

### **Accessible Summary**

A group of adults with mild to moderate learning difficulties said they found it hard at times to find someone to talk to who understands them. They said this is important because everybody should have someone to talk to and share their feelings with. They wanted to know what had been written about this and what research had been done. A literature review was undertaken and found that:

- The emotional lives of adults with learning difficulties have not been researched very much.
- Supporters often don't realise that people with learning difficulties would like more opportunities to talk and share their feelings.
- Adults with learning difficulties are good at supporting each other and that more could be done to help this to happen.

### **Summary**

Adults with mild or moderate learning difficulties identified a need for more opportunities to access appropriate emotional support. A narrative literature review provides evidence that emotional unrest exists but receives little attention from supporters due to an emphasis on practical issues associated with an inclusion agenda. The review highlights a lack of research on emotional support for adults and explores reasons for this. Factors associated with dealing with emotional unrest, such as self-esteem / self-awareness, a person's attitude to having learning difficulties, emotional competency and friendship issues are discussed. The value that people with learning difficulties place on support from others with learning difficulties, i.e. peer support, emerges as a theme and an argument is presented for further inclusive research in this area.

## **Introduction**

*“There’s nothing really offered to people with learning disabilities, you know there’s nothing on offer so you just bottle it up”*

*“We want to find different and creative ways of talking about our feelings”*

These quotes from adults with mild to moderate learning difficulties illustrate experiences of a lack of accessible emotional support. This was described as wider opportunities to talk about everyday experiences and feelings with someone who could empathise with experiences. As the identified need was not a level requiring clinical/professional involvement, it is referred to hereon in as sub-clinical emotional support. I, a university researcher, facilitated five workshops to enable deeper exploration of the issue identified by the five adults. Support staff accompanied members, contributing only if invited to by those they supported. Mindful of the tendency for work with people with learning difficulties to be approached from a starting point of what they can't do rather than what they can, termed 'deficit thinking' (Goodley, 2000, Dagnan, 2008), I adopted a 'strengths based approach'. The benefits of this approach have been evidenced in relation to improving social networks and enhancing well-being (Pattoni, 2012). In this case, it ensured the focus and direction of discussion was driven by the group.

Members of the group live independently with some support. They work as trainers of service providers on issues related to learning difficulties. Following an initial two workshops, two other adults with learning difficulties, members of an advocacy organisation, unknown to the original members, were invited to join. This was in order to ascertain whether the identified issue resonated with others' experiences, which it did. Within the group, I observed members offering one another support and demonstrating significant levels of empathy. They were keen to explore what is known about adults with learning difficulties supporting one another emotionally and, once introduced to the notion of peer support, wanted to understand its potential for addressing the identified need. We established that a narrative literature review was necessary as such enables links to be made between studies on a range of relevant topics (Beaumeister and Leary, 1997). The aims were to identify evidence related to: the need for sub-clinical emotional support; factors associated with dealing with emotions; adults with learning difficulties providing emotional support; gaps in the literature and potential for further research. The group asked that I conducted the review and fed back to them. The group considered the results and we co-presented findings to a local learning disability research forum.

### **Identification of literature**

The search centred on material related to adults (aged 18 or above), with mild or moderate learning difficulties living in non-residential settings. The time period covered was 1990 to 2013. Literature on therapeutic/clinical interventions was not prioritised.

Academic databases: CINAHL; Psychinfo; Conference Proceedings Citation Index; IngentaConnect; IBSS; NHS Evidence; Social Care Online and Social Sciences Citation Index. Reference lists identified further relevant literature.

Although people with learning difficulties prefer to use this term (BILD), searches also included:

- Learning disability/ies
- Intellectual impairment
- Intellectual disability/ies

In conjunction with:

- Emotional support
- Emotions
- Emotional Intelligence/competence
- Resilience
- Well-being
- Quality of Life
- Peer Support
- Mutual aid
- Friends/friendship

The above terms were agreed by the group. They clearly identified that the sought after opportunities to talk about feelings were unlikely to be provided by paid workers or family for two reasons. Firstly, in their experience, such support had generally not been

forthcoming. Secondly, relationships with family members and supporters were recognised as being a cause of emotional unrest at times.

