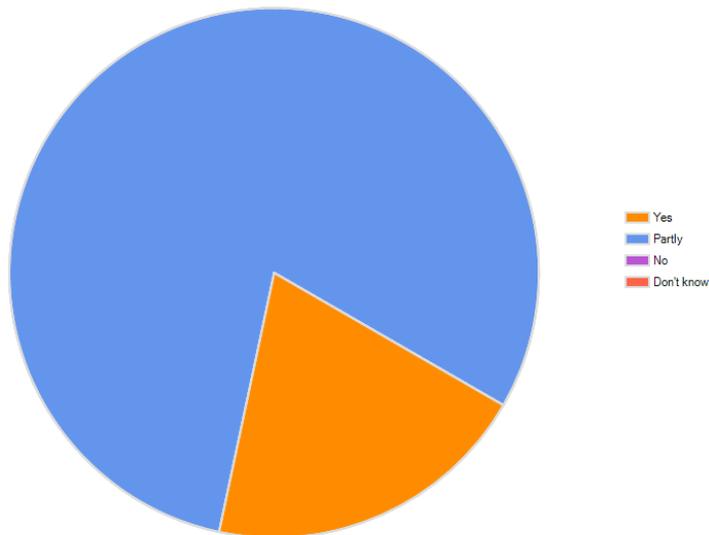


Figure 4

When respondents were concerned that a person was depressed they took a variety of actions, as illustrated in figure 5. The most common 'always' responses were to speak to parents/carers, seek advice from a line manager, review the routine and activities of the person, encourage the parents/carers to speak to the GP and refer them to someone within or outside the school.

What have you done when you were concerned that a young person had depression?

