

‘It’s like an itch and I want to get it away but it’s still there’: understandings and experiences of anxiety and depression among young people with intellectual disabilities

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This paper reports findings from a study funded by the Foundation for People with Learning Disabilities which aimed to explore experiences of anxiety and depression among 17 young people with learning disabilities in Scotland. A series of unstructured interviews were conducted with the young people while one semi-structured interview took place with their families and/or with relevant professionals. The young people talked about their distress in various ways, including medical terms, bodily sensations, feelings and emotions, behaviours, and specific fears. Those who could identify the cause(s) of their distress referred to stressful life events, troublesome medical conditions, difficulties negotiating the transition to adulthood, and social isolation. The young people said relatively little about what helped reduce their distress: a few had good formal or informal support while others had tried to develop their own coping strategies. The findings are discussed in relation to social crisis theory. Policy and practice implications are highlighted.

Keywords: young people; learning disabilities; mental health; user views

Introduction

This paper reports findings from a two-year study funded by the Foundation for People with Learning Disabilities (Wilson et al. 2005) and conducted in Scotland. The research aimed to:

- explore how young people with intellectual disabilities understand and experience anxiety and depression;
- examine their perceptions of how these conditions impact on their lives;
- explore how parents and carers identify and cope with anxiety and depression in young people;
- examine how service providers support these families.

In this paper the focus will be very much on the first aim, examining the young people’s understandings and experiences of anxiety and depression.

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We begin by outlining some key points from the literature on subjective well-being and influences from the wider social environment. This section also touches on identity issues among young people with intellectual disabilities. After discussing the research methods used and describing the participants, we report how young people talked about their anxiety/depression, the factors they associated with their distress, and the support they found helpful. The concluding section discusses these findings in the light of social crisis theory and draws out the implications for policy and practice.

Research context

In 2002, The Foundation for People with Learning Disabilities published the results of its year-long enquiry into the mental well-being of young people with learning disabilities. Reflecting the findings of other research (Emerson 2003), it found a heightened vulnerability to emotional distress and a growing recognition that young people's needs were poorly met by services. Emerson and Hatton (2007) carried out a secondary analysis of the 1999 and 2004 surveys of the mental health of children, conducted by the British government. They found a far higher point prevalence of psychiatric disorders (36%) amongst the children with intellectual disabilities than amongst their non-disabled peers (8%). Moreover, the children with intellectual disabilities had more exposure to social disadvantage, which in turn was found to be significantly associated with emotional distress. These findings serve as a powerful reminder that a focus on these young people's intellectual disabilities may lead to common social determinants of mental health being overlooked. In addition, it might be argued that their cognitive impairments mean that young people with intellectual impairments have fewer personal resources to deal with stresses caused by environmental factors such as poverty, family breakdown, and other significant life challenges.

Comparing these groups of young people on general measures of disadvantage also fails to identify the particular social experiences faced by those with intellectual disabilities that might lead to distress. For example, stigma may have a number of consequences for young people ranging from outright rejection through to more subtle forms of discrimination such as overprotection from families who love and care for them. Many current policy initiatives, such as encouraging integration into mainstream schooling, do aim to counteract these young people's stigmatized status and help them gain greater acceptance from their peers. Unfortunately, a change in attitude often lags behind structural and organizational change. A recent study into the experience of young people in special and mainstream schools found that those in mainstream settings often experienced stigmatized treatment such as demeaning comments from both fellow pupils and teachers (Cooney et al. 2006).

Other aspects of the social experience of people with intellectual disabilities also fit with known vulnerability factors such as anxiety and depression. In particular, there is considerable evidence that they often have limited social networks and support (Murray 2002; Morris 2002). Lunsky and Benson (2001) pointed to the link between fraught relationships and depression. Perhaps it is understandable that if people have few close relationships, then inter-personal conflict will have a heightened impact on their well-being. Social exclusion may also result in people enjoying fewer positive social roles, another factor which could heighten vulnerability to emotional distress (Linville 1987). For example, when they face difficulties with

one aspect of their lives, such as work, there may be limited opportunity to compensate with successes in other areas, such as parenting or being active in the life of the community.

