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Supporting people with learning disabilities and mental health needs: service users' experiences

Introduction

Mental health issues account for nearly one quarter of ill health in the United Kingdom. The government strategy entitled 'No Health without Mental Health' (Department of Health, 2011) acknowledges the importance of mental health for all sections of the population. The prevalence of mental health needs in adults with learning disabilities has been reported to be higher than in the general population (Cooper et al., 2007). Estimates of prevalence range between 30% to 50% (Joint Commissioning Panel for Mental Health, 2013) and 25%-40% (Mental Health Foundation, 2007). A number of issues have been highlighted to explain these variations in estimates of prevalence, which include: dissimilarities in the sample population of individual studies; differing research methodologies; the way in which diagnoses had been made; type of prevalence that was reported; the inclusion or exclusion of challenging behaviour (Whitaker and Read, 2006; Buckles et al., 2013). Minimal attention was given to the mental health issues of individuals with learning disabilities during the period the policy of institutionalisation reached its peak (Hatton, 2002). Recent decades have witnessed some improvements, with recognition of the needs of adults with a mental health diagnosis specifically addressed in the National Institute for Health and Care Excellence (NICE) Guidelines (NG54) published in 2016. Although introduction of NICE guidance is welcomed, the actual impact and implementation of the guidelines remains to be seen, especially with the evident lack of adapted assessment tools and interventions to meet the mental health needs of people with learning disabilities.

Service users' viewpoints

People with learning disabilities' views concerning their experiences of mental health care, however, had received scarce attention until studies such as those by Donner et al (2010), Young and Chesson (2006), Scior and Longo (2005), undertaken in more recent times. The focus of these studies has been on mental health care related to inpatient situations rather than support available in community settings (O'Brien and Rose, 2010). This article discusses a research project which aimed to further explore and address this particular gap in current research literature.

The research project: Aim

The aim of the project was to enable the active involvement of adults with learning disabilities, who live in community settings, in producing knowledge about their viewpoints of the care and support they had experienced regarding their mental ill-health.

Participants

Seven adults (6 men and 1 woman: 6 White British and 1 from an Ethnic Minority group) with mild or moderate learning disabilities, who had histories of mental ill-health, consented to participating in the project. Six research participants lived in community homes, supported by care staff, and one participant lived with their family. The participants' ages ranged between 24 to 72 years, and they had been diagnosed as presenting a spectrum of psychiatric disorders, including: Schizophrenia, Psychotic symptoms, Depression and Obsessive Compulsive Disorder. Also, six of the participants had a history of displaying behaviours that challenge.

Selection of participants took place through purposive sampling with the assistance of two major local service providers, whose service organizations covered different geographical catchment areas in South East England. Purposive sampling enables researchers to single out a specific group, situation, or individual, because they represent some attribute or process which the researchers are interested in investigating (Silverman, 2005). The project was reviewed and approved by the local Research Ethics Committee, and personal consent of individual participants was formally obtained and continued to be reviewed until completion of the research.

Data production

The main means of producing data comprised undertaking two semi-structured interviews, which were audio-taped and based on the Free Association Narrative Interview method (Hollway and Jefferson, 2000, 2013), with every participant (see Figure 1) . This innovatory, psychosocial approach to biographical interviewing evolved from Hollway and Jefferson's modification of the biographical-interpretive method (Chamberlayne et al., 2000), and usage of free association by means of narrative interviews. Within the sphere of psychoanalytic practice, free association has been employed as a method for producing lines of thought which assist in gaining access to what is meaningful for the individual being analysed (Rycroft, 1995; Colman, 2009).

Hollway and Jefferson (2000, 2013) emphasise researchers are unable to be detached and should scrutinize their personal association with the mode of investigation, as this will aid in forming the way they explain data obtained from the research interview. Their approach recognizes the importance of unconscious dynamics within the interview, and is congruent with the researcher's use of reflexivity (Finlay and Gough, 2003).

Additional data was acquired from consultations with key care staff, and reviewing individual participant's records kept by their service providers. Data analysis entailed examining all of the information accumulated about each research participant. Precedence was given to the free associations of participants rather than coherence in their respective narratives, and particular attention was allocated to links and contradictions in the material regarding each participant.

