The JUDITH Trust

Mental Health Services for Adults with Learning Disabilities

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FOREWORD

DR ANNETTE LAWSON OBE

The Judith Trust is a family foundation which seeks to work for better lives for people – women and men, boys and girls – who have both learning disabilities and mental ill-health. Annette Lawson and Peter LeVay Lawrence, founders of the Trust, are respectively sister and brother of Judith after whom the Trust is named and whose own problems and life govern the nature of the work.

Our experience as 'carers' ourselves and of the care Judith has received and receives now, is that there is frequently a lack of knowledge and understanding of the issues and hence substantial variation in the quality of care. Yet, some people make great carers and these may not be the most knowledgeable: perhaps they have a quality of empathetic understanding which is recognised by those for whom they care? Perhaps their training enables them to relate well to the person and to know what questions to ask and how to listen? We, together with the expert members of our Joint Board of Trustees and Advisors which sets policy and determines the work of the Trust, decided to commission research which might answer the question, What Makes a Good Carer? We felt a good deal of research seeks to understand bad practice or what does not work without understanding what does work.

The group of researchers under the leadership of Dr John Rose and Dr Biza Kroese in the School of Psychology at the University of Birmingham, working with Professor Ann Davies of the Centre of Excellence in Mental Health (CEIMH), were chosen by the Judith Trust to carry out this piece of work. The work was conducted with Dudley Primary Care Trust and South Staffordshire and Shropshire Healthcare NHS Foundation Trust and in this way was able to cover a mix of areas – i.e. rural and urban – with varying provision - both residential and community settings - and access to users of the those services as well as those of the private and voluntary sector.

The group posed the following tasks:

- Identify what service users and paid workers consider desirable personal qualities for people working in this field to possess
- Explore experiences of staff and service users to identify strengths and weaknesses of current service provision for adults with learning disabilities and mental health problems
- Collate suggestions for service improvements and training/supervision programmes

The work began and ended with the service users themselves: the first meeting was convened with service users and very early on they were introduced to the innovative technique being put in place by CEIMH of digital story-telling. Service users tell their stories and then their stories are used in the research with staff and carers to illuminate the way they worked and discuss how they felt and how practice might be improved. Of course, the highest standards of consent and practice are in place.

Depressingly, the outcome of the research stresses the gap between services for people with learning disabilities and those with mental illness and this despite good government initiatives such as the Green Light for Mental Health (2004) which sought precisely to narrow this gap and ensure mental health services were available and accessible to those with both problems. The very first publication of the Judith Trust identified this gap (Joined Up Care: good practice in services for people with learning disabilities and mental health needs, 1998) and all our work since, including this research, finds a lack of training in schools of psychiatry and medicine and in nursing and social work that gives staff the knowledge and skills they need to work with both problems simultaneously. The audit of the University itself, included in the Appendix to the report, demonstrates the poor range of teaching about the two problems together.

The researchers summarise thus:

"As working with adults with learning disabilities and mental health problems requires **knowledge and experience** in not just one but two complex areas of clinical expertise, **appropriate and ongoing training is essential if workers at all levels (including at managerial and professional levels) are to be, and feel confident that they are, adequately equipped (ARL's emphasis)."**

Readers of the report will find many practical suggestions as to how to achieve this ongoing training. The research found that indeed the personal characteristics of 'good' carers of all kinds, and at every level, were important; recognising these should form part of the original selection process so that subsequent training is most likely to lead to good outcomes.

There are also innovative ideas, such as virtual teams with the range of expertise needed, to enable the closure of the gaps in service provision and indeed to prevent turf battles and better serve the needs of the individual service user.

Battles also are identified between the needs of families of those with the two problems and the individual user, or at least a conflict of interest, but by "adopting a 'family centred approach' by which the needs of the family as a whole are considered as important factors in determining positive outcomes for an individual service user", such conflicts could be reduced. Indeed more complex psychological understandings of these issues with access to psychotherapeutic help is also recommended.