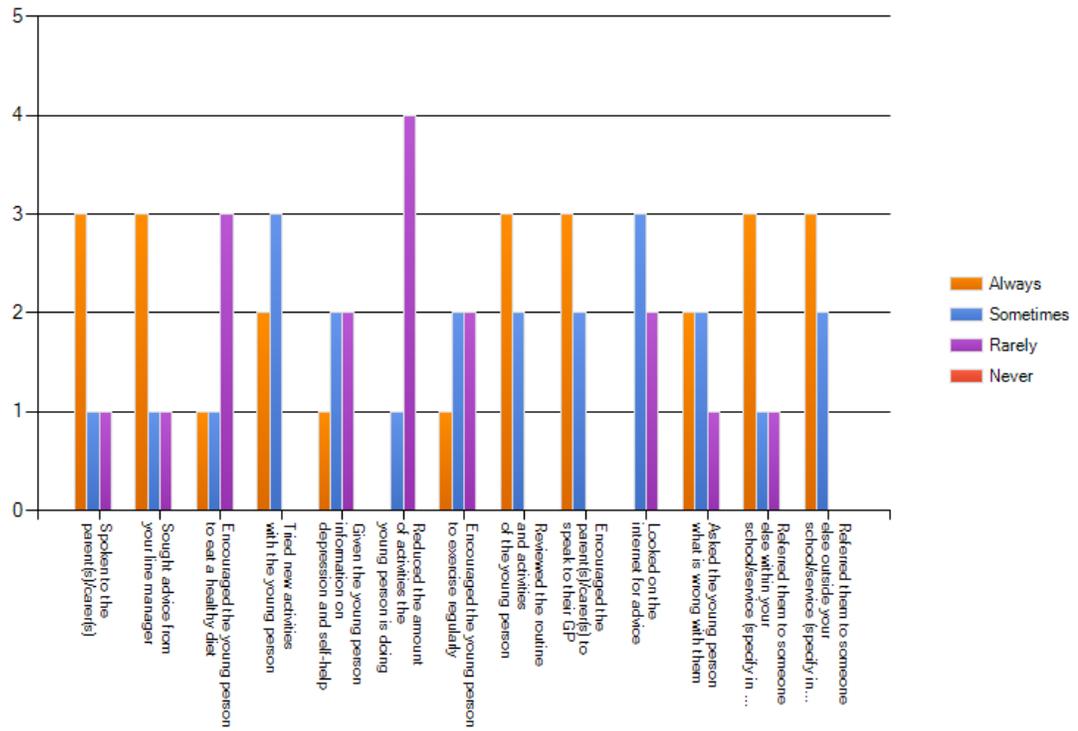


Figure 5

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 Partnership working

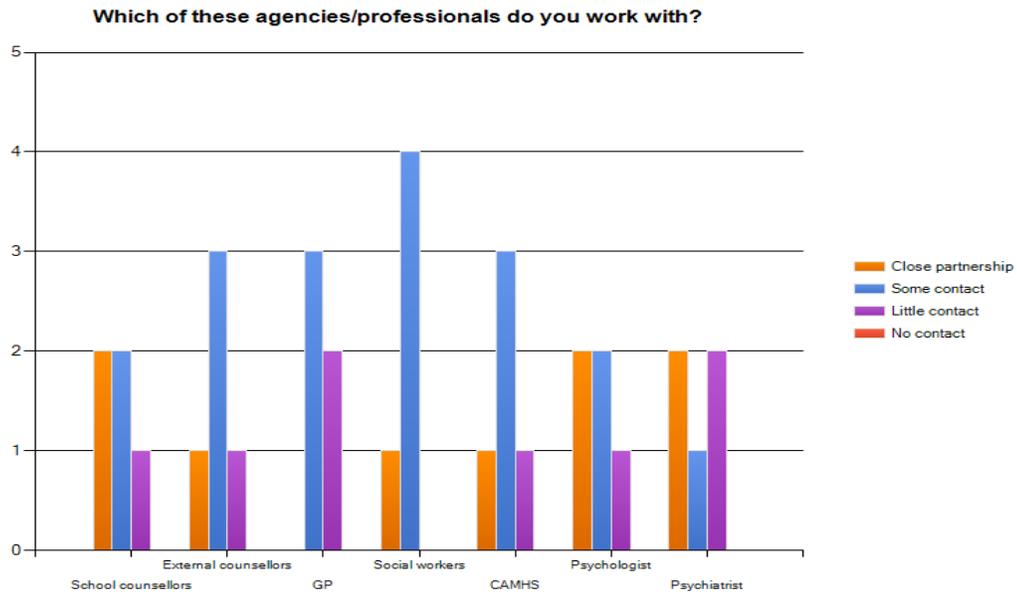


Figure 6

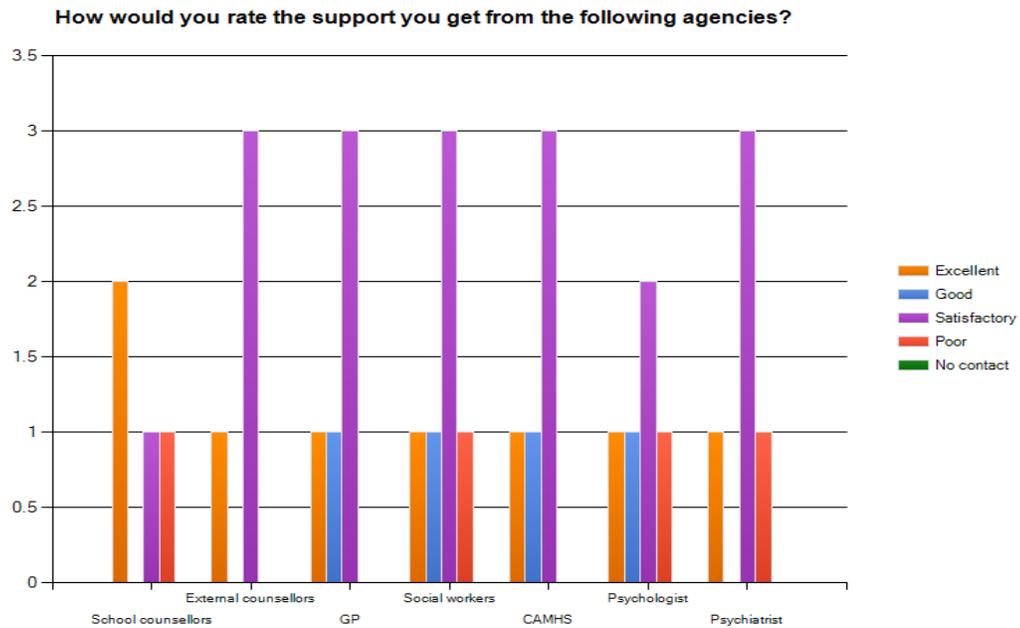


Figure 7

Figure 6 illustrates that all respondents work in partnership with mental health and other professionals. Figure 7 show that these relationships are, in the main, considered to be 'satisfactory'. School counsellors received most 'excellent' ratings; these were the only professionals listed who were internal to the schools.

