Meeting the mental health needs of a young person with an intellectual disability: a case study

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Meeting the mental health needs of a young person with intellectual disability: A case study

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Abstract

Young people with intellectual disabilities are at greater risk of developing mental health issues. However, their mental health needs are often not recognised and therefore remain untreated. This article discusses a case study concerning a young man whose mental health needs were first noted in adolescence, and describes his experiences of accessing appropriate services and interventions. Community-based services have provided treatment and support, enabling him to continue living with his family.

The case study represents one individual's experiences but highlights issues that are relevant to other young service-users, service providers and professional practitioners.

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Introduction.

Young people with intellectual disabilities are at increased risk of experiencing mental health issues (Mazza et al., 2019; Buckley et al., 2020), and can manifest any of the complete range of psychiatric disorders (Royal College of Psychiatrists, 2016). However, although adolescents with intellectual disabilities may have significant mental health needs which affect their functional abilities, these are often not identified and thus remain untreated (Hassiotis and Turk, 2012). Explanations for not identifying such mental health needs include: inadequate screening and detection; reduced access to mental health services; the phenomenon of 'diagnostic overshadowing,' whereby mental health symptoms are mistakenly ascribed to an individual's intellectual disability (Austin et al., 2018; Buckley et al., 2020). Research findings have consistently indicated around a third of children and young people with intellectual disabilities develop mental health issues, which compares to 11 per cent of those with only a physical disability or a chronic illness, and eight per cent of children and young people in the wider population (Bernard, 2020).

A number of factors concerning this increased risk for mental health issues among young people with intellectual disabilities have been highlighted, including intrinsic biological and psychological factors, higher levels of social and economic disadvantage, as well as cultural and environmental factors (Faust and Scior, 2008; Young-Southward et al., 2017; Bernard, 2020). The psychiatric disorders commonly reported in children and adolescents with intellectual disabilities, resulting from a systematic review and analysis of pertinent studies (Buckley et al., 2020), encompassed the following: Attention deficit hyperactivity disorder(ADHD) (39%), anxiety disorders (7-34%), conduct and externalising disorders (3-21%) and depressive disorder (3-5%).

ADHD, intellectual disabilities, and autistic spectrum disorder are all neurodevelopmental disorders, which are lifelong conditions and affect various areas of functioning (McCarthy and Chaplin, 2018). Co-existing mental health issues are markedly increased amongst young people with these disorders (Hanna, 2020). Specific psychiatric diagnoses are clinically defined according to a systematised classification method, such as the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013; Buckley et al., 2020).

At present, there is scarce evidence concerning the efficacy of psychological interventions with young people who have intellectual disabilities. This is partly due to the heterogeneous character of these young people, which presents challenges in terms of designing, carrying out and interpreting studies. Therefore, as evidence-based interventions have already been developed for children and young people with mental health issues without intellectual disabilities, modified versions of these approaches can be applied (Ahmed, 2020). Moreover studies are required that investigate the experiences and life course journeys of young people with intellectual disabilities, which focus on their preparation for adulthood and effect of support for individuals and their families regarding mental health (National Institute for Health and Care Excellence (NICE), 2016).

This article discusses a case study about a young man with intellectual disability whose particular mental health needs first became evident during adolescence, and describes his personal experience of accessing appropriate services and interventions to meet those needs.

Case study: Ahmet

Ahmet (i.e. a pseudonym) is a young man aged twenty four years with mild intellectual disability who has a history of behavioural challenges, and co-existing mental health issues related to obsessive-compulsive disorder. He immigrated to England from Turkey, with his family, during early childhood. Ahmet attended a school that supported children with special educational needs, and his mental health issues initially became evident when he left school aged sixteen years. He lives with his parents and two younger siblings in an apartment located in a central city neighbourhood. Ahmet attends a day service for people with intellectual disabilities on one day a week, and goes to classes at a Further Education College on two days each week.

Method

Ahmet participated in a research study investigating adult service users' experiences regarding their mental health care. Two service managers of an organisation supporting people with intellectual disabilities living in a large inner city area assisted with Ahmet's recruitment for the study. They acted as 'gatekeepers' by enabling a researcher to access their service settings (Silverman, 2017), and also provided information to assist in identifying potential participants. Research participants were identified by purposive sampling; which is an approach that allows a researcher to single out groups, situations or individuals because they illustrate characteristics or processes he or she has an interest in investigating (Silverman, 2017).