These ideas are important: when ignored, these problems lead to risks which could be averted – risks to the mental health of the individual with learning disabilities and perhaps also to the well-being of the families and carers.

The Judith Trust customarily sets up a steering group to learn about and monitor the research we fund and we had an excellent experience with the Birmingham Group. The balance struck in the final report between ensuring users had access to the research and the quality of the work itself is evidence of this. In addition, the emphasis we place on taking a gender perspective led to a separate paper which is of importance in its own right indicating why users' experience may be better or worse because of whether they are themselves male or female and whether they are being looked after by female or male carers (Part II in this publication).

In this paper readers will again find a range of actions which could lead to better outcomes with lower risk of poor treatment and care for both women and men. I quote just one recommendation because, following another piece of Judith Trust funded research undertaken by Laurence Taggart at the University of Ulster's School of Nursing, a women's group of service users was established and has evidently been empowering to its learning disabled members.

Biza Kroese writes:

"Evaluate the benefits of same sex support groups for women and men with learning disabilities and mental health problems, particularly groups which adopt a community psychology approach i.e. the use of psychological methods to enrich the lives of the powerless, with a focus on change and action to improve well-being and tackle the causes of health inequalities."

'Health Inequalities': this remains a key problem for people who have both learning disabilities and mental illness. It needs to change.

Annette Lawson
Chair - The Judith Trust

What is the problem?

People with learning disabilities and mental health problems do not always receive good services, because there are very few people who have been trained or have experience in both mental health and learning disabilities. The different services do not always work well together and people do not always get the help and support they need.

What did we do?

We asked service users and staff who work in learning disabilities services what they think are good services and how we can make them better.

What did we find?

We found strong agreement that for services to be good, staff need to have a real interest in the people they support. Staff need good supervision and on-going training and they need to be treated well themselves and protected from lots of paperwork and big workloads.

Service users and staff said that good communication between services is important to make sure that everyone is working towards the same goals. They also said that we need to think about carers and supporters because people's families and support workers have needs to.

We need to help people as soon as possible so that we can stop their problems from getting worse. We need to think about all the reasons why people have mental health problems and a lot of these are to do with people being lonely, bored, not allowed to make choices and having nothing to look forward to. Some people have had very sad, painful or frightening things happen to them and this can make them have problems in later life.

Ways forward?

We have listed the ideas that our participants think will make things better.

They fall into two areas:

1. Finding and keeping good staff.
2. Giving the right support at the right time.

Finding and keeping good staff

- When we take on new people, service users should help with choosing workers who have good 'people skills' and who are really interested in the job
- Give new staff proper training and let them watch other workers before they start to work on their own
- Give staff time to talk with people who have been in the job longer and who can give them advice and confidence
- Give more training in mental health and learning disabilities to nurses, doctors, social workers and other professionals when they are still at university
- Give community team staff and their managers' on-going training in what it is like to have a learning disability and mental health problems, so they can help people in the right way. They need to know about medication and learn how to talk to people when they are upset and how to help them relax
- Give on-going training to support workers so that they will notice early on if people are sad, frightened or confused and can understand what they are going through. Support workers must also know what to do to get help
- Give the staff who work in psychiatric hospitals training in what it is like to have a learning disability so that they can communicate better when people have to go into hospital and may struggle with new and complicated things; or have someone who already knows about learning disabilities work on the ward
- Give staff time to get together to talk about their work and how to deal with new or difficult problems and make sure that staff from learning disability services meet with staff from mental health services, so that they can learn from each other
- Stop giving staff so much paperwork. Only ask them to fill in forms if it helps to make the service better. Give nurses who are managed by social services enough time to help service users as health workers