People who have mild intellectual disabilities with clinically significant problems of anxiety and depression have been found to express their distress in a similar fashion to their non-disabled peers. This includes somatic symptoms, and cognitive and behavioural elements such as a sense of helplessness, loss of enjoyment, and withdrawal from activities (Mindham and Espie 2003; Cuthill, Espie, and Cooper 2003; Ebensen and Bensen 2005). However, the question of whether stigma or discrimination makes young people more vulnerable to mental health problems such as anxiety and depression remains a moot point. Social interactionist theories (Mead 1936) propose that others' reactions play an important role in determining people's self-perceptions. Yet social interactionist theories also take a more developmental view, and highlight the interaction between individuals and their social environment. This means that people's sense of self is relational, in that it is built upon a broader understanding of the social world of which they are a part. Hence, people with mild intellectual disabilities might reject unfair treatment, just as others would, especially if such treatment is hurtful (Jahoda and Markova 2004).

Having a sense of self in relation to the wider social world also means that people have a sense of who they want to be, and a key task of reaching adulthood is developing one's own identity. An important aim of this qualitative study was to gain insight into young people's understanding of their emotional difficulties, in the context of their wider lives, at a time when they were seeking to establish their identities as adults.

Study methods

Seventeen young people, living in two health board areas in Scotland, were recruited to the study. Using purposive sampling, they were identified through a number of agencies – mental health services for people with intellectual disabilities, Further Education (FE) colleges, special schools, and voluntary organizations. All had either been diagnosed with anxiety/depression or else serious concerns about their emotional well-being had been raised by parents or professionals. Thus, some participants were receiving support or treatment for their mental distress while others were not. Young people were given accessible information sheets about the study and had an opportunity to discuss the implications of participation with one of the research team before being asked if they wished to sign a consent form. However, consent was treated as an ongoing issue throughout the study, with researchers regularly checking that each young person wished to remain involved. A key person known to each individual, such as a community nurse or FE tutor, was identified for the researchers to contact should the young person become distressed during the course of an interview.

Nind (2008) offers a useful review of the challenges associated with interviewing people with learning disabilities. She notes that Booth and Booth (1994) reported inarticulateness in some of the parents with learning disabilities whom they interviewed: this was partly associated with low self-esteem and anxiety and may be heightened among participants in the present study. Booth and Booth stress the importance of taking time to build up rapport and trust between researcher and participant. Lewis (2004) found that narratives often worked better than structured

questions, while Goodley (1998) recommends 'natural exchanges' which may involve some direct questioning.

We also felt it was crucial to take time to get to know the participants and encourage them to feel comfortable with the researcher. Each participant was visited over a 6–12 month period. The number of visits varied depending on when individuals were recruited to the study, their willingness to remain in it and changes in their personal circumstances. Some individuals experienced particular difficulties during the fieldwork period and, with their continuing permission, were visited more often: for example, one person had a number of hospital admissions and the researcher visited him there. More common fieldwork settings included the young people's home, school, or college. The research team developed a topic guide covering various aspects of the young person's life, including daytime activities or occupation, family and friends, interests, and ambitions. We did not take the guide with us when meeting a young person but referred to it between visits to ensure coverage of all topics. The aim was to build up an overall picture of the young person's life before exploring their mental distress in depth. To do so effectively, it was vital that the authors retain a flexible approach, adapting not only questions and comments but also the timing and length of each session to suit individuals' abilities, changing circumstances and fluctuating emotional state.

It is not always easy for people to articulate their feelings of anxiety and depression – the very nature of these conditions may inhibit them from doing so. For some young people with intellectual disabilities, a limited ability to express themselves in words, coupled with confusion about what is happening to them, may increase the difficulty of articulating their distress. For a few, feelings were expressed more through actions than words. For example, Gary found it hard to put his feelings into words but regularly paced up and down his sitting room during the researcher's visits. In most cases, a conventional interview format – where researcher and respondent may spend an hour or so seated facing each other, the former posing questions but keeping relatively quiet, the latter answering questions, hopefully in some detail – would not have worked in this study. Therefore, to further facilitate communication with and self-expression by the participants, verbal methods were augmented with both activity and visual techniques. For example, the researchers accompanied some young people to cafés, pubs, or bowling alleys or they went walking together. The use of photographs in research with people with learning disabilities dates back to at least the late 1980s (Simons, Booth, and Booth 1989) when researchers took photographs of the long-stay hospital people were leaving and the new community hostels into which they were moving, using these as cues to prompt discussion during interviews. In our study, some participants were given a disposable camera and invited to take photographs of people, places, and events that were important to them. This again provided a focus for activity and discussion acting as a springboard for exploring other issues. The researcher often invited a participant to accompany him/her to the shop to collect the developed film and then to a café where they could look at and discuss the photographs, with the participant invited to comment on each one.