The criteria for selecting potential participants were: 1) adult service users (i.e. aged over 18 years), 2) with diagnosed intellectual disabilities and co-existing mental health needs, and 3) possessing sufficient verbal skills to be understood by others in their daily lives. Overall, ten service users were identified as fulfilling the selection criteria. Seven of these were invited, and subsequently consented, to participate in the study. Ahmet was the youngest participant.

Ethical issues

The ethics committee of a local health authority reviewed, and fully approved, the research proposal regarding the study (Department of Health, 2005). All practical steps were taken in enabling Ahmet to make an informed decision about his involvement in the study (Department of Constitutional Affairs, 2007). The first author initially met with Ahmet and his key workers on two occasions at the day service he attended, to acquaint Ahmet with the object of the research interviews. A leaflet about the study, providing information in user-friendly language, was given to Ahmet so he could further discuss his proposed participation in the research with his family and key workers. Ahmet verbally consented to participating in the study, and the first author was able to confirm Ahmet's capacity to provide informed consent (Department of Constitutional Affairs, 2007).

Data production

Two in-depth, semi-structured interviews provided the principal means of data production, and were carried out in a conference room at the service organisation's headquarters. There was a four week interval between the interviews. Each interview was audio-taped and based on the 'Free Association Narrative Interview' method, adopting questions that were as open-ended as practicable regarding topic areas in Table 1. This psychosocial research approach evolved through the work of Hollway and Jefferson (2000, 2013). It is underpinned by a theoretical framework incorporating aspects of psychoanalytic psychology and social theory, and uses free association in conducting biographical narrative interviews. Free association is an important technique that has been used within psychoanalytic practice to stimulate pathways of thought which permit access to what is meaningful for the individual being analysed (Colman, 2015).

Data analysis

Data analysis entailed examining all the data that had been accumulated about Ahmet. This data included: 1) verbatim transcripts and audio-recordings of the two interviews with Ahmet, 2) information regarding Ahmet's care, support and therapeutic interventions obtained from consultations with relevant service managers and key support staff, 3) detailed field notes and documentation of researcher reflexivity. Hollway and Jefferson (2013) underline the importance of 'holistic interpretation', which requires the whole data to be considered when seeking to explain part of it. Participants' free associations are given precedence over the coherence of their narratives.

Analysis of data from the interviews was carried out at two levels: 1) the interaction between researcher and Ahmet was scrutinised as individuals will defend themselves against any anxiety arising from information given in a research context; 2) the content of interviews regarding Ahmet's replies to questioning, covering the topic areas indicated in Table 1, was analysed. Reference to various data sources (e.g. key support staff, service provider's records, field notes) contributed to ensuring the authenticity and accuracy of data produced by research interviews.

Findings

Ahmet recalled his mental health issues had initially been recognised around the time he finished his secondary education when aged sixteen, and began going to a Further Education College. He had not been able to deal with the course work requirements at college, and his everyday life became difficult as he began increasingly to manifest compulsive behaviour. Ahmet affirmed:

> 'The illness just came, it simply just came. I felt…things were coming down. Started first washing my hands, all over the place…cleaning, cleaning, cleaning. There was one time, History, Maths… All these subjects, I couldn't handle it'.

Ahmet's compulsive behaviour became more problematic at home and while he was at college. He started to use detergent in place of soap, and repeatedly cleansed his hands before meals. Additionally, Ahmet became preoccupied with constantly cleaning his bedroom as well as pouring 'cologne' (i.e. perfumed liquid) around rooms in the family home, causing difficulties for family members. Ahmet became irritable and aggressive if an attempt was made to stop his washing and cleaning activities. He also engaged in repetitively watching action packed and violent movies or television programmes, which he collected on digital video disks, for prolonged durations without a break. Ahmet recalled an incident at college in which he became 'very upset' and distressed during a teaching session, and disrupted the session so much he was removed from the classroom. He recollected teaching staff telling him:

> ‘Finally, you’re not coming back in this class again. We’re going to take you out (of) this as you…seem to be in a mental state. You are not going to get upset, okay? We’re going to take you out.’