Giving the right support at the right time

- Make sure that the regular health checks that people receive also cover mental health so that if people are sad, frightened, angry or confused a lot of the time, they can be helped as soon as possible
- Don't just say someone is unsuitable for a service and exclude them, but work with other services to help the person. All services must work together instead of 'passing the buck'
- All mental health services must be open to people with learning disabilities, including memory clinics and talking therapies
- Families and support staff have needs to and they must be listened to, because if they are unhappy, the service user will also be made unhappy
- Sometimes we need to discuss problems in private and sometimes it is good to talk about problems together with family or support workers. Psychologists and counsellors should be able to help with both of these

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INTRODUCTION

This research was funded by The Judith Trust to investigate the views of service users', support staff and community team members' and the services currently provided to adults with learning disabilities and mental health problems, and what they consider to be desirable qualities for staff to possess.

A qualitative methodology was adopted in order to identify dominant themes in the discourse of these stakeholder groups. Data were collected through focus group discussions as well as individual interviews. The number of participants totalled 54 (16 service users and 38 staff).

Recurring themes included: selection, supervision and training of staff; early intervention; individual as well as systemic therapeutic approaches; and service accessibility and co-ordination. A number of suggestions for improving services have been identified and are discussed in the context of current service policies and procedures.

This report should be of interest to the following groups:

» Carers, support workers and clinicians working in Learning Disability and Mental Health services

» Managers, local government and national policy makers.

An accessible format is available for service users.
Please visit our website **www.judithtrust.org.uk**

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Mental health & learning disabilities

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Mental health & Learning Disabilities

Adults with learning disabilities appear to be at greater risk of developing mental health problems for a number of reasons, some of which are medical (e.g. dementia) but many others are related to the environment in which they have grown up in, and the treatment they have received from those around them, ranging from on the one hand excessive control and protection, to on the other, neglect and abuse. They are also more likely to be exposed to social factors which are considered determinants of (general but also mental) health: poverty, poor housing, unemployment, social exclusion and overt discrimination. Moreover, challenging behaviour and mental illness are often indistinguishable, indicating that many more people with learning disabilities may suffer mental health problems than are identified by services.

Definition of mental health problems:
The term ‘mental health problems’ is one that encompasses a range of experiences. Mental health might usefully be viewed as a continuum, from mental well-being through to a severe and enduring mental illness. One in four adults is said to experience significant mental health difficulties in any one year although only a minority of people may experience these to such a degree that they may be diagnosed as having a mental illness, requiring the involvement of specialist services and support.

Mental health problems include:

- Anxiety
- Depression
- Eating problems
- Postnatal depression
- Dementia
- Phobias
- Personality disorders
- Bipolar disorder (manic depression)
- Obsessive compulsive disorder
- Schizophrenia

The psychiatric diagnostic process poses a number of methodological problems for learning disability specialists and prevalence figures vary widely across studies. Therefore, there are no reliable statistics available on how many adults with learning disabilities have mental health problems (1). However, there is a consensus that they are at least as prevalent as in the general population with most researchers concluding that rates are higher (2). A number of reasons have been proposed for higher prevalence which will be discussed below.

Prevalence
Because of methodological problems, especially problems with self-report, prevalence figures have varied widely across studies. However, there is strong evidence of higher rates of psychological and emotional difficulties. A recent study found that if challenging behaviour and autistic spectrum disorders are included, over 40% of the adult population with learning disabilities can be said to have additional mental health needs (3)

When people with learning disabilities have mental health problems, the causes have often been linked to the difficulties that people have encountered as a result of their disabilities. For example, being highly dependent on others and having limited opportunities to make choices for oneself can prevent people from developing self-esteem, a sense that their life is worth living and that the future holds interesting and achievable challenges. Meaningful relationships are often lacking and few develop the roles of paid worker, consumer, sexual partner or parent in their life-time, all of which provide most adults with positive, albeit at times stressful, experiences. This, together with frequently encountering failure, stigma, prejudice and a lack of competence-enhancing social support are likely to result in depression and anxiety (4).