Some young people were also lent a camcorder to make a video diary: this proved to be a rich source of information and insight. The camcorder was set up in a place in the participant's house where he/she was able to film in private and talk openly to camera about their activities and feelings. The young people were shown how to turn the video camera off and on. Again, the researcher would meet the individual once

the film was developed to review the material and invite them to explain what was going on at the time, why they chose to film that particular scene and so on. Visual methods had the added benefit of offering the young people some measure of control over data collection, thus slightly redressing the balance of power between researcher and researched. These techniques enabled them to bring significant issues to the researchers' attention, and proved especially useful where an individual had not been very forthcoming in one-to-one conversation. Indeed, sometimes emotions were expressed in the video diary which had not come to the fore during interviews. For example, during several interviews, 21 year old Karen had sat with her head down, made no eye contact with the researcher, and said little. The researcher was surprised when Karen's video diary revealed that she had prepared a number of questions (e.g. Who do you live with? What are your hobbies? What do you want to do in the future?) to ask – and answer – herself, with some enthusiasm, looking down at her prepared written responses then back up to camera to deliver them. The video diary also showed Karen expressing a desire to take on more 'adult' activities such as cooking and independent travel but then repeating what her mother had told her – she was not allowed to do these things and was not capable of them.

With respondents' permission, the interviews were tape recorded wherever possible. When fieldwork was conducted 'on the move', the researcher wrote up notes as soon as possible thereafter. All the audio recordings were fully transcribed: some took longer than others, e.g. where a participant had a speech impairment or spoke quietly. To capture the interplay between visual and oral methods, 'photo-transcripts' of interviews were produced, with each developed photo inserted in that point of the text where the 'meaning' of the image had been discussed with the participant.

Since data had been collected in different formats for different participants, it was necessary to develop a common framework for analysis. The transcripts were carefully read and re-read, a brief 'pen portrait' was developed for each person outlining their circumstances and 'story', followed by an initial analysis of themes and concepts identified under each of the three main research questions. This was sub-divided into more detailed themes, e.g. how young people think about themselves, how they act in the world, how they report their distress; is it similar/different to non-disabled youngsters? This was an inductive process, following Miles and Huberman (1993), conducted manually. It was shared between the authors, each being responsible for presenting the initial analysis of 'their' cases to the rest of the team as a basis for discussion, comparison, and further joint analysis, allowing the development of broader categories. Attention was paid to emerging patterns as well as 'outliers' or unusual cases.

Data had also been collected from different people for each case study – the young person with learning disabilities, one or occasionally two paid workers supporting the person, and usually a family relative as well. Different accounts were not used to 'test validity', which is more appropriate to quantitative research, but to gain a range of perspectives, thus building up a richer and more authentic understanding of each young person's situation.

Sample characteristics

The 17 young people were aged between 16 and 26 and comprised nine men and eight women. All had what might be described as mild to moderate intellectual disabilities. They lived in central Scotland, seven served by a health board covering

Table 1. Summary of participant characteristics.

Pseudonym	Age	Circumstances	Type of difficulties	Help and support
Moira	19	Lives with parents Attends college p/t. Seeking employment	Epilepsy Symptoms of anxiety	Treatment for epilepsy Support from tutors at college
Sam	16	Lives with carer Attends a special school	Diagnosed with low mood/ depression and impulsivity	Bereavement counselling Psychological support Parenting support for carer. Social Work input
Karen	19	Lives with mother Attends college full time	Diagnosed with anxiety and depression	Treatment for epilepsy Psychological support Parenting support for carer. Referred to befriending service and Social Work
Jason	26	Lives with family Enjoyed part-time job but no longer working	Diagnosed with acute anxiety	Psychological support Social Work input
Susan	19	Lives with mother Recently left school and attends college	Psychiatrist noted symptoms consistent with anxiety and depression	Referred to community team
Michelle	19	Lives with family Attends college	Disputed diagnosis (anxiety or epilepsy?)	Referred to residential unit for epilepsy assessment Seeing college councillor and community learning disability team.
Joseph	17	Lives with family No occupation at first, then got a job in a supermarket.	Diagnosed with anxiety	GP referred to psychiatrist Also referred to a supported employment scheme
Adam	17	Lives with mother and sister Attends college	Acute anxiety reported by college.	None
Steve	25	Lives with parents Attends day centre three days a week	Diagnosed with depression	Had community nurse; social worker; clinical psychologist Referred to neuropsychologist Psychologist
Lorna	23	Lives with parents Attends day centre	Diagnosed with anxiety and depression	
Ann		Lives between mother and great-aunt Stopped attending day centre. Had short work placement. No job	Diagnosed with anxiety and depression	Community learning disability team
Mike	20	Community landlady/ Leaving Care Service Part-time job in a supermarket	No specific diagnosis but felt depressed	Social worker and psychologist