The use of this psychosocial approach, however, will probably be limited in studies involving participants with learning disabilities. Open-ended questions are an essential part of free association narrative interviewing, but these have been indicated as suitable for people with a greater degree of cognitive and verbal abilities (Perry, 2004). Its usage with participants who possess lower degrees of cognitive and communicative ability would hence be less feasible.

Main findings

The biographical information about older participants revealed the majority, in their early lives, were service users at a time in the twentieth century when mental health issues, and the emotional lives, of individuals with learning disabilities had been widely overlooked (Arthur, 2003). Historically, there was a deep-seated reluctance to accept that people with learning disabilities had any emotional capabilities which permitted awareness of their social conditions (Hollins and Sinason, 2000).

Recognition of mental health needs

The circumstances with regard to recognizing the mental ill-health of research participants broadly reflected the diverse experiences and events in their lives that were painful (e.g.

removal from their family, segregation, institutionalisation, major transitions, bereavement and loss), and developments within services during past decades. Narratives relating to participants' experiences highlighted the significance of stressful occurrences, such as loss of a parent or near relative, as risk factors in people with learning disabilities' lives. Such events in their lives have been linked to behavioural challenges and psychological problems (Hulbert-Williams and Hastings, 2008; Hastings et al, 2004).

'Harry' (see Figure 2), who was a research participant in his early 60's, recalled that he had experienced a "nervous breakdown" and been "affected...very badly by three deaths in the family..." One of these deaths had been that of his mother and he had become very distressed, and presented behaviours that greatly challenged support staff at the community home where he resided, for a number of months. 'Harry' was subsequently admitted to the Psychiatric Unit of the local District General Hospital, where he received treatment as an in-patient.

Recognizing mental health issues in individuals with learning disabilities is generally a complicated process (Priest and Gibbs, 2004). Emotional difficulties that an individual experiences tend to be attributed to their disability as opposed to their emotional condition or requirements (Hollins and Sinason, 2000). The notion of 'diagnostic overshadowing' has been applied to characterize the circumstance whereby observations of any alterations in temperament and behaviour have been understood as a component of the person's learning disability; and this has helped to account for research findings that mental health issues have been underdiagnosed in individuals with learning disabilities (Reiss, 1994).

Moreover, emotional or mental health issues might be masked or displayed in forms which vary from the norm; often through the person's behaviour (Hollins and Sinason, 2000).

Therefore mental health issues may become evident as a consequence of a change in behaviour, especially if the individual has not manifested this kind of behaviour in the past and may find it difficult to verbally express their distress (Burke, 2014).

Challenging behaviour

The term 'challenging behaviour' was initially introduced in the United Kingdom by Blunden and Allen (1987) and signified the perception of problematic behaviour had changed, and instead of being regarded as an intrinsic problem of the person, it became the contemporary standpoint that such behaviour presents a challenge to other people (Hodges, 2003). It is critical that carers consider whether the behaviours could have a physical cause, or whether they provide a way of communicating an emotion or need (Burke, 2014). In terms of best clinical practice, it has been suggested that individuals with learning disabilities who manifest behavioural challenges require, at minimum, an assessment by both a psychiatrist and a clinical psychologist in order 'that the presenting behaviours are examined jointly through psychiatric, applied behavioural and psychotherapeutic frameworks' (Allen, 2008: 288).

Six research participants had a history of presenting behaviours that challenge. Examples of the types of behavioural challenges they had displayed included: being verbally and physically aggressive with others, self-injurious behaviour, non-compliance, mood disturbances, social withdrawal, and inappropriate sexual behaviour.

However only 'Ahmet', who was the youngest participant, made direct reference to a period when he recalled his behaviour had progressively deteriorated. This occurred when he was aged sixteen years, during his transition from a school which afforded support for children with special needs, to a Further Education College. He had found it difficult to cope with his

college work, and experienced a decline in his daily life because his behaviour became increasingly compulsive and problematic. 'Ahmet' recalled an incident when he had been "very upset" in a class at college, and his emotional and behavioural outburst had disrupted the teaching session. He recollected the following:

"...then the teachers took me out and said 'Finally, you're not coming back (into class) again. We're going to take you out of this as you...seem to be in a mental (state)...Are you (sic) not going to get upset, okay? ...We're going to take you out.' The work was hard, but also it was the first time in college."

Subsequently, during his second research interview, Ahmet provided an insight into the personal distress he had experienced in recent years regarding his behaviour, which had challenged his family and paid carers, stating:

"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."