Meaningful relationships
“No one flourishes unless at least one other person is irrationally attached to them” (5)

As is the case for the rest of the population, trauma and abuse (including physical, sexual, financial and emotional abuse) are also reasons why people with learning disabilities may suffer psychological problems, particularly psychotic symptoms such as hearing voices or having chronic delusions (6). Rates of abuse are higher in the learning disabilities population (because of high dependency on others and difficulties in recognising and reporting abuse) which may account for the finding that the prevalence rates for the diagnosis of, for example, schizophrenia have been reported to be three times higher than expected (7).

Risk factors

The Department of Health with Central England People First and Lancaster University (2005) carried out a survey of nearly 3000 adults with a range of learning disabilities in England (8). The results showed that they were not yet 'included as equal members of society'.

For example:

- 40% said they were bullied at school
- A third said they did not feel safe in their homes
- 64% in supported accommodation had no choice over who they lived with or where
- Half were still living with their parents
- Only 17% were in paid work and many of these worked less than 16 hours a week
- Two thirds who were unemployed said they wanted a job
- 31% said they did not have any contact with friends
- One in 15 had children and of these only 52% looked after them
- More than half said someone else controlled their money and less than 20% received Direct Payments

Moreover, they are likely to be exposed to social factors which are considered determinants of (general but also mental) health: poverty, poor housing, unemployment, social exclusion and overt discrimination (9).

Many people with severe learning disabilities are said to show challenging behaviour with an age specific prevalence peak of between 20 and 49 years (10). Causes associated with challenging behaviour include environmental, psychological, specific genetic factors and in some cases physical pain due to untreated medical disorders (11). When people have little or no ability to express themselves verbally (and are therefore unable to report on feelings and thoughts), it is often difficult to distinguish between mental illness and challenging behaviour, as clinicians may not be able to establish what the underlying psychological experiences are, which cause the observed challenging behaviours.

Dementia is also associated with psychological distress and challenging behaviour. Prevalence amongst older people with learning disabilities has been reported to be more than three times higher (22% versus 6% for people 65+) by some authors, partly due to adults with Down's syndrome having a high risk of early onset dementia (12).

Service responses to people with mental health problems and learning disabilities

Services for people with learning disabilities have become more sensitive to psychological needs and the dire consequences of impoverished and segregated institutional care. However, the current service responses when people with learning disabilities experience mental health problems are still lacking in terms of co-ordination, accessibility, and essential knowledge and experience on the part of both mental health and learning disabilities staff.

Efforts to reduce the psychological distress that is so frequently experienced by people with learning disabilities must consider the quality of current services and how they can best provide prevention, early intervention and good crisis management for this group of service users with complex needs. Also, as most adults with learning disabilities are likely to spend large amounts of time in service settings and in contact with paid support workers and other service providers whose input and interventions can help or hinder recovery, the quality of services is vital in determining how the service users' mental health problems affect their quality of life.

The traditional model of service provision was a medical one where people with learning disabilities (whether they had mental health problems or not) were considered to be a life-long patients, best placed in long-stay hospitals, cared for by medical and nursing staff (13). More recently, community care has been successfully promoted as the more acceptable and effective model of support and many adults with learning disabilities, including those with mental health problems, now live in integrated settings. Social role valorisation as a service objective(14) has had a major influence and has made commissioners and providers consider ways in which to help people at risk of being labelled, devalued and excluded, achieve 'valued roles' in their families and communities, so as to improve their living conditions and thus their psychological well-being.

The 'Green Light for Mental Health' paper published in 2004 is a framework and self-audit toolkit for improving mental health support services for people with learning disabilities (15). It provides a picture of what services should be aiming to achieve, including quality outcomes, and a self-assessment checklist. It is aimed at Mental Health Local Implementation Teams and Learning Disability Partnership Boards. It promotes access for people with learning disabilities to generic mental health services and good liaison between mental health and learning disabilities services in order to prevent people being rejected from both services due to rigid and stringent eligibility criteria on both sides. This in turn may prevent psychologically distressed people 'falling through the net' and not receiving any services at all.