Table 1 (Continued)

Pseudonym	Age	Circumstances	Type of difficulties	Help and support
Paul	18	Lives with family Looking for work	School reported anxiety	None
Sarah	16	Living in hostels No occupation	Hostel reported depression	Community learning disability team
Darren	26	Lives with family	Diagnosed with anxiety	Psychiatric intervention Medication. Community nurse support
Mel	22	Lives with family	Diagnosed with anxiety and depression	Psychiatric intervention Medication Community nurse support
Gary	20	Living at home with father Not working, previously had full-time job	Diagnosed with depression and acute anxiety	Psychiatric intervention Community nurse support Medication Period of time in hospital

Note: We have no verbal data from Lorna or Steve and limited verbal data from Jason and Sarah. There are good, and in several cases very rich, data from the other 13.

rural areas and small towns; 10 served by a city health board. Table 1 summarises the characteristics of the young people (using pseudonyms).

Family carers and key health and social care professionals working with each young person were also interviewed, on one occasion each. These interviews focused on how parents responded to and managed anxiety and depression in their sons or daughters and the support available from formal services. Occasional references to these data are made in this paper.

Findings

Our first research aim was to explore how young people with intellectual disabilities understand and experience anxiety and depression. This aim was operationalized through three research questions, namely: How do young people describe/report their anxiety or depression? What do they see as the causes of their difficulties? What do they find helpful in alleviating distress? The key findings relating to these three questions are presented below.

1. How did the young people report or describe their anxiety/depression?

The young people were seldom explicitly asked to describe or report their feelings as such. As described above, the researchers visited individuals on several occasions and would often begin by asking how things had been going, or what had been happening, since they last met. If a participant chose to talk about events likely to be difficult or distressing in some way, the researcher might ask how this had made the young person feel. Similarly, if the participants described themselves as upset or worried, the researcher would encourage them to elaborate. For example, one fieldworker had this exchange with Sam, aged 16:

Sam: Sometimes I feel depressed when I'm in the house.

Researcher: How would someone know you're depressed? What are you like when you feel like that?

Sam: I've never got a smile on ma face.

In some cases, the progress or development of a young person's distress was reflected in their responses over time, with different perceptions being reported at various points as individual feelings or circumstances fluctuated, improved, or worsened.

The 13 young people who reported their feelings of distress did so, broadly speaking, in five different ways:

- in 'medical terms'
- by describing bodily sensations
- describing feelings/emotions
- reporting behaviours
- identifying particular fears

First, common *medical terms* were used by several young people, usually on a one-off basis. They described themselves, for example, as 'anxious', 'depressed', 'having a nervous breakdown', '[having] an illness...no¹ well...nerves'. It was not always clear exactly what the young people understood by terms like 'anxious' and 'depressed' nor, more significantly, what they meant when applying these terms to themselves. Some individuals may have been told, by parents or professionals, that they 'had' these conditions, a possibility reinforced by the medical model implicit in their use of diagnostic terms, the reference to 'illness' and also 'nerves', an old-fashioned term denoting anxiety.

Young people had more to say about the *bodily or physical sensations* they experienced. Sometimes this information was volunteered; sometimes it was in response to the researcher's question. For example, Joseph aged 17 said he felt nervous about his new job in a supermarket:

Researcher: When you say you feel a wee bit nervous, can you feel it in your body like?

Joseph: Yes, I've had a few... if somebody is asking something I get a bit panicky. I can feel it.

Researcher: What do you mean?

Joseph: I can feel my face going red a bit and my breathing can get bad but that's not happened for a while now.

Joseph also reported having asthma, eczema, and breathing and sleeping difficulties. He felt unable to stay in the house on his own because he became agitated and anxious when he saw people walking past outside. His mother described Joseph as shy and lacking in confidence. Other participants reported feeling 'sick', 'dizzy', and 'vomiting'. These might be described as 'physiological symptoms' but the accounts were very much in the young people's own words – 'my insides going fast... stomach churning – it makes me shiver' and 'sitting all pure scrunched up', the latter phrase vividly capturing the 'slumped' position of someone experiencing depression.