Personal thoughts and feelings

'David' was a participant in his early fifties, who had been admitted to a community home for long-term care following his mother's death, when he was around forty years old. The loss of his mother, who had been his primary care giver, resulted in other losses, such as: loss of his home, local neighbourhood and established routines. During the first year after his admission, he had been referred to a psychiatrist and diagnosed as presenting depressive and psychotic symptoms. David recalled the considerable upheaval in his life

after the loss of his mother. He still had a vivid memory of the sadness that he felt when originally admitted to the community home, and commented:

“That was not very ...um...very nice ...for...for meself. I mean looking at four...four walls. Only four walls...only...four walls looking ...from wall...to wall. I said to meself...This is not my kind of...cup of tea. I didn’t know...who ...to turn to.”

‘Ted’, who was in his late fifties, had spent several years of his earlier life in a large long-stay hospital. During the first research interview, he had stated:

“I do have mental health problems...yeah, I hallucinate...I hear voices...I am schizophrenic...schizophrenic.”

Although Ted reported he was still ‘bitter inside’ regarding some experiences of institutional life, which concerned his recollections of power differentials between staff and residents, he lamented the closure of the hospital where he had lived. He said the institution had been a ‘home’ for its residents. In the second research interview, Ted had gone on to state:

“The outside world is too much for people like me...It’s too much pressure... too much. The outside world is a mad house... the outside world. We ask a question, they just ignore you, just walk by... without saying a word. The outside world is like this...No use feeling alive sometimes...you just want to be dead.”

‘Ahmet’ referred to his teenage years when his obsessive and compulsive behaviour became increasingly onerous, and commented:

“Some of the things back then was too horrific to even imagine... I mean... it was like a film with, you know, a film with, how can I say, a film with...a lot of things happening.

One time I cleaned the whole place (i.e. rooms in the family home) with 'cologna' (i.e. cologne)".

"I felt ...OCD, felt things were coming down. Started first washing my hands, all over the place...cleaning, cleaning, cleaning... There was one time ...all these subjects (i.e. referring to his college courses) ... I couldn't handle it..."

Ahmet recalled that he had been referred to mental health services because he

"was really, really messed up...They (i.e. mental health practitioners) 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. I was diagnosed with lots of things - OCD, Obsessive Compulsive Disorder...Learning Difficulties...mainly short temper".

Care and support

Six research participants reside in group homes, located in suburban neighbourhoods, with other adults who have learning disabilities. Residents' care and support needs are met by a care team covering a 24 hour period. The older participants generally required assistance with some aspects of their daily lives. This ranged from supporting them to comprehend written information, budget their money, and shop for groceries, to assistance with mobility; and personal tasks, such as getting dressed and bathing. Residents with diagnosed mental health needs present an additional level of complexity in terms of the support they require. Each of the participants, including the individual who lived in their family home, is

regularly seen by a psychiatrist regarding therapeutic interventions prescribed for their mental health issues.

Involvement in care management decisions

The six older research participants each indicated awareness of having a 'Life Plan', or person-centred care plan, and confirmed their involvement in meetings that included their key carer, and professional practitioners who were responsible for their general wellbeing and mental health care, and managing their group homes. They also demonstrated awareness that the main purpose of these meetings, which took place annually, was to reassess their care plans. Participants were able to discuss their everyday activities during the meetings, along with any personal aspirations, such as: potential changes in their occupational or recreational activities, increasing community engagement.

Discussion

This project has a limitation in that data analysis was based on a relatively small sample of case studies which conceivably limits generalisation of findings, however the individual and common experiences of participants will reflect the experiences of a much wider population of adult service users with learning disabilities. A number of findings, for example, resonate with findings from other research, and have relevance for those engaged in policy making, service provision and practice.

Impact of a 'learning disability' identity

Five participants did not recognise the social identity (i.e. classification as a person with learning disabilities) assigned to them. Prior research has indicated several individuals with learning disabilities did not seem aware of their learning disabled identity (Beart et al., 2005;

Davies and Jenkins, 1997). They either rejected the label which services had allocated to them, or did not use the term voluntarily to define themselves (Finlay and Lyons, 1998, 2000; Edgerton, 1993). Some authors have suggested that the degree of consciousness regarding disability and social identity may be affected by poor cognitive development (Cunningham et al., 2000), and denial may be employed as a defence mechanism to counteract experiences of stigmatization and coping with distress related to the identity (Sinason, 2010). Moreover, it has been suggested lack of awareness of the learning disability identity may be a consequence of over-protection by significant others in an individual's life, and lack of disclosure by parents (Todd and Shearn, 1997).