Green Light Self-Audit Toolkit (15)

The 12 key requirements of the framework being assessed are:

1. Local partnerships with primary care service
2. Local partnerships with people with learning disabilities
3. Local partnerships with carers of people with learning disabilities
4. Agreed criteria and boundaries between services
5. Transition protocols
6. Police and criminal justice services
7. Sharing information and accessing Care Plans
8. CPA - Person-centred and whole life planning
9. Culturally specific services
10. Workforce planning
11. Representative workforce
12. Mental Health Promotion

For full details of the key requirements listed in the 'Green Light for Mental Health' self-assessment checklist, download Part B from the following link: **www.cqc.org.uk**

A user's view of CBT

"I talk about it more now and I feel a lot better, relaxed. I feel this great big weight come off my shoulders and I feel thingy, and that weight can stay away altogether and I feel a lot better" (19)

However, in 2011, seven years since the start of the Green Light initiative, services for adults with learning disabilities are still said to be lacking in both quantity and quality.

Despite a more holistic and social approach being adopted by most services, to this day psychotropic medication is a common first choice response to psychological distress and challenging behaviour. A very high proportion of adults are prescribed such drugs (which may have considerable harmful side-effects), often without a specific diagnosis and no evidence for their effectiveness (15). Recently produced UK guidelines (16) for prescribing and reviewing psychotropic medication for challenging behaviour may eventually help to improve this situation.

Talking (psycho) therapies, which are now the treatment of choice for many mental health problems in the general population, are rarely accessible to adults with learning disabilities, although there has been a recent trend for (the few) mental health clinicians working with people with learning disabilities to incorporate adapted versions of cognitive behavioural therapy (CBT) and other psychotherapies and counselling approaches into their clinical practice (17). There is growing evidence that these treatments are both effective (17) and highly valued by service users and their carers (18,19).

A further problem in meeting the standards set by the 'Green Light Tool Kit' is the lack of training received by staff working in learning disabilities services on mental health problems and likewise, the lack of knowledge and experience mental health staff have of learning disabilities (20). The majority of professionals and support staff working in learning disabilities services come in regular contact with service users who have mental health problems, yet a minority receive any training in this complex area (21). Recent evidence indicates that even brief training can increase confidence, attitudes and working practices in staff (22). It is important that 'front line' workers are able to recognise the symptoms of mental illness and have the confidence to refer to specialist services when needed, as often service users themselves do not have the ability or opportunity to self-refer.

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The Research

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The Research

Aims of the research

Despite the Green Light initiative, mental health services for service users with learning disabilities remain deficient both in terms of quality and access. To date, little or no research has investigated what service users with learning disabilities and mental health problems, or staff members consider desirable personal qualities for workers and the type of services they consider most effective.

As both of these stakeholder groups have unique insights in, and experiences of, the way in which services respond, a series of studies were designed in order to:

1. Identify what service users and paid workers consider desirable personal qualities for people working in this field to possess

2. Explore experiences of staff and service users to identify strengths and weaknesses of current service provision for adults with learning disabilities and mental health problems

3. Collate suggestions for service improvements and training/supervision programmes

Methodology

The researchers met with a small steering group which included clinicians, academic staff and a service user, to discuss the project aims and how best to achieve them. Ethical issues were addressed by gaining ethical approval from NRES and the Ethical Committee of the University of Birmingham and adhering to ethical principles regarding informed consent and confidentiality.

It was decided that informants were to include a wide range of staff drawn from urban as well as rural areas, residential as well as community settings, and qualified professionals as well as unqualified staff. All staff participants were recruited through the relevant local service managers who were asked to distribute information leaflets to their staff and pass on potential participants' (i.e. individual members of staff who had expressed an initial interest in the study to their manager) details to the lead researcher. Members of staff were then contacted to ask for their written consent and to arrange a convenient time and venue for the interview to take place. Participants were aware that they could withdraw their consent at any time and any data relating to them would then be destroyed.