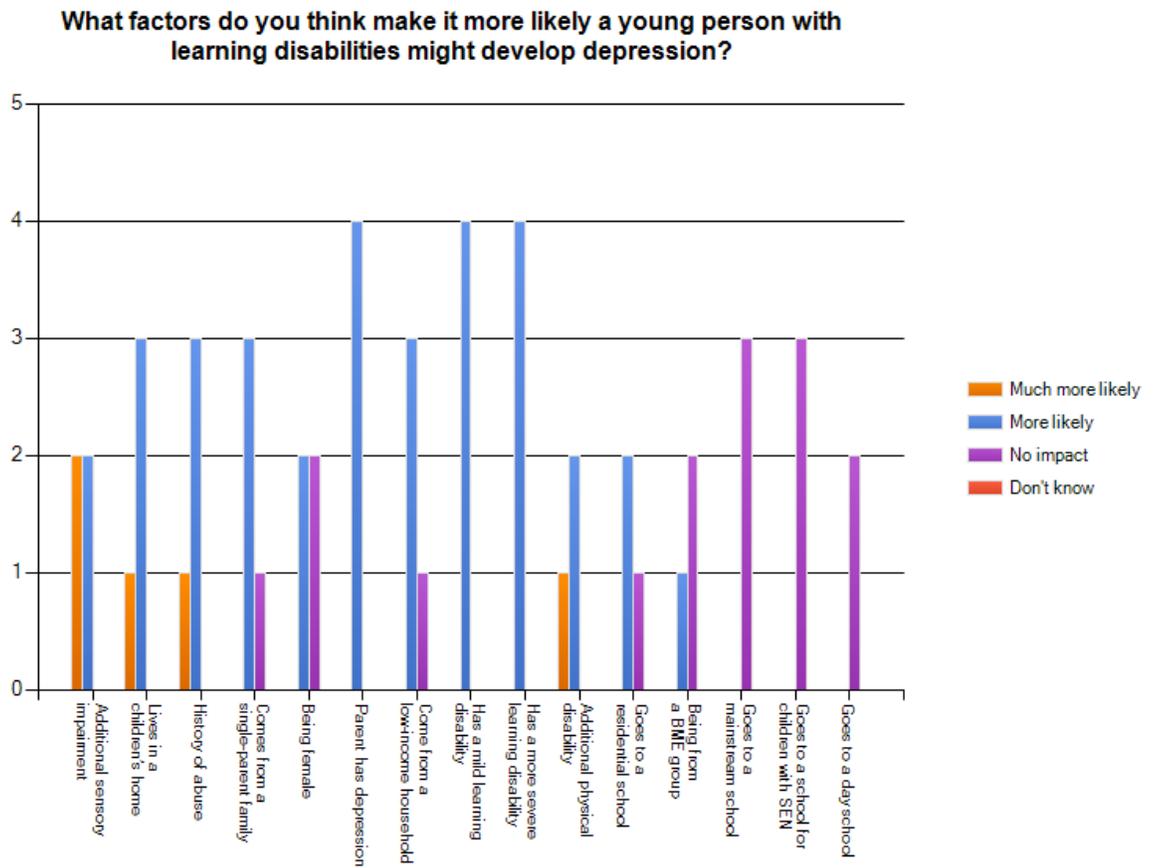


Figure 8

Figure 8 shows the perceived risk factors for depression amongst respondents. Environmental factors were considered to be the greatest risk, such as a parent with depression, coming from a single-parent family, living in a children's home and coming from a low-income household. A history of abuse was also considered a risk factor. Both having a mild learning disability and having a more severe learning disability were considered to increase the risk of depression.