Thirdly, some young people described their mental distress in terms of *feelings or emotions*, notably fear, anger and despair. A couple described themselves as 'apprehensive' or 'scared', another as 'irritable and grumpy' while a third was 'stomping and raging'. A handful of participants implied there was little point in

carrying on living: 'I'm tired of life' said one; 'I wish I was deid²' said another while a third was described by his aunt as having a 'death wish'. Susan was a young woman living with her mother in a deprived inner city area. There was a history of domestic violence within the family and Susan's father was currently facing charges of assaulting his daughter. Susan was not looking forward to acting as a witness in the trial. She had various physical health problems and her school attendance had been low for some time, possibly due to bullying. Susan said:

One day everybody was sitting bawling at us, sometimes for nothing. What's the point in me being here, know what I mean? Just getting pure moaned at. May as well be deid, know what I mean?

Several young people described *behaviours* which seemed indicative of anxiety or depression, some making that link themselves. Escapism or comfort-seeking is a common response to unpleasant feelings: three young people reported drinking excessively and another complained that she was putting on weight through eating too much. Lethargy and a loss of interest in usual activities, another common expression of depression, affected several. Karen, aged 19, lived with her mother who also had an anxiety disorder and, according to Karen's nurse therapist, struggled to support her daughter. The nurse described Karen as becoming increasingly isolated, impacting on her self-esteem. Karen herself reported:

At the weekend I usually stay in. I may go to the shops with my ma but not often. She tries to get me to go to the town an' all that but I cannae³ be bothered going and I don't want to get ready. I don't want to wash my hair an' all that. I just want to sit about . . . I sometimes don't get up till three o'clock in the afternoon and I'm just going to get ready [for bed] at half nine.

Aggression toward self or others was another noticeable feature, with as many as five young people self-harming or threatening to kill themselves (three told us this directly; in two other cases, parents did). For example, Sam, at 16 the youngest participant, regularly got into fights at school and in the local neighbourhood, coming to the attention of the police. One night he slit his wrists and was rushed to hospital. In his short life Sam had experienced much trauma, having recently lost his mother, never having met his father, and now being anxious that the cousin with whom he lived might ask for him to be placed in a children's home.

Some participants described their anxieties in terms of *specific fears*, usually associated with meeting new people, going into unknown situations or taking on new challenges. Adam, aged 17, was 'anxious as hell' when he started college because he feared no-one would like him or speak to him:

Whenever I try something new I'm anxious. That's just the way I am. It's not the way I was brought up; it's just the way I am . . . I feel a bit sick, you know what I mean.

Situations where they would lack control, such as flying or undergoing medical procedures, were also mentioned. These are worries which many people experience at some point. However, the issues were heightened for these young people because their anxiety about unknown people and situations could be reinforced by the way other people responded to them, including bullying or harassment, or by the nature

of their impairments; for example, someone with autistic spectrum disorder may experience change and lack of control as very disturbing.

Not only were some of these young people articulate in expressing their distress, a few also chose to describe how it felt to have such experiences – and to distinguish these ‘secondary’ feelings from the ‘primary’ emotions of anxiety and depression. Some felt embarrassed or ashamed, fearing that others would consider their anxieties ‘stupid’ or notice their physical manifestation, such as ‘shaking’ or frequent trips to the toilet. One young man (in something of an under-statement) commented ‘It’s like an itch and I want to get it away but it’s still there’. This kind of ‘distress about distress’ is not uncommon (Wells 1997). A couple of participants had considerable insight into the nature of their difficulties, one admitting that his fear of being disliked was ‘irrational’ because he knew that a lot of people did like him. Adam, in a joint interview with his mother, who was telling the researcher about her son’s fondness for strict routine, responded: ‘I know it’s sad, Mum, but it keeps me right’.

2. What factors did the young people link to their distress?

The extent to which the young people identified a reason for their distress was variable. Some made an explicit link between perceived cause and effect; others talked about stressful events in a more general way. The 13 individuals who reported feeling distressed all made reference to the cause. Interestingly Ann, who gave no indication, verbal or otherwise, of feeling anxious or depressed (despite being diagnosed with anxiety and depression by a Community Learning Disability Team) reported that she was seeing a nurse because she had been ‘bad... stealing things... staying out all night’. It is unfortunate that she apparently thought a referral to nursing support was some form of punishment or moral correction.