It was also agreed that service users would be asked to participate and that they should have personal experience of having a learning disability and additional mental health problems. Service users were also approached via local managers and clinicians and were provided with accessible information leaflets about the study before they were asked for their written consent. All service user participants were deemed to have the capacity to consent.

As the research focussed on the personal experiences of the participants, it was decided not to use standardised questionnaires but to employ an open-ended qualitative methodology in order to influence as little as possible the choice of topics discussed and the criteria utilised to judge the quality of the services and the people employed within. For this purpose, semi-structured interviews were designed to prompt discussion.

Two different qualitative methodologies were used to collect the qualitative data. First, a stakeholders' event was organised during which a number of focus groups (23) were conducted with service users and a variety of staff, all of whom had had experience of the services under discussion. Subsequently, individual interviews were conducted with staff members employed in residential and community learning disability services. The responses of a total of 54 participants (16 service users and 38 staff) were included in the qualitative analysis. The methodologies are discussed in more detail below.

Stakeholder focus groups

A stakeholders' event was held during which four focus group discussions were facilitated and recorded. It was decided to have same-sex groups in order for the participants to feel they could discuss private experiences as openly as possible. It was known that a number of female service users had experienced abuse from men, and their current mental health problems were closely linked to these experiences, making open discussion about mental health services in the proximity of men difficult.

The four focus groups were: female service users (N=8), male service users (N=8), female staff (N=10) and male staff (N=6). All service users were known to have learning disabilities and also experienced mental health problems. The staff groups included staff with a variety of roles in supporting adults with learning disabilities including support staff (N=7) , a team assistant, nurses (N=2), an assistant social worker, a counsellor, psychologists (N=3) and an advocate.

All groups included no less than six and no more than ten members. Group discussions were limited to one hour. All four focus groups were co-facilitated by two experienced professionals and the two service user groups also had a co-facilitator who was a service user. The discussions were digitally recorded and transcribed verbatim.

Focus group questions:

- What makes a good worker?
- What are workers who are not so good like?
- Is it important for staff to have qualifications (training)?
- If you/a service user started feeling bad (low/upset), who can help?

THE RESEARCH

Individual interviews

One-to-one interviews were conducted with a broad range of staff members who worked directly with adults with learning disabilities and mental health problems, including support workers and team leaders from residential services and professionals working in multidisciplinary community teams for adults with learning disabilities. All interviews were digitally recorded and transcribed verbatim.

The residential staff members (N=12) were sampled from urban (N=6) and rural settings (N=6) and from a range of statutory, private and voluntary services. They included two team leaders, one senior support worker and seven support workers. Their ages ranged from 20 to 52 years (mean=38) and ten participants were female and two male.

Qualifications included NVQ 1, 2 and 3, BTEC, and one RNMH (highest qualifications ranging from 2 to 4 award levels;24) Four staff members had received in-house training in at least one topic relevant to the mental health needs of people with learning disabilities (Mental health, Bipolar Disorder, Autism, Challenging Behaviour).

The peripatetic professionals (N=10) were drawn from a number of teams covering urban (N= 4) and rural (N=6) areas. They included five community nurses, four social workers, and one assistant psychologist. Their ages ranged from 24-64 (mean=43) and seven participants were female and three male.

Qualifications included a master's degree in Social Work, a diploma in Social Work, first degrees in Sociology and Psychology, RNLD and RNMH (highest qualifications ranging from level 5 to 7 award level;24) and four staff members stated they had received in-house training in topics relevant to the mental health needs of their service users (Mental Health and Learning Disabilities, Drugs and Alcohol, Dual Diagnosis).

Staff participants were invited to be interviewed on a single occasion for no longer than one hour at a place most convenient to them (usually a quiet office at their place of work). They were also asked to complete a brief questionnaire detailing their age, gender, employment and qualifications.