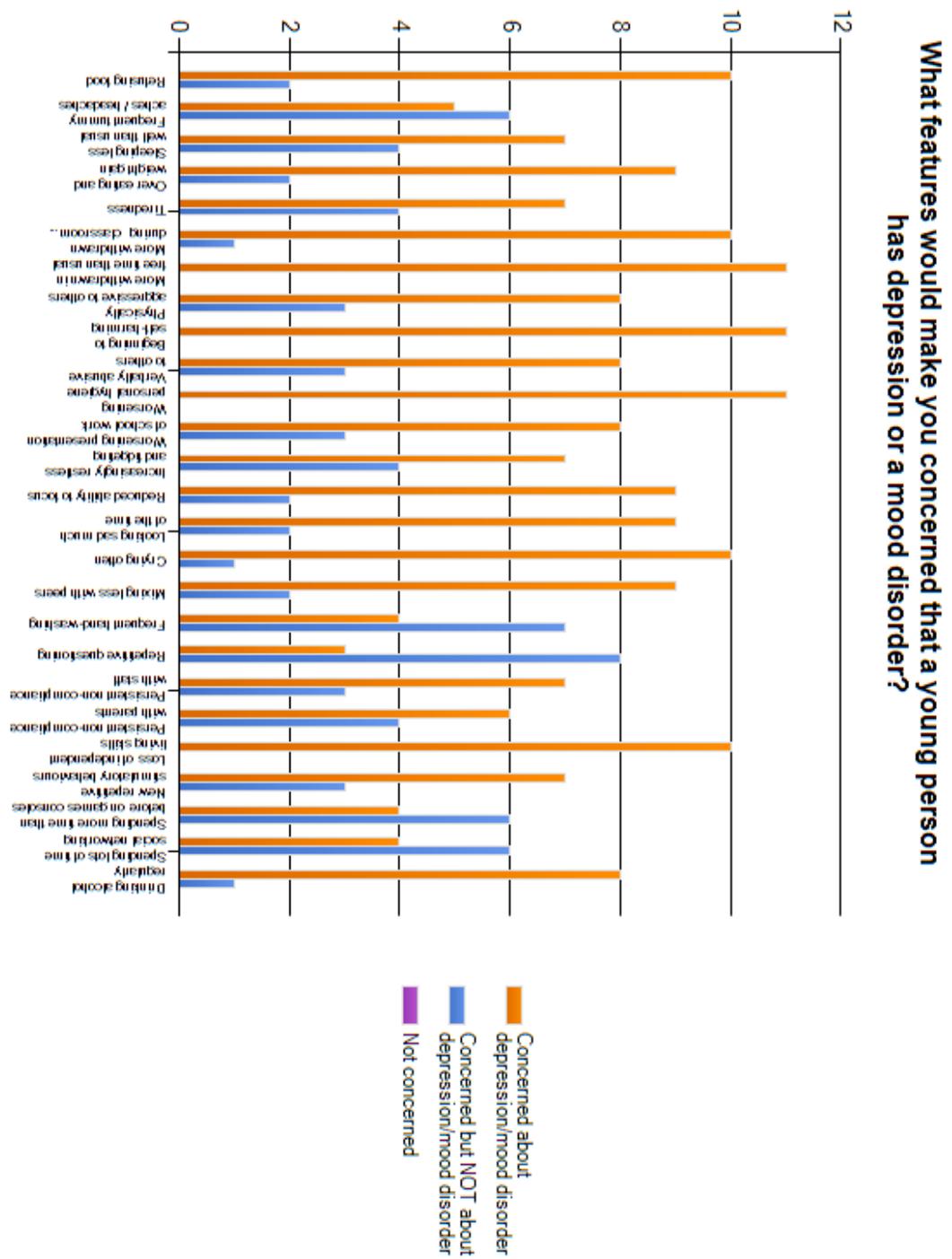


Figure 9

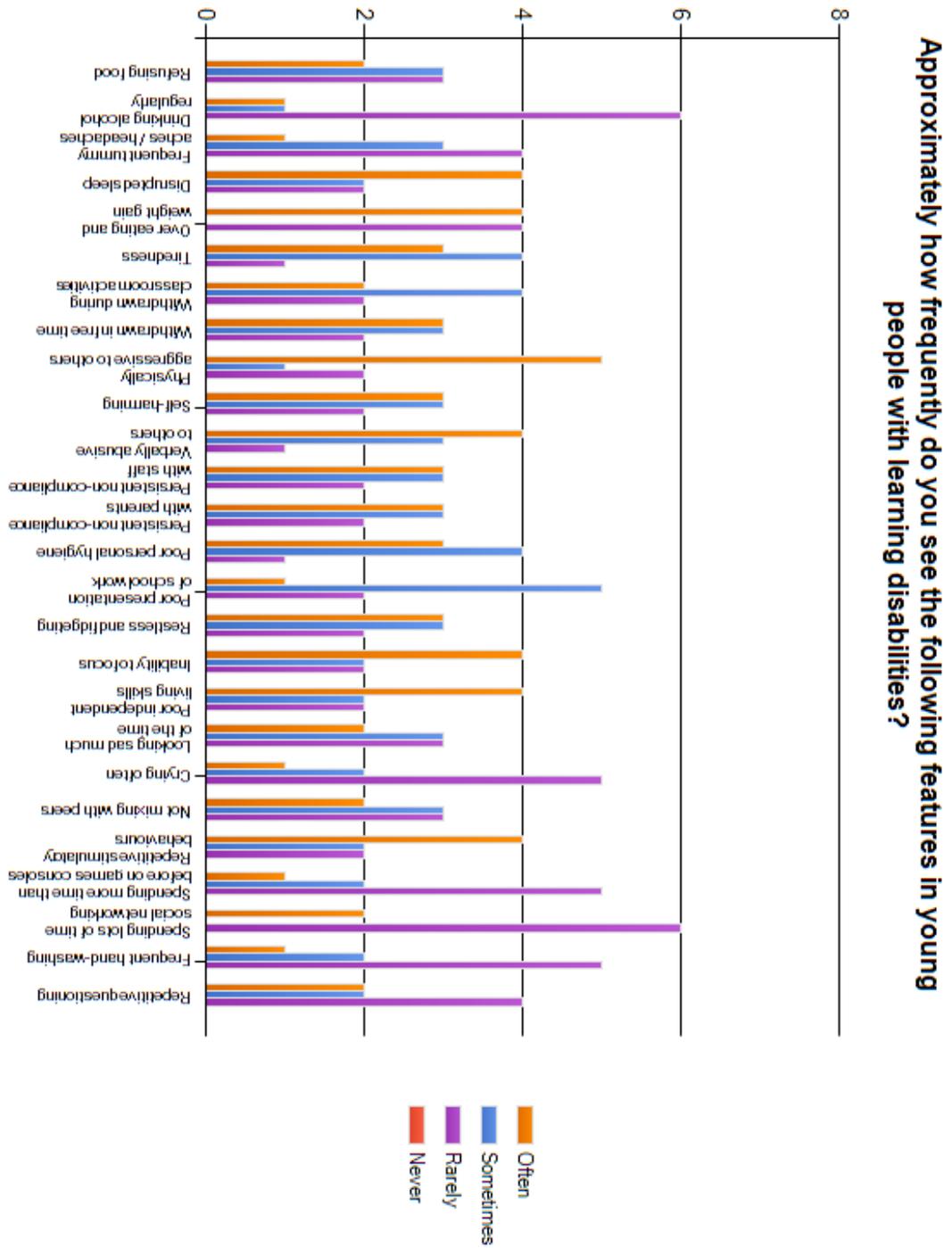


Figure 10

Figure 9 illustrates factors which would make a person concerned that a young person has depression. Figure 10 indicates the frequency with which these

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behaviours are seen in young people with learning disabilities. Many of the signs which would be of concern are also frequently seen in young people with learning disabilities, such as tiredness, withdrawn in the classroom and free time, poor personal hygiene and poor independent living skills.

Discussion

Findings of the survey

The number of responses to the survey was too low to draw meaningful conclusions from them. Future work must consider how participation rates can be increased. However, some important themes can be noted.

Multi-disciplinary working

The respondents varied greatly in their roles and settings. This is illustrative of the fact that young people with learning disabilities are supported in a great variety of settings and by multi-disciplinary teams. All respondents also had contact with other professionals including school and external counsellors, GPs, Social Workers, CAMHS Teams, Psychologists and Psychiatrists. This is in line with the National Service Framework for children and young people (DH, 2004) which identifies the importance of multi-disciplinary support. However, it can also lead to confusion and inconsistency between service providers (Raghavan, 2010); this was the experience of Sam and his mother (Appendix 1). In fact, most respondents rated the quality of support from external agencies as only 'satisfactory'. DH (ibid) guidance also asserts that children with disabilities must have equal access to CAMHS, but in practice this has not happened effectively; Wright et al (2008) note that increased numbers of CAMHS are now meeting this target, but without additional training or resources, which brings into question the quality of the service. Models of service provision are discussed below.