The literature exploring the emotional lives of people with learning difficulties is not extensive. Emotional needs tend to be researched either in terms of children and young people (eg Greenham, 1999, Nelson and Harwood, 2011) and/or in relation to clinical mental health issues (eg Taylor et al., 2013, Prout and Browning, 2011). Therefore this review covered a range of outputs. The following were found relevant: Articles based on ten qualitative, five quantitative, two mixed methods studies; three on secondary or meta analysis; two literature reviews; six book chapters and six discursive articles / editorials.

Literature is considered in relation to evidence of emotional unrest and factors associated with dealing with this. Individual factors include self-awareness/self-esteem, awareness of / attitude to learning difficulties and emotional competency. Wider factors considered are friendship and peer support. Having identified that the emotional needs of adults with learning difficulties are under researched, the literature is examined to understand why this might be.

## **1 Evidence of emotional unrest**

The group recognised that it was important to understand what knowledge of the emotional lives of adults with learning difficulties exists. Research, such as the meta-analysis on fifty eight studies conducted by Nelson and Harwood (2012), indicates that children and

adolescents with learning difficulties have lower levels of emotional well-being than the general population. Klassen et al. (2011) examined whether this trend continues into adulthood. They conducted a meta-analysis of studies focussed on adults. Fifteen met their inclusion criteria. A similar picture emerged for adults in that they too internalise problems to a greater extent than non-learning disabled adults, experiencing disturbances of emotions and moods which can result in sub-clinical anxiety or depression. Further evidence is provided in the Foundation for People with Learning Disabilities' report on mental well-being based on a literature review and national survey. It highlights that the level of mental health problems for adults is equivalent to and, according to some studies, higher than the general population (Burke, 2014).

The Literature identifies a number of challenges associated with an increased risk to mental health including restricted employment and leisure opportunities, debt, difficulties with relationships, stigmatisation, disablism, lack of self-determination and poor self-image (Taylor and Knapp, 2013, Beart et al., 2005, Hatton and Taylor, 2010). Evidence illustrates the impact of such challenges on the emotional lives of people with learning difficulties. For example, findings from analysis of a cross sectional survey of adults with learning difficulties includes clear associations between poorer levels of self-reported health and well-being and a) experiencing bullying and disablism and b) greater levels of social and material hardship (Emerson, 2010, Emerson and Hatton, 2008). Emerson and Johoda (2013), in their book chapter on factors determining emotional and behavioural difficulties, cite evidence of negative impacts of social marginalisation, low socio-economic position and/or poverty. The significance of this, it is argued, is due to a high tendency for people with learning difficulties

to live in lower socio-economic conditions. Psychological causes of emotional unrest, particularly the effects of stigmatisation and social comparisons, have been explored (Beart et al., 2005, Paterson et al., 2012) and are discussed more below.

A review of the literature clearly shows that adults with learning difficulties experience emotional unrest at both clinical and sub-clinical levels. Reasons include social deprivations, marginalisation, prejudice, stigmatisation and bullying that the label of learning disabled brings with it.

## **2 Factors associated with dealing with emotions**

A strengths based approach requires consideration of the resources and strategies people draw on to manage risks and challenges in order to protect their emotional well-being. Firstly factors related to the individual: self esteem; awareness of / attitude to learning difficulties and emotional competency are explored. We then go on to consider factors that are relational by looking at literature on friendship and peer support.

### **2.1 Self esteem / self awareness**

Although many issues could present risks to emotional well-being, not everyone experiences emotional problems. Morrison and Cosden (1997), using a risk and resilience framework to review literature, found that raised levels of self-esteem and self-awareness, particularly in relation to disability, are a protective factor from risk of emotional maladjustment. Lower

levels of self-esteem are found to be positively related to higher perceptions of stigma (Paterson et al. 2012), i.e. experiencing an '*attribute that is deeply discrediting*' (Goffman 1990, 13). However, Paterson et al., in their quantitative study utilising stigma, social comparison and self-esteem measures with 43 adults, highlight that this relationship is complex in that low self-esteem can sensitise a person to the effects of stigmatisation.