Transition

Ahmet indicated his mental health needs became evident during a major change in his adolescence, which was leaving school to begin further education. Adolescence and the transition from childhood to becoming an adult can be a period of considerable upheaval for many young people, and may result in mental health issues (Austin et al., 2018). Historically, the importance of adolescence for young people with intellectual disabilities was mainly disregarded or even doubted, though research evidence in recent times has increasingly shown these young people are at greater risk of experiencing mental health issues (Faust and Scior, 2008; Mazza et al., 2019). Whilst transition has been viewed as largely concerned with individuals moving from school to work, it can also be perceived as an extended period which spans most of adolescence and initial period of adulthood. In a systematic review about transition, this period was defined as taking place between 13 and 24 years of age, which includes the time before leaving school that happens between the ages 16 and 18 in the United Kingdom, and early years of adulthood (Young-Southward et al., 2017).

Assessment and diagnosis

Due to the growing challenges presented by the marked alteration in Ahmet’s behaviour noticed by family members and teachers, he was taken to see the family’s general practitioner. However, prior to this, Ahmet recollected his parents had contacted people from their religious community for advice regarding where to obtain support for his behavioural challenges. The general practitioner referred him for an assessment by a consultant psychiatrist who was able to communicate with Ahmet’s parents in their native language, which greatly assisted their understanding of the situation. After this psychiatric consultation, arrangements were made for Ahmet to have additional clinical investigations at a specialist mental health service. Recalling his early appointments at the specialist service, Ahmet stated:

> ‘Um, well…it was like the first tests they did, was first thing I knew was they were

> talking, talking tests. Like talking about what the problems were like at home, the music you listen to, what do you do (?) …cos, I can remember, I tried to force back the memory…They were showing that, there were signs showing that I was mentally ill'.

> 'The IQ tests were in the middle of all this, they did other tests. I can't remember every other test they did, but they did everything that they could'.

Diagnosis is a single component of a broader assessment which encompasses a young individual's typical level of functioning within their social setting, including home and educational contexts. Along with psychiatric and psychological assessments, other assessments which focus on particular domains such as communication, motor and sensory disorders, necessitate the added knowledge and skills of professional practitioners in speech and language therapy, physiotherapy and occupational therapy (Royal College of Psychiatrists, 2016). Ahmet recollected that he 'went to all branches…' of the mental health service and was involved in various psychological, psychiatric, physical and neurological assessments, including neuroimaging techniques which offer a means of exploring extrinsic and genetic conditions regarding brain development and ageing (Harding and Robertson, 2010). The severity of obsessive thoughts and compulsive behaviours is often evaluated by applying the Yale-Brown Obsessive Compulsive Scale Symptom Checklist (Uchendu, 2018). Following completion of these investigations, Ahmet recalled he 'was diagnosed with lots of things…OCD, Obsessive-compulsive disorder, learning difficulties, mainly short temper'.

Obsessive-compulsive disorder

Determining a diagnosis was a crucial factor in formulating interventions to meet Ahmet's mental health needs. Obsessive-compulsive disorder (OCD) is characterised by an individual having unwanted and repetitive obsessive thoughts, feelings, deliberations and sensations, as well as compulsive behaviours which they may carry out repeatedly (Uchendu, 2018). It is an anxiety disorder that generally arises in childhood or early adulthood (Raghavan and

Patel, 2005; Uchendu, 2018), and is likely to be as common in children or young people with intellectual disabilities as the mainstream population (Emerson and Hatton, 2007). Nevertheless, it is a disorder that can be easily overlooked in individuals with intellectual disabilities as they may not be capable of conceptualising or describing intrusive thoughts (e.g. 'ego-dystonic' thoughts, which are distressing, unpleasant and inconsistent with the individual's personality and how they elect to behave), and compulsions may be misconstrued as tics or intractable, recurrent behaviours (Hanna, 2020).