Level of concern and response

All of the respondents had, at some time, been concerned that a young person with learning disabilities had been depressed, signalling that this is an important issue to address. They took a variety of actions in response to this. The most common 'always' responses were to speak to parents/carers, seek advice from a line manager, review the routine and activities of the person, encourage the parents/carers to speak to the GP and refer them to someone within or outside the school. Respondents are therefore rightly recognising that this is an issue which they cannot address alone, rather one which requires professional and familial support. After the referral, 20% felt confident the person got the help they needed, with 80% feeling this was only 'partly met'; this indicates ongoing concerns which are not being met. As stated above, following referral, support from external professionals was only deemed to be 'satisfactory' by most respondents.

Training

There was a high level of recent training within the group on both mental health and depression in young people with learning disabilities, and all respondents rated this as very helpful. It would be useful to ascertain the content of the training. From the above discussion of responses to concern, it is likely that the emphasis is on identifying signs of concern and referring for support. This is indeed the approach taken by the National Association of Special Schools, in their recently launched e-learning package 'Making Sense of Mental Health' (NASS website, 2012)

Awareness of symptoms of depression

Many of the symptoms which would be of concern are also frequently seen in young people with learning disabilities, such as tiredness, withdrawn in the classroom and free time, poor personal hygiene and poor independent living skills. This illustrates the importance of knowing the person well, over a period of time. Where there is high staff turnover, poor record keeping and a lack of communication between school and home, it is less likely that changes will be noticed in order to raise concerns. Training therefore needs to focus on effective record-keeping and communication processes within and between organisations. These are key skills which need considered at every stage of the staffing process, from recruitment and selection, through induction and supervision. Management skills to ensure effective processes are in place which allow competent staff to carry out these important duties, are also essential. The Judith Trust has carried out extensive research into 'what makes a good carer?' (Stenfert Kroese and Rose, 2011).

What resources exist already?

Prevention

Zippy's Friends is a package for use by primary school teachers to promote the mental health and emotional well-being of all children. It is currently used in 27 countries and has been used on over 700,000 children (private correspondence with Zippy's Friends). Zippy's Friends for Learners with Special Needs has been developed in 2 forms: the inclusion supplement, for those with mild SEN in mainstream schools, and the special needs supplement, for those with more complex needs in SEN schools. These are currently in the early stages of being piloted. Funding is being sought for a formal evaluation of the new resources.

Recommendation 1: to act as independent evaluators for the pilot, or to fund the evaluation. Initial discussions with Zippy's Friends have been held and the Judith Trust Board (11/12/12) agreed to consider this project further, with more detailed information, at the next Board meeting.

Early Identification and Referral

The National Association of Special Schools (NASS) launched an e-learning resource for schools in October 2012. It "provides a new model of responding to the mental health needs of pupils by addressing issues such as, the identification of mental health concerns, resources for recording this information, and information about sharing and signposting concerns both within the work setting and externally to other professionals, such as CAMHS." (NASS website). This resources was distributed free of charge to NASS schools in October 2012, and is available for others to purchase.

Recommendation 2: audit the application of this resource. Once established, it may be worth considering how depression specifically can be addressed through the resource.

Accessible resources for people with learning disabilities

Appendix 3 lists a variety of accessible resources which exist to support people to understand their emotional well-being and to communicate their needs in this area;

those listed deal specifically with depression, and associated feelings of sadness. These illustrate a range of approaches, including picture symbols, stories, practical activities and easy-read information packs, thus catering for a diverse range of learning needs.

Mental Health Service Provision

In July 2012, the National Development Team for Inclusion (NDTi) published 'Reasonably Adjusted', guidelines for including people with learning disabilities in Adult Mental Health Services. This document contains a wealth of material pertaining to all areas, including accessible environments, appointment planning, information sharing, inpatient treatment and support for those in prison. Much of the material could apply to children and young people, or be easily adjusted to do so. There is currently no similar guidance for CAMHS.

Recommendation 3: To approach NDTi with a view to joint working to develop guidance for CAMHS on the inclusion of young people with learning disabilities, based on 'Reasonably Adjusted' (2012). The Judith Trust has experience of developing national good practice guidelines, having co-authored the MAPG on Forced Marriage and Learning Disabilities in 2010.

Transition

The Social Care Institute for Excellence has a film promoting good practice in mental health transitions (SCIE Website). This promotes 3 key principles of good practice

- Developing services that are flexible and welcoming to young people.
- Making sure that young people have access to a designated lead professional.
- Effective collaborative work between services.

Whilst this film does not relate to people with learning disabilities, the model still applies.

Models of service provision

Wright et al (2008) discuss 3 possible models for delivery of mental health services to young people with learning disabilities:

1. a lifetime, stand-alone, learning disability service
2. disability specialist CAMHS services
3. learning disability CAMHS services within a generic CAMHS team

They conclude that option (3) is the most practical and most likely to be successful.