Jahoda et al. (2010) recognise the complexity of issues related to self-esteem and awareness and their relationship to mental well-being. Utilising an ethnographic case study approach, they highlight the relevance of social as well as interpersonal issues. From a social perspective, Beart et al. (2004) report findings from a qualitative study with eight self-advocates on group membership. Positive changes in self-concept were identified as resulting from being listened to and valued within a supportive environment. One element of group membership is comparison with others. Paterson et al. (2012) suggest that protection from negative social comparisons and the potential to raise levels of self-esteem may be related to adults with learning difficulties having opportunities to adopt a variety of roles in life. Utilising the theory of 'psychological complexity' (Linville 1987 cited in Paterson et al., 2012), they argue that such opportunities can offer outlets for a variety of aspects of the self.

## **2.2 Awareness of / attitude to learning difficulties**

A person's awareness of, and attitude to, having learning difficulties relates to levels of self-esteem. This is evidenced in Goldberg et al.'s (2003) qualitative study involving interviews with 41 adults, part of a 20 year longitudinal study. Along with Klasson et al. (2011), they argue that those who compartmentalise learning difficulties, accepting it as a facet of who they are but not necessarily the dominant or defining one, are likely to have higher levels of self-esteem in adult life. Rather than denying impairment or rejecting related terms/labels, some people choose rather to reject the negative connotations and stereotyping that accompany them (Paterson et al. 2012, Jahoda et al. 2010).

People's attitude to having learning difficulties is raised within discussions of emotional competency. Klasson et al. (2011) suggest that an important aspect of developing greater emotional competency, and thus emotional well-being, is having an understanding of the role that a history of learning difficulties plays. Psychological effects that can result from experiencing learning difficulties in childhood can persist into adulthood. Recognition of this enables greater awareness of, and potentially ability to deal with, ensuing emotional challenges. This resonates with the work of Szivos and Griffiths (1990). Through group therapy they explored group processes involved in 'coming to terms' with having learning difficulties. One conclusion was that many adults with learning difficulties benefit emotionally from opportunities to explore together that they face difficulties in some aspects of their lives.

### **2.3 Emotional competency**

*“Emotional competence can be defined as an individual difference in how effectively people deal with emotions and emotionally charged problems” (Ciarrochi and Scott, 2006, pg 232)*

Although people with learning difficulties can sometimes struggle to recognise emotions, experimental studies demonstrate that those with mild learning difficulties can: recognize and label emotions; discriminate thoughts, feelings, and behaviours and make connections between feelings and life events (see overview in Taylor and Knapp, 2013 ). Research suggests that working with people to develop their emotional competency could reap benefits in terms of increased life satisfaction. Rey et al.’s (2013) quantitative study, used a variety of scales related to people’s assessments of their subjective quality of life. They report a ‘positive and significant association’ between emotional competence and life satisfaction/happiness, noting that *“EC dimensions were predictors of well-being beyond socio-demographic variables and dispositional affectivity”* (pg 146).

Factors associated with an individual in relation to dealing with emotional unrest have been identified from the literature. Raised self-esteem, self-awareness in relation to having learning difficulties and developed emotional competency are shown to play a protective role in relation to emotional health and well-being. We move now to consider literature related to specific relationships, i.e. friendship and peer support.

## **2.4 Friendship**

Friendship, along with other means of social support, positively impacts on both physical and mental health (WHO, 2003, Knox and Hickson, 2008). However, the sparse research, predominantly qualitative, with adults with learning difficulties shows how friendships can be unstable, requiring support when they go wrong, as noted in McKenzie's (2010) book chapter on friendships and social networks.