Digital stories

In order to prompt thought and discussion, brief digital recordings (25) of the experiences of people with mild learning disabilities and mental health problems were presented before the interview commenced. These brief (one minute) anonymous audio recordings, spoken by actors and accompanied by still photographs, were shown on a laptop and provided typical scenarios for staff to remind them of the impact of mental health issues on the lives of people with learning disabilities.

Interview questions

- What makes a good worker? Think about where service users felt safe.
- What do people do that service users find helpful?
- What is the ideal worker like?
- Why are some workers not so good?
- What experience and training do workers need?
- What do people need to know before they start work?
- How can workers be helped to do a good job?
- What should managers and supervisors do to help workers do a good job?
- Is it important for people to have had formal training to do a good job?
- If one of the service users you work with became unwell what sort of services would you hope would be available for them?

Data analysis

The data was analysed using Interpretive Phenomenological Analysis (IPA; 26). This is a qualitative method that has been developed to understand the experiences of individuals and the meanings that they give to these experiences. The approach focuses on individual subjective experiences through the process of analysis and interpretation by the researcher. Each case is analysed in detail in order to elicit key themes. The approach can be used to understand themes that emerge within individual cases and that are shared across cases. The process involves verbatim transcribing of the interview to produce a written transcript. Care was taken to ensure that the content of the emerging themes was grounded in the original data. An audit of the initial three interviews was carried out in the form of independent analysis of the transcripts by two of the researchers who then compared and discussed in detail their emerging themes. Good agreement was found.

Teaching audit

In order to investigate the amount and type of teaching at university level relevant to clinical practice for people with learning disabilities and mental health, an audit was conducted at the University of Birmingham. Academic staff responsible for pertinent teaching programmes were contacted and asked to provide information on a postal questionnaire. A brief overview of this audit, presenting the results and conclusions is attached to the current report as an appendix (see page 27).

> ***"We asked service users and staff what they think are good services and how we can make them better."***

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Findings

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Findings

The findings of the focus groups and the individual interviews will be collated for the purpose of this report. They will be presented separately and in more detail in papers to be submitted for publication in peer reviewed journals.

A number of common themes arose across the studies as well as some unique or less common ideas and observations. They are presented below with direct quotes from participants to illustrate each theme. The quotes were chosen to illustrate and clarify the themes and are presented here verbatim. Themes relating to desirable personal qualities of staff are first presented, followed by themes relevant to the quality of mental health services for adults with learning disabilities.

Key

Themes will be illustrated by quotes. A code after the quote will identify which group the participant belongs to:

- SU = service user;
- RS = residential staff;
- CS = community staff

Desirable staff qualities

The qualities which, according to our respondents, are most desirable for staff working with service users with learning disabilities and mental health problems include: having a genuine interest in working with people and building up trusting relationships within professional boundaries; having good communication skills and the ability to be open and honest yet gentle and sensitive; providing support in a way that is perceived as ‘competence promoting’ rather than ‘competence inhibiting’ (27); and being able to understand and acknowledge that past experiences may have been central in causing current mental health problems and may influence their reactions to current events and interventions.

Being interested, not just there for the money

The most frequently mentioned desirable personal qualities for staff were having a genuine interest in the people they worked with, not having preconceived ideas, the ability to spend time with service users, and to ask the ‘right’ questions and listen to what they had to say so that they can get to know them as unique individuals.