The young people attributed their emotional distress to a wide range of factors, mostly environmental in nature, which can be grouped into four different categories – stressful life events, physical/medical conditions, transition to adulthood, and social isolation. Some of these are common issues affecting many people at different points of the life cycle. However, for a variety of reasons discussed shortly, they tended to be heightened and prolonged for these young people. In addition, most of them faced multiple stressors, with difficulties in one area causing or exacerbating those in another.

The collective ‘tally’ of *stressful life events* faced by the participants was remarkably high, given their young age. Between them, they had experienced the serious illness and/or deaths of close family and/or friends, long-term family conflicts, parental separation or divorce, domestic violence as witness and/or victim, as well as bullying, harassment and violence outside the home. A few led chaotic lives with little security or structure, which may have been both a contributor to and a result of their emotional distress. Ann, mentioned above, moved homes frequently, often missed appointments and stopped attending her day centre. The authors were unable to contact her for a follow-up interview because calls to her mobile telephone went unanswered and her community nurse did not have new contact details for Ann. The fact that most participants came from relatively deprived social backgrounds is likely to have heightened their susceptibility to adverse life events.

Secondly, about half the sample attributed their difficulties at least in part to *physical or medical conditions*. The link between physical and mental ill-health is well established (Moorey 1996) and it is not surprising that dealing with uncomfortable

and difficult conditions like irritable bowel syndrome or dystonia should cause distress. Michelle, aged 19, had been diagnosed with epilepsy at three years old but a recent assessment concluded she was not epileptic after all. Michelle's family believed they often witnessed her having epileptic seizures but were now told these were panic attacks. Michelle's tutor at FE college told us she had not witnessed any epileptic seizures: she believed Michelle deliberately fabricated shaking fits to attract attention. These conflicting views led to some tension between family and college, with Michelle seen variously as victim or manipulator. However, so-called 'pseudo-seizures' are a recognised call for help which, if unheeded, can leave people feeling their distress is not being taken seriously.

A number of participants discussed the difficulties they were experiencing in *the transition to adulthood*. This process inevitably involved change which could be experienced as loss. Paul missed the comfort and security of being at school, which he described as 'a happy wee environment': 'It's just our own wee world . . . can't live in it all day no matter how much we want tae⁴'. He was finding it hard to get paid work, compounded by discomfort when meeting new people and a fear of failure. Gary, who at one point had both a job and a flat, later gave these up and returned to living with his father because the demands of holding down a job and running his own house, with inadequate formal support, were too much. Although they did not express it in these terms, a number of participants were torn between wanting to lead more independent or 'adult' lives and the restrictions imposed on them by parental stricture, limited opportunities, inadequate support, and/or the nature of their impairments. Several compared themselves unfavourably to people of a similar age, known or unknown, or those seen as more 'normal' (a word used by some participants) or successful than themselves. Karen's nurse therapist reported her saying 'How come I'm different from my brothers and I'm stupid and how come my nephew can count and I can't and he's 7?' Difference, not relating to cognitive ability but to emerging sexuality, was also an issue for Darren who traced the onset of his anxiety to an incident when, he said, he had seen two men kissing in a gay bar. Darren also thought he had overheard his neighbours calling him a 'poof'.

A number of professionals pointed out that these young people had mild intellectual disabilities and were very aware of their similarities and (actual or perceived) differences from non-disabled peers. At the same time, their relative abilities, when compared to people with higher support needs, meant they were not always eligible, and seldom a priority, to receive services. A few had enough autonomy to sometimes find themselves in situations where they were vulnerable to exploitation or abuse.

There was a strong sense of *social isolation* among many of the young people. Linked to the difficulty of securing paid employment was the lack of meaningful occupation reported by several participants (and reported in relation to others by parents and professionals). They tended to spend much of their time at home with very little to do besides watching TV or DVDs, leading to boredom, frustration, and sometimes anger. Again, it was not only what they said but what they did which showed their isolation. Gary's video diary powerfully illustrated his sense of boredom and purposelessness, as he filmed himself lying on his bed for days on end, watching the same DVD over and over again, and occasionally shouting out that he hated Mondays, or Tuesdays, or . . . Not only did most of the participants lack the social company associated with paid work but they had limited contacts with peer groups and few close friends. It was not easy for them to maintain or initiate contacts

with former school friends or fellow college students. There were exceptions, with one or two respondents identifying good friends from whom they received some support. One FE college made a point of helping young people meet up for regular nights out. However, some young people reported conflictual relationships with 'friends', marked by frequent arguments and fallings out.