One way in which people might access support around friendships is from paid workers. However, George et al. (2011) found in their qualitative study with ten front-line staff that issues such as service planning and modification of behaviour tended to be prioritised over emotional needs. Such prioritisation may be a result of challenges staff experience identifying emotional or mental health concerns in those they support, as identified in Arthur's (2003) review of literature on the emotional lives of people with learning disabilities. Supporters' prioritisation of practical over emotional support and failure to understand the importance of formation and maintenance of friendships is highlighted in findings from McVilly et al.'s (2006) work with a group of eleven self-advocates. The advocates reviewed findings from a study on experiences of loneliness of adults with learning difficulties. Advocates verified findings suggesting that providers of support need to have a deeper understanding and awareness of the experiences and aspirations of those they support. In terms of the policy environment, McConkey (2010), in a book chapter on promoting friendship, suggests it is inherently risk averse. It is argued that supporters need to engage in positive risk taking to better enable friendships for adults with learning difficulties. These issues are important given the power that support workers have in terms of enabling or destroying individuals' relationships, as highlighted in Knox and Hickson's

(2008) qualitative study on the meaning of close friendships for four adults. Their research highlights that peer friendships are the closest and most valued by people with learning disabilities. However, within a policy environment focused on integration, supporters may pay more attention to friendships with those without learning difficulties, as identified by Wall (1998) writing from a Social Work perspective. This risks detrimentally devaluing peer friendships (Chappell, 1994).

An element of support is assistance with development of social skills. However, Emerson and McVilly's (2004) study, based on data collected from a sample of adults with learning difficulties within the context of audit based reviews, found this insufficient. In exploring friendship activity, they found the setting in which people live to be more significant in determining the shape of activities with friends than personal characteristics and so argue that interventions at a system level are also necessary. This conclusion is corroborated by ethnographic research carried out within an 'intentional community', ie one based on a co-operative model with explicit common values (Randell and Cumella, 2009). Such a living arrangement provided good opportunities for friendship due to the explicit importance and promotion of community and an absence of staff/resident power relationships. In particular, this setting was found to enable highly valued friendships between people with learning difficulties.

Therefore, the literature indicates that whilst friendships may be a useful resource for adults with learning difficulties to help them manage emotional unrest, there may be few opportunities, and inadequate support, to develop and maintain them.

## **2.5 Peer Support**

The group whose work initiated this literature review noted the value of support from one another. Therefore the notion of peer support was included. Peer support is a well-recognised and used mechanism in the areas of disabilities, addictions, mental health and long-term conditions (Barnes and Mercer 2006, Mental Health Foundation, 2012). Peer support is based upon the conviction that people with like experiences are better able to relate to those they support, offering '*more authentic empathy and validation*' (Mead and Macneil, 2006, pg 29).

Peer support between adults with learning difficulties is an under researched area. This is despite observations of it contributing to emotional coping strategies by adults identified as living successful lives in a qualitative, longitudinal study (Goldberg et al. 2003).

Furthermore, psychologists have observed unexpected benefits for members of therapeutic groups from peer interactions and support (Heneage et al., 2012, Marwood and Hewitt, 2013). The research that does exist, focused largely on children and young people, identifies benefits of peer support in relation to talking about feelings (Williams and Heslop, 2006). Evidence of mutual support between adults with learning difficulties tends to focus on self-advocacy (Buchanan and Walmsley, 2006; Goodley, 2005), where meeting together,

sharing experiences and supporting one another is central, albeit with a focus on rights rather than emotional support (National Centre for Independent Living, 2008). Buchanan and Walmsley's (2006) review of the history of self advocacy shows how adults with learning difficulties are strengthened by working together, sharing skills and developing confidence.

Participatory research by Keyes and Brandon (2012) goes some way to addressing the gap in research related to peer support. They document ways in which members of a theatre group support and nurture each other, both within the confines of the group as well as beyond its boundaries. They comment upon the unique quality of peer to peer relationships which *"challenges assumptions that people with LD lack insight into interpersonal interaction"* (pg 18).

### **3. Why is sub-clinical emotional need/support under-researched?**

Despite evidence of emotional unrest, the emotional and mental health needs of adults with learning difficulties have historically received little attention (Taylor and Knapp, 2013).