The Clinical Psychologist interviewed for this study works within such a service (appendix 2). The interview notes the limitations of her service in relation to who gets referred and when, eligibility criteria and variability in the provision and delivery of such a service.

Recommendation 4: to survey CAMHS provision for people with learning disabilities to establish current working practices and highlight models of good practice, which could be incorporated into good practice guidelines suggested in Recommendation 3. In any survey, consideration would need to be given as to how to ensure adequate response rates, and the collection of adequate qualitative data.

Personal experiences

Due to the time and resource limitations of this short project, it did not explore the issues from the perspective of young people with learning disabilities themselves. However, the central importance of this is recognised and any future work stemming from this project must incorporate this perspective.

Reid and Button (1995) note that work rarely focuses on the experiences of individuals, rather being more focused on studying them from the outside. Much of the research identified by this project, through searches of online academic libraries, indeed support this. Many of the studies quoted in the literature review seek “formal verification procedures and empirical truth...seek(ing) explanations that are context-free and universal” (ibid p.602), framing the issues from a biomedical perspective. Approaches from an individual perspective are, in contrast, “context sensitive and particular” (ibid, p.602). This situation arises for 2 main reasons. One is the value placed in our society on rigorous scientific enquiry. Another, in the context of understanding learning disabilities, is the communicative difficulties which exist in many people in this group. However, studies (Reid and Button, 1995; Stalker et al, 2011) demonstrate how effective this approach can be with people with mild/moderate learning disabilities, and creative approaches can be used to enable those with more complex needs to communicate their experiences.

Recommendation 5: any future work should ensure the perspective of the individual is included. Despite the challenges this presents, studies cited demonstrate how personal experiences can be effectively expressed and enhance wider understanding of depression in people with learning disabilities.

People with mild learning disabilities

The diagnosis of a ‘learning disability’ is a medical construct defined in relation to IQ and functional abilities, including motor and social skills, with subcategories relating to severity (Bernard, 2010). ICD-10 classifies an IQ of 50-69 as ‘mild learning disability’. Particular issues arise in relation to depression, and mental health generally, in this group.

Those with mild learning disabilities are most likely to be within mainstream services, and receive least support, especially as services are cut in the current economic climate. The interview conducted with a Clinical Psychologist specialising in learning disabilities within a CAMHS Team, illustrates this. Criteria for referral to her service have recently been restricted to those with an IQ of 55 or below only. Those with milder learning disabilities, i.e. IQ 55-69, remain within the mainstream CAMHS provision.

Those with milder learning disabilities are, however, more likely to experience some of the risk factors for depression. As young people in a mainstream school, they may have similar aspiration to those of their non-disabled peers, but fewer opportunities

to realise these (Raghavan, 2010). Adolescence is a time “when young people are expected to acquire skills, go through physical and psychological maturation and assume a social identity that will enable them to fully participate in their communities” (Groce, 2004, p.14). However, many opportunities are not afforded to this group – joining sports teams, religious rites of passage, dating, making choices about where to live and who to live with, job-related training and so on (Groce, 2004). Those with milder learning disabilities may have a better understanding that their future trajectory may be different to that of their peers, or of their own aspirations, than a person with more complex needs, who may be unable to comprehend this.

Reid and Button’s (1995) study, looked at the question of ‘Who am I?’. From listening to 6 young people with mild learning disabilities, in a US mainstream school with a ‘special ed’ resource, they summarise:

“I am a person who is sometimes and in some ways unacceptable as a friend and classmate, as a brother or sister, and as a son or daughter. I am not retarded, but neither am I as able as most of my peers. I am not clear, however, about what my problems are. I am a person who, because of difficulties in school, has little control over my life. I have few choices and little voice in the decisions that affect me. I find life rather hard and people rather intimidating, but I get along as best I can” (ibid, p. 612). The image in Appendix 4 comes from the same research and illustrates powerfully one young person’s experiences of schooling.

Recommendation 6: Any future work should ensure that the scope includes people with mild learning disabilities, although they may be excluded from specialist services. For example, in recommendation 4, the survey would need to cover the eligibility criteria for specialist services and how the needs of those with mild learning disabilities are met within CAMHS.

Recommendation 7: Consideration should be given to a research project which addresses the particular needs and vulnerabilities of those with mild learning disabilities in relation to depression.

Race, Ethnicity and Gender

There were no studies found which looked at the mental health of young people with learning disabilities from BME communities. Nor were there studies which looked specifically at risk factors or experiences of young males and females as distinct groups. As outlined in the Literature Review (Parmalee, 2012; Riolo, 2005) both gender and race have been shown to be linked to depression, with Parmalee asserting that those with disabilities from different racial and gender groups experience different rates of depression.

O’Hara (2003) examined cultural competence in learning disability provision and identifies many barriers to accessing appropriate support. She asserts that those from BME communities with learning disabilities experience ‘double jeopardy’ and women within this group experience ‘triple jeopardy’. Groce (2004) asserts stigma

and prejudice to be the greatest barrier facing young people with disabilities, and that this disproportionately affects females and those from minority ethnic groups. O'Hara (ibid) notes much of the research in this area focuses on South Asian communities which experience three times the prevalence rates of learning disabilities than the wider population. This group is more likely to present to the GP with somatic symptoms rather than emotional or psychological ones, and are less likely to access specialist services. They are also disproportionately affected by lower incomes, poor housing and residence status affecting access to benefits and services. The involvement of large, extended families, with no obvious 'main carer' may affect communication, as would the use of an interpreter where the family do not speak English (O'Hara, 2003).