3. What did the young people find helpful in alleviating their distress?

Although 11 young people made some comments about the support they received or would like to receive, overall they had relatively little to say about what they found helpful in alleviating their distress: any opinions they did give tended to be in response to direct questions from the researcher. This may be because, overall, they were not receiving a great deal of support and/or that they did not find it particularly helpful or relevant. What they did say can be reported under four broad categories.

First, the participants talked about *their own coping strategies*, including:

- trying to keep a positive attitude
- keeping calm, for example, through breathing exercises or counting to 10
- maintaining a daily routine: one young man reported he got up in the morning when family members rose for work, even though he had nowhere to go
- staying at home to keep out of trouble
- using alcohol to boost confidence
- 'always look after number one first'

These strategies variously show evidence of agency, resilience, and self-awareness among the young people, although a couple admitted they sometimes struggled to maintain positive coping strategies or that certain short-term 'fixes' could prove unhelpful in the long run. In some cases (such as the calming exercises), activities had been suggested by a professional; in others (such as observing routine), the young person was acting on his own initiative.

Secondly, a few participants stressed the benefits of *interesting occupation*. 'Keeping busy', as Joseph put it, can help take one's mind off anxiety-provoking or depressing thoughts. Equally, it may give stimulus, status, and social contact, helping prevent such feelings occurring in the first place. Mike had a 'success story' to tell. He had been told that his part-time job might become full-time. He liked the structure work gave him and reported feeling more confident and better able to talk to people since undergoing training and getting a job:

[I'm] totally changed to what I was four years ago, completely changed. My image has changed, my health has changed, eh, my financial life has changed.

A couple of young women identified *informal support*, in both cases from their mother, as helpful. However one of these participants also reported problematic relations with her mother at times. Given that other research has found that young disabled people often identify their parents, and particularly mothers, as a very significant source of support (Closs 1998; Thomas 1999) it is striking that so few in this sample chose to do so. Indeed, as reported above, several of these families were embroiled in ongoing conflict. The lack of protection associated with close family

relationships may have left these young people with a heightened vulnerability to emotional distress.

Seven participants reported that some aspect of *professional support* had been helpful although most did not elaborate or say how it had helped. The services identified ranged from medical (e.g. psychiatrist, community psychiatric nurses) to social care (social work, community landlady, voluntary agency) to alternative therapy. Darren was very appreciative of the community nurse who visited him every three weeks. He called the nurse 'my pal' and reported that seeing him had made Darren 'a better person'. Practical help was appreciated – with finding a job or learning to travel independently – as was advice and guidance. Medication was seen as having limited usefulness: it made 'some' difference to Joseph and helped Mel 'a wee bit but not much'. Several participants were also critical of services, the main complaint being that professionals often failed to maintain contact. (This was also a comment made about families by some professionals.)

Discussion and conclusions

The experiences of anxiety and depression reported by young people with intellectual disabilities in this study are in many ways similar to those experienced by the general population both in terms of emotional and physiological sensation, and perceived cause and effect. Rosen (1997) identified three types of crisis:

- *developmental* – those crises experienced at key developmental or psychodynamic life stages
- *situational* – reactive crises, for example, following loss of job or bereavement
- *complex* – referring to severe trauma following disasters, or complex mental illness

This typology helpfully locates crisis within the 'normal' range of human experience, suggesting that many crises are a natural response to either the 'rites of passage' people encounter as they grow older or else to certain common, if often unpredictable, life events. 'Complex' crises, while least common and probably least predictable, are arguably part of a continuum rather than a quite distinct experience. Many of the young people's difficulties were sparked off by a mixture of developmental and/or situational crises and the high level of stressful life events they experienced can partly be related to social disadvantage which, as noted earlier in the paper, is linked to emotional distress (Emerson and Hatton 2007). Others were associated with poor relationships with people around them and with boredom and lack of occupation. It could be argued that these findings show the importance, as some professionals argued, of taking a 'normalising' rather than 'pathologising' approach to the emotional distress experienced by young people with intellectual disabilities.