Research findings indicate that carers frequently avoided employing the designation of learning disability, and a small number were active in concealing this label as they feared it could distress the individual they cared for (Davies and Jenkins, 1997; Todd and Shearn, 1997). Further investigation is required concerning this identity conflict as it may have ramifications for services and clinical work, in which queries about the potential impact of a 'learning disability' identity still need to be answered (Beart et al, 2005; Craig et al, 2002). Additionally, the need for more research has been advocated into the way individuals with learning disabilities internalise the stigma attached to the classification of learning disability (Ali et al, 2012); plus the stigma and discrimination often connected with mental health issues increases these challenges (Thornicroft, 2006).

Emotional needs

The emotional lives of individuals with learning disabilities were frequently disregarded in the past (Arthur, 2003), particularly at the time when most of the older participants had lived in institutional settings. Nevertheless, despite presumptions concerning a deficit in

emotional capability, and incapacity to develop it, have been disputed during recent years, it can be argued that such beliefs still permeate the form of support which is available to individuals with learning disabilities (MacDonald, 2015). Contemporary service providers need to ensure care staff, especially those without recognized health or social care qualifications, who fulfil vital roles in service users' everyday lives, have sufficient instruction in mental health issues (Costello et al, 2010).

Person-centred planning

Person-centred planning affords a critical means of attaining enhanced life experiences for individuals with learning disabilities (Sanderson, 2007), and forms an indispensable part of government policy (Department of Health, 2001, 2009). Six of the participants had a person-centred plan, which was reappraised each year. A study investigating the outcomes of person-centred planning found service users who possessed a plan were enabled to experience positive benefits, as for example: increased community participation, greater contact with relatives and friends, increases in personal choice (Robertson et al, 2005). Nonetheless, the study also discovered individuals with mental health issues or behavioural challenges were not so likely to have a plan (Robertson et al, 2005).

Occupational activities

Occupational activities offered by local day services were an important factor in most research participants' lives. In addition, two participants attended educational classes for adults provided by Further Education Colleges. Research has highlighted meaningful daily activities as a pivotal issue in service provision for individuals with learning disabilities and mental health issues (O'Brien and Rose, 2010). Social interventions, as for example,

supporting service users to participate in activities during the day, constitute an essential part of mental health care (Hardy et al, 2005).

Building relationships

Befriending schemes provide a way of dealing with the social isolation encountered by many individuals with learning disabilities (Heslop, 2005). Volunteers from local communities had befriended two research participants. These participants were clearly pleased to have had opportunities to develop a relationship with the volunteers, who went to visit the participants in their community homes, in addition to taking them on outings (e.g. attending football matches; going for a meal at volunteer's home). These volunteers were members of a befriending scheme established by local organizations providing support for service users with learning disabilities.

Conclusion

The viewpoints of individuals with learning disabilities and coexisting mental health issues have mostly been unexplored until recent years. The service users who participated in this project are enabled to reside in their local communities, and are prescribed therapeutic interventions regarding their mental ill-health by specialist psychiatrists based in general mental health services. Their personal narratives, it is hoped, will contribute to the growth of knowledge related to the experiences and events in the lives of people with learning disabilities and mental health issues, and accounts of their passages through diverse services. Further research is recommended that investigates the perspectives of individuals with learning disabilities concerning the mental health care they have experienced; together with an increased focus on training for those with a mental health diagnosis, so they are empowered to better understand their condition and recovery concepts.

Implications for practice

- 1) Being aware that people with learning disabilities are at an increased risk of developing mental health issues.
- 2) Awareness that mental health issues may evolve and present in different ways from individuals without learning disabilities, and that these issues are often overlooked in people with learning disabilities.
- 3) Empowering people with learning disabilities to actively participate in their own mental health care.
- 4) Supporting people with learning disabilities and a mental health diagnosis to access and engage with meaningful daily activities.
- 5) Importance of developing a person-centred care plan for each individual with learning disabilities and a mental health diagnosis.