Recommendation 8: Any future project undertaken must examine racial and gender differences in risk, presentation and accessing treatment and support.

Conclusion

There is much research into depression in young people, and to depression in adults with learning disabilities, but gaps exist in both knowledge and good practice guidance on supporting young people with learning disabilities with depression. Research cited indicates that this group experiences significant risk factors for depression and it is therefore important that further work is carried out in this area.

The recommendations made reflect a variety of options available in research, collating and disseminating good practice, and auditing of existing resources. The Judith Trust Project Group for this Scoping Exercise, and the wider Judith Trust Board, will need to reflect upon these options and agree how to proceed with this important area of work.

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Sam is 17 and has autism. Like any other child, Sam has been through many changes and difficult times. Sam's parents divorced and Sam moved house, area and schools a number of times. Each time he went through major changes, Sam's family have supported him through it. When Sam was diagnosed with autism, Sam had a period of tearfulness and upset and also regressed. Sam's family supported him and he settled down once again.

Sam cannot express his feelings. Some effort was made to teach Sam about emotions through picture cards. However, this was done in a clinical setting and was never used in 'real life' settings like home and school. The work was done by a professional with no relationship with Sam, who showed no warmth towards him, and to whom he did not respond. The focus by other professionals on his behaviour, rather than his feelings, has led to Sam being less expressive about his feelings, and to an increase in challenging behaviour.

Following challenges at school, Sam was home educated for 2 years. During this time, his mum supported his emotional expression through music and art. Sam's artwork was produced with great concentration and love. Sam had opportunities to express his emotions through music tailored to his needs; calming tranquility music, classical music, summer pop favourites (but nothing too loud), Annie Lennox, Hayley Westenra and more. Sam enjoyed long country walks, giving him exercise and fresh air.

During the period of transition, many professionals became involved with Sam's life. Sam got anxious, and once again became tearful, upset and showed signs of regressing, including becoming incontinent. Sam's mum describes this difficult time using the words 'lethargic', 'withdrawn', 'disinterested' – with hindsight she feels what she was really talking about was Sam being depressed.

Sam moved away from home to a residential setting. Sam has a strong attachment to his mum and no emotional support was given around moving away from her. Despite a Sensory Assessment providing guidance on reducing sensory input, Sam has been placed in 'sensory overload' settings. Sam regressed further, his behaviour changed, and once again he became tearful.

Sam became incontinent. Sam's mum knows this has happened at other stressful times, and is a sign of anxiety. This is being addressed by working on developing his continence skills. Sam's mum feels that this ignores the fact that Sam was continent at the age of 3, and that there is an underlying cause which is not being addressed.

Another sign of anxiety and distress in Sam is that he starts to tear paper. Sam's mum has supported him at these times and limited this behaviour. In his new setting, they are giving him paper to tear. Once again, there is no consideration as to why this might be happening and what emotional support Sam might need. Paper tearing is seen as an 'autistic behaviour', not as a sign of emotional need.

Since Sam has left home, his behaviour has deteriorated. Sam no longer does art, or goes for country walks. Sam's mum feels that, as his behaviour gets worse, the staff's approach focuses more on crisis management than prevention. She feels the staff speak to him in a sarcastic and threatening way. She knows that physical interventions have been used on him. The question is always "How do we stop him doing this?" Nobody seems to be asking "Why is he doing this?"

Sam's mum would like to move him somewhere more supportive, and closer to home. However, she is mindful that he will need to move from children's services to adult services in just over a year. She worries about moving him twice in a short period of time, so for now, he will stay where he is. She worries about how he will respond to the process of Transition.

Sam's mum feels Sam has been let down by the system. Moving from one area to another she has seen different practices and felt better supported in an area where learning disability and mental health services were more integrated, and where Sam was offered some counselling, albeit briefly. She feels confused about who is who, and what roles people play, within Sam's current care.

Sam's mum would like to see more creative therapies being used to allow Sam to express himself through music, dance and art. She would like services to focus on individuals and not on the child's diagnosis or their age. She would like Sam to be seen and supported as a child with emotional needs.

Appendix 2: **Summary of points made by Clinical Psychologist**

The Project Officer was contacted by a Clinical Psychologist working with children and young people with learning disabilities, in a London-based CAMHS Team. Below is a summary of the key points raised in the discussion.