The individual frequently carries out specific actions or rituals repeatedly to rid themselves of the obsessive thoughts, and therefore reduce anxiety. Performance of these actions is not pleasurable and may result in 'wasting' extended periods of time, but failure to undertake the actions will result in increased levels of anxiety (Priest and Gibbs, 2004; Hanna, 2020). Recollecting the time when his compulsive behaviour became very difficult, Ahmet commented:

> 'Some of the things back then was too horrific to even imagine, I mean … it was like a film, you know, a film with, how can I say, a film with …a lot of things happening… One time I cleaned the whole place with cologne.'

Interventions and support

Ahmet commenced having antidepressant medication prescribed by a consultant psychiatrist after his OCD was diagnosed, and has continued to have pharmacological interventions since he was aged seventeen. Psychotropic drugs like antidepressants act by increasing brain levels of serotonin and noradrenalin, and assist in decreasing anxiety symptoms experienced in this disorder (Raghavan and Patel, 2005; Uchendu, 2018). Clinical trials indicate drugs which have a potent effect on inhibiting serotonin reuptake (i.e. reabsorption of serotonin), known as Selective Serotonin Reuptake Inhibitors (SSRIs), have been beneficial in treating OCD in children and adolescents (Dunkerley, 2020).

Since the initial identification of Ahmet's mental health needs, he and his family have been supported by specialist mental health services for young people, and latterly for adults, with intellectual disabilities. This has involved Ahmet being regularly visited at home by a community intellectual disability nurse or a clinical psychologist, who are core members of these respective services' community teams. During the early interventions to treat Ahmet's assessed needs, psychoeducation discussions occurred with his family members, in which explanations were given concerning the nature of OCD and therapeutic interventions required. Psychological interventions included cognitive behavioural strategies regarding exposure and response prevention (Uchendu, 2018). Modified versions of these strategies have been effective in treating individuals with intellectual disabilities. Exposure in OCD involves gradually exposing the individual to things which make them anxious (e.g. germ contamination) until their anxiety decreases. Response prevention encourages an individual to make a choice not to engage in compulsive behaviour when experiencing something they find distressing (Benson et al., 2016)

Care management

Ahmet's care programme and interventions continue to be co-ordinated by a multi-professional community team including a psychologist, intellectual disability nurses, behavioural support specialist and psychiatrist. Ahmet became an adult service user when aged eighteen, and started to attend a day service one day each week for personalised occupational interventions (e.g. outings with support workers to shops, cafes, leisure centre, cinemas). Attendance at this day service has continued to the present, and has offered respite to Ahmet's parents who are his main carers. Ahmet's compulsive behaviour has significantly improved in recent years, but he continues to present challenges to his family and support workers at the day service, generally through episodes of aggressive and verbally abusive behaviour. He disclosed personal distress concerning these outbursts:

> 'They have been quite painful because…painful for myself. Why am I so aggressive? Why am I so bad? Why am I so messed up? Why do I have to talk about negativity all the time? There's always, always, always been negativity throughout most of the time.'

Ahmet's mental health needs and treatment are reviewed biannually by a psychiatrist, usually at an out-patient clinic. His care programme is reviewed annually, and Ahmet confirmed his participation in decisions concerning goals and interventions. Positive outcomes agreed at these reviews in recent times included: opportunities for Ahmet to go on holidays with service users from the day service, and attending classes in basic computer skills at a Further Education College on two days a week.

Discussion

This case study concerning Ahmet represents only one individual's experiences, however his personal accounts highlight issues and findings from other studies, and literature, about young people with intellectual disabilities who present mental health needs.

Leaving school

The transitional phase related to leaving school can be traumatic for young people with intellectual disabilities and their families as it frequently leads to loss of friendships, besides relationships and social networks (Raghavan et al., 2013). Research has indicated the negative effects experienced by many young people with intellectual disabilities as to the disproportionate impact of this transition (Williams and Heslop, 2005; Young-Southward et al., 2017; Austin et al., 2018). Nonetheless, the emotional distress several young people experienced was not generally perceived as being symptomatic of mental health issues, until incidents occurred during which individuals exhibited violence or behaviours that challenge (Williams and Heslop, 2005; Austin et al., 2018).