The relative lack of qualitative, in-depth studies focussed on the voice of people with learning difficulties themselves, is highlighted by Beart et al. (2005). In their review of studies related to the subjective experience of people with learning difficulties and identity, it was observed that few met their criteria of a) not being purely quantitative and b) based on interviews with people themselves rather than carers. It is argued that the inattention stems from either reluctance or a lack of confidence in recognising and addressing emotions experienced by people with learning difficulties (Arthur, 2003). Historically people with learning difficulties were assumed to lack awareness of their social situation and so not be

affected by it (Emerson and Jahoda, 2013). Alongside this, approaches to work with adults with learning difficulties have been critiqued for neglecting their subjective experience. For example, Szivos and Griffiths' (1990) argue that commentary on the 'normalisation' approach lacks reference "*to the individual as a feeling, sensate, being*" (pg 334).

## **Discussion**

The stimulus for this review, i.e. adults with learning difficulties identifying a need for emotional support, illustrates adults with mild to moderate learning difficulties' capabilities in relation to identification of emotions and support needs. The literature illuminates how attitudes to, and knowledge of, emotional competency in adults with learning difficulties might explain this need. Although assumptions around a lack of emotional competency and inability to develop it have been challenged, arguably such assumptions still inform the shape of support on offer. These are manifest within identified challenges support workers face in recognising emotional problems in those they support and associated gaps in training (George et al., 2011), alongside a policy context prioritising social inclusion, skill development and risk management.

The literature evidences that higher levels of emotional competency, self-esteem and understanding of the role that learning difficulties plays within lives are associated with greater mental well-being. This potentially contributes to a person's resilience. The notion of 'resilience' is a feature of commentary on people with learning difficulties' well-being (Emerson and Jahoda, 2013, Dagnan, 2008, Goodley, 2005). Goodley (2005), in an article

critiquing the relationship between the aims of learning disability related policy and the self-advocacy movement, argues that a shift from a focus on deficits to a focus on emotional well-being and a person centred approach, increases an individual's resilience. Resilience in this context refers to an individual's capacity to experience difficult life events, which may cause stress or anxiety, but have the ability to avoid long-term negative psychological effects. These arguments are highly relevant to the issue of sub-clinical emotional support when considered in terms of prevention of more acute mental health issues and need for clinical interventions.

Dagnan (2008), in discussing individual interventions linked to mental health, suggests resilience could be fostered to a greater extent if developments in the mental health field were mirrored. He cites the recovery movement, incorporating peer support, which is based on hope and development of skills for accepting, managing and living successfully with a mental health condition. Such resonates with the cited importance of attitude to, and understanding of, learning difficulties. Dagnan contrasts this with the focus on deficits and disadvantage that underpin approaches to research related to mental health in adults with learning difficulties. There is a turn towards inclusive research with people with learning **difficulties**, i.e. an approach underpinned by notions of co-production of knowledge (Nind and Vinha, 2014). The topic of emotional support needs could benefit from such an approach.

The capacity for, and practice of, adults with mild to moderate learning difficulties supporting each other emotionally emerges from this review. Evidence exists that the

empathy and support demonstrated within the group that provoked this review of literature occurs in other settings, alongside the value that adults place upon peer relationships. Evidence suggests that emphasis on inclusion and 'normalisation' has obstructed recognition and appreciation of valued relationships between adults with learning difficulties by supporters. Thus opportunities for establishing and maintaining such relationships can be restricted.

### **Conclusions**

The literature reviewed illustrates the contribution to knowledge made by varying research methods. The section on factors associated with dealing with emotions illustrates the way in which qualitative studies can complement quantitative work, enabling the voice of people with learning difficulties to emerge and add depth to understanding. The literature suggests that adults with mild or moderate learning difficulties support each other. However, there is a gap in the literature with regards to whether such peers are a source of sub-clinical emotional support. Therefore, in-keeping with a focus on ability, further qualitative research in this area would benefit from being inclusive, driven by the experiences of adults with learning difficulties themselves. An inclusive approach, based upon reflective practice (Nind and Vinha, 2014), will contribute to facilitating the direct voice of people with learning difficulties.

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