Service provision:

- Not all boroughs or areas have such a specialist service
- Where such services exist, they vary in size, referral criteria, practices etc
- Work is needed to ascertain and evaluate the practices of such services

Referrals and criteria:

- Criteria for referrals to the learning disability service within CAMHS has been restricted to those with IQ of approx 55 (previously IQ of 70) – those with mild learning disabilities are therefore now reliant on mainstream CAMHS services
- Most referrals are children in SEN schools, not mainstream schools. More children from mainstream schools were seen prior to the change in referral criteria
- Most young people are referred because of behavioural problems which affects their ability to function at school, at home and/or in the community
- Often referrals occur when a child is at risk of exclusion from school
- Children with learning disabilities without behavioural problems would not get referred to CAMHS
- A greater understanding of the signs and symptoms amongst parents, teachers and support staff would lead to earlier intervention, rather than crisis-point intervention. This would make interventions more effective and reduce costs to all services.
- GPs sometimes refer and are an important link in getting support for children with learning disabilities
- Those with IQs 55-70 are rarely eligible for Adult Learning Disability Services and may or may not qualify for Adult Mental Health Services

Diagnosis:

- Differential diagnosis can be difficult; it is rarely clear cut
- In the mainstream CAMHS there are some individuals who are referred for suspected depression and then get identified as having Aspergers
- Physical health is also an important consideration – behaviour may be a sign of physical problems, and physical problems may be a sign of an underlying emotional problem – hard to unpack it, especially when the person has learning disabilities and may not be able to express themselves

Training on mental health:

- Most mental health training for staff within schools focuses on promoting mental well-being. It rarely focuses on signs, symptoms and what to do if you are concerned.

Interventions:

- Most interventions are systemic, working with parents, carers and schools
- A lot of support is needed to encourage communication between parents and services e.g. foster carers, school, after-school clubs etc
- Family therapy can be offered
- 1:1 therapy can be offered if the person is able to engage
- No creative therapies are available via this CAMHS
- When working with a child with a learning disability, specialist schools may have the attitude that 'we know everything about learning' and therefore don't always respond positively to external involvement. If mental health is mentioned, then the balance changes and they are more responsive to external input.

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Appendix 3: **Accessible resources on Depression**

All about feeling down

A booklet for young people with learning disabilities
The Foundation for People with Learning Disabilities

Depression.

What is depression? What causes depression? What treatments are available?
From Change, Units 19/20, Unity Business Centre,
26 Roundhay Road, Leeds, LS7 1AB.
Tel:0113 243 0202

Coping with stress

From BILD Publications,
Plymbridge Distributors,
Plymbridge House, Plymouth, PL6 7PZ.
Tel:01752 202301

Feeling blue

From Book Sales,
Royal College of Psychiatrists,
17 Belgrave Square,
London, SW1X 8PG.
Tel:020 7235 2351 x146

Zippy's friends for children with Special Needs

<http://www.partnershipforchildren.org.uk/teachers/zippy-s-friends-for-children-with-special-needs.html>

Change Picture Bundles

Mental Health Part 1: <http://www.changepeople.co.uk/productDetails.php?id=1915>
Mental Health Part 2:
<http://www.changepeople.co.uk/productDetails.php?id=1916&type=5>

Sonia feels sad

Book
Sheila Hollins and Roger Banks. Illustrated by Lisa Kopper
<http://www.booksbeyondwords.co.uk/node/42>

From Reid and Button (1995)

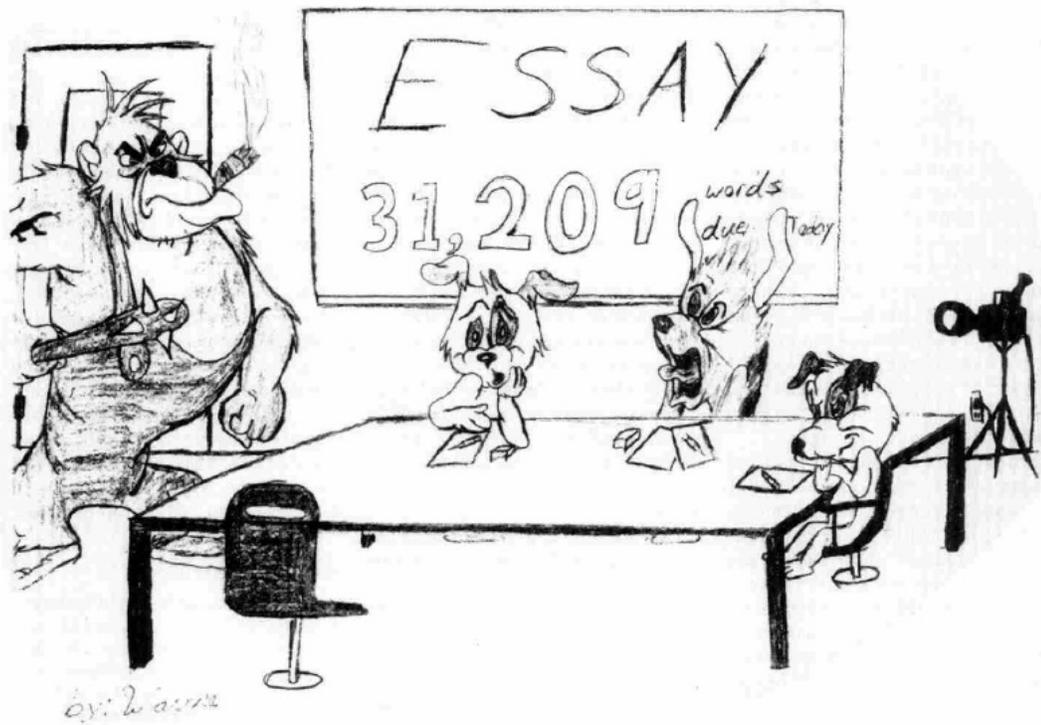


FIGURE 1. Wayne's vision of schooling.