However, the developmental crises facing these young people differed in significant aspects from that facing many other young people entering adulthood. For example, the health worries reported by some participants reflects epidemiological work which shows that people with intellectual disabilities have more mental and physical health problems than others (Bhaumik et al. 2008). On a wider sphere, as they looked into the future the young people may have discerned a range of 'possible selves' – images of what they might become, what they would like to

become and what they were afraid of becoming (Markus and Nurius 1986). Most wanted an 'ordinary' life – a job, friends, positive relationships with their families, good health, or in some cases a girlfriend or boyfriend. A key part of youth culture is to be the same as one's peers (Hughes, Russell, and Paterson 2005): these young people were acutely aware of how they were seen or treated *differently* on various dimensions, including other people's expectations of them and the opportunities available to them: this could be reflected in their own estimation of their abilities. At the very time when other young people were gaining the markers of adult status, our participants were becoming increasingly aware of the additional barriers they faced. These barriers, arising from a mixture of attitudinal, structural, and personal factors, were exacerbated by a lack of support for important aspects of adult life, including a secure home, paid employment or meaningful occupation, and satisfying social relationships.

Indeed, the study suggests that typical stressors were often heightened and prolonged for these young people. Several experienced multiple stressors which impacted on each other, creating a vicious circle out of which it was difficult to break. Caplan (1964, 1989), who developed social crisis theory, identified three phases of crisis. During the first stage, an individual feels increasing anxiety as it becomes clear that a particular problem will not be resolved easily or quickly. During the second stage, the person exhausts their own coping resources and experiences some degree of breakdown or disorganization. It is at this point, according to Caplan (1989), that the individual looks to informal support networks for help – or to formal services. The third stage will see resolution of the crisis – although not necessarily a positive one. Caplan argued that a crisis is a short-term event which, if left alone, will resolve itself – the critical issue being whether or not, as part of that process, the person gains insight into themselves and their situation and thus develops more effective coping strategies in future. The accounts given by some young people in this study showed insight, resilience, and agency. They worked hard to try to make sense of their complex lives and the distressing emotions they experienced, despite the many restrictions and barriers they faced.

However, Caplan (1989) argued that resolution may take a more negative turn, perhaps involving self harm or acute psychiatric illness, and failing to address the underlying cause of the crisis. Once a 'maladaptive' approach is taken, people are more likely to respond in the same way in future, becoming trapped in a vicious circle. Some participants appeared to fall into this category. Factors predictive of outcomes include the person's own perception of events, since cognitive understandings impact on individuals' ability to cope, the support available and the individual's coping mechanisms (Aguilera and Messick 1980, quoted in Crompton 1996). As discussed at the beginning of the paper, the presence of cognitive impairment may mean fewer personal resources are available to deal with stressful life events.

Caplan (1964) believed the *timing* of any intervention was critical, and that help offered during the second phase of crisis was most likely to be effective, as people become more dependent on others and are most amenable to external help and guidance (Crine 1981). However, as noted earlier, and as this research also shows, young people with intellectual disabilities often have limited social networks and supports (Murray 2002; Morris 2002). There is therefore a need to raise awareness among both family carers and professionals about mental health problems in young people with intellectual disabilities. Our study included several young people whose

anxiety and depression were at relatively low levels, highlighting the importance of responding to less ‘challenging’ expressions of distress in young people. Information and awareness raising also needs to be aimed at young people with learning disabilities in schools and college, stressing that, while a certain amount of low-level worry is common among teenagers and young adults, it should not dominate their mood and thoughts nor prevent them from carrying out usual activities. Young people also need accessible information about when and where to find appropriate services and help.

Our interviews with professionals showed that many were focused on providing different forms of practical help to enable their clients to lead more independent lives. Nevertheless, this research echoes findings of previous studies reporting a shortage of suitable opportunities and services for young people with learning disabilities. Several had left college with no job or structured activity to move onto and many would have welcomed more social activities. There is a need for more practical support, such as help with shopping, meal preparation, and independent travel, and easier access to ‘ordinary’ life opportunities. This should be complemented by much more explicit and robust emotional support. Many would benefit from having a designated support worker with the time to listen, support them to express and explore feelings, offer reassurance, and help boost confidence and morale. This needs to be addressed urgently if young people with learning disabilities are to lead fulfilling and satisfying lives – and if inclusion is to become a reality.

Notes

1. A Scottish abbreviation of ‘not’.
2. A Scottish form of ‘dead’.
3. A Scottish form of ‘cannot’.
4. A Scottish form of ‘to’.

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