Support for families

Ahmet's family has played a pivotal role in supporting him in his everyday life. Families can provide significant support to family members with intellectual disabilities and mental health issues, through assisting them to cope with, and overcome, the difficulties presented by their condition (NICE, 2016). Thus services need to offer well-timed responses, and be accessible, as well as acceptable, to families because the success of therapeutic interventions frequently hinges on their active participation (Royal College of Psychiatrists, 2016; Ahmed, 2020). Although being a family carer offers rewards, research has shown parents looking after a young person with intellectual disability and mental health needs are subject to increased responsibilities and stress, as a consequence of their child's additional needs (Faust and Scior, 2008: NICE, 2016). Greater levels of personal and material support will be needed by many families, and all will require consideration to be given to their social and cultural histories, including issues such as: ethnicity, religious beliefs, language and culture, besides the consequences of discrimination (Royal College of Psychiatrists, 2016).

Community-based services

Ahmet was able to access specialist community mental health services available in the catchment area where he lives. Service models for young people with intellectual disabilities and mental health needs in England, nonetheless, vary according to location and are dependent on local resources, priorities and different service initiatives (Lovell and Laxton-Kane, 2020). Ideally, these services will be a fundamental part of all-inclusive community services including, for example, social services, child health and education, as well as being supported by clear policies and procedures (Royal College of Psychiatrists, 2016). Child and adolescent mental health services (CAMHS) and intellectual disability services will be the most immediate connections for these services. Service development in the United Kingdom generally focuses on: need and outcome for young service users; matters concerning transition to adulthood; and a community-based approach combining various services that support mental health, comprising education and employment, along with primary care agencies (Royal College of Psychiatrists, 2016).

Recommendations for research

Research studies which explore the experiences and life course journeys of young people during adolescence are required. It is recommended such studies investigate the ambitions and personal goals of young people, besides support for their mental health needs (NICE, 2016). Research evidence regarding the experiences and mental health of young people with intellectual disabilities during their preparation for adulthood would aid the development of preventative strategies (NICE, 2016).

Key points

Drawing on findings related to this case study, some key points concerning service providers, intellectual disability nurses and other professional practitioners employed in health, social care and education are indicated, as follows:

1) Transitions for young people with intellectual disabilities need to be planned as far in advance as feasible, and they and their family or carers should be involved in relevant arrangements (NICE, 2016).
2) Young service users with intellectual disabilities and mental health needs should have a person-centred mental health care plan, which involves their family members, carers or support workers (NICE, 2016).
3) Ensure pertinent training about mental health, together with high-quality supervision, are provided for health, social care and educational staff employed in supporting young people with intellectual disabilities (NICE, 2016).
4) Meaningful occupational interventions, including involvement in mainstream activities and community-based learning opportunities, are an important therapeutic element in supporting people with intellectual disabilities and mental health needs (NICE, 2016).

Limitations

This study is limited to one individual's experiences but is grounded in a real-world service context and therefore noteworthy regarding its ecological validity, so has relevance to young service users in similar situations. The research approach proved effective in enabling Ahmet's active participation in data production, nevertheless there is likely to be a limitation on its usage due to the cognitive and verbal skill levels required of participants.

Conclusion

The care and support one young person with intellectual disability experienced to meet their mental health needs is outlined in this case study. However the study raises issues which are relevant to a wider population of young service users with intellectual disabilities. Adolescence and early adulthood is a significant period in which young people experience increased stressful situations related to major transitions, such as moving from child to adult services, leaving school to attend further education, or starting employment. Young people may present mental health issues during this period, but these are frequently overlooked and go unmet. Hence intellectual disability nurses and other professional practitioners working in health, social care and educational settings, can play critical roles in identifying the mental health needs of young people with intellectual disabilities. These practitioners may also be actively involved in co-ordinating service providers, in terms of planning and arranging appropriate support for young people during their transitions and preparation for adulthood.

Table 1: Topic areas covered in research interviews

1. Recognition of mental health needs – The interviewer sought to obtain Ahmet’s perception of when in his life, and how, his mental health needs were first identified.

2. The care and support provided when Ahmet’s mental health needs had been recognised.

3. Ahmet’s personal thoughts and feelings concerning his experience of mental health issues.

4. The level of care and support that Ahmet currently required to live in his local community.

5. Ahmet’s viewpoint concerning his involvement (or otherwise) in decisions about his care management.

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