Service users did not always experience these desirable qualities and one person reported that staff members do not always ask the ‘right’ questions e.g.:

“ ...it makes me upset because staff come and see me and ask me why I’m in my room and not what is wrong.” SU

They valued staff

“...who keep you company if you want it” SU

Service users were acutely aware that not all staff have an interest in working with them and/or appear to judge them. For example:

“Some are too idle and don’t always care. They do it for money, not to help people. The ones that are good are interested ...” SU

“... they [staff who commute] don’t live in our area they don’t get to work until late and they are rushed. They should get a job closer to where they live really” SU

“Some staff I wouldn’t go to because they have a bad attitude. I go to staff who listen to you and not judge you” SU

Most staff participants expressed similar views to those of the service users. They stressed the importance of:

“Getting to know each client on an individual basis” RS

“Taking the time to know each client” CS

and reported as bad practice those who:

“...haven’t got the time or they don’t put the time aside to explore anything so they often see the behaviour or the outcome of the [mental health] problem rather than see it building up.” CS

indicating that if staff spent more time with service users and took more interest in them, they may avoid mental health crises from occurring.

Some staff described how they made an effort to take an interest in their service users’ hobbies so that spending time together became pleasurable and relaxed for both:

“ Most of the male users like to go fishing so....I ain’t got a first clue about fishing so I’ve learnt how to put the rods together... [laughs]” RS

A number of staff spoke of the importance of being interested in the service user, yet maintaining appropriate boundaries. For example:

“There need to be very clear boundaries with the people that I work with about ‘this is acceptable and this is not, if you do this, this is the consequence’ and you know that might sound quite harsh but if that, if that doesn’t work or if someone backs down then it is literally...I mean last week I had a person that has now been admitted to [assessment and treatment unit] umm because I don’t feel the boundaries were in place properly so just the situation got out of control and very dangerous...” CS

Staff members were aware that having time together with service users was the only way in which to develop a trusting relationship which not only allowed the latter to ‘open up’ but also gave them a sense of being valued. For example:

“I would be concerned sometimes that people tell you what they think you want to hear rather than what they feel and are thinking...I’ve been out with a client, he, he used to like going out for breakfast so I used to meet him...and then after a while, he, he would talk to me (and he had schizophrenia) and he would tell me, he called the chap[the voice he heard] a name and he would tell me he was sitting on his shoulder and telling him stuff. So we were having this three-way conversation but obviously you don’t get that until you’ve gained their trust really. So I think it’s important to be yourself and be open and honest and not promising to be able to cure everything like that.” CS

However, many staff complained that it was difficult to find the time to spend with service users, as this residential worker explained:

“Not that I mind doing the admin work, I do it, but to have proper time, not to feel pressurised by having to do...not just your daily notes, it’s, you might be key worker to somebody, you’ve got review risk assessment things and lots of things what you’ve got to do...having to think ‘yeah I really would like to help you do that but today in the diary we’ve got this, and this and this and there’s only two of us [staff] today’.” RS

Other personal qualities mentioned by staff which indicate that working with this client group needs genuine interest, commitment, dedication and flexibility include

"wanting to make a difference" RS; "like a terrier" ("we get hold and we don't let go") CS; and" going outside the job description" CS

Communication styles and techniques

Both service users and staff stressed the importance of, and spoke at length about, the style in which staff communicate:

"A person who is quite open and approachable. Sometimes that is quite hard to quantify ...but I think there is an openness and warmth..." CS

"...somebody who is not removed, using lots of titles to hide behind" CS

"Someone who asks the right questions" SU

The word 'gentle' was used by a number of participants. For example:

"...also just be quite umm gentle in your, well you need to be able to judge a situation and, and then react to it appropriately so that it's a softly softly approach..." CS

and

"...it's gently,gently. You can't force people to do things and you know just because you think that it's right, it might not actually be right for them...Just listening to them and see what you can do." CS

Other inter-personal skills mentioned by staff were: being empathic, not blaming or judging, showing respect, patience and being able to see "the whole picture". Service users stated that they appreciated staff who "you can trust" and who "... believe in me" indicating that they too value a sensitive, respectful approach.

Technical knowledge about how best to communicate with adults with learning disabilities and mental health problems was mentioned as important by a number of participants, both service users and staff. For example:

"Some people might have difficulty with the job because they can't understand people with learning difficulties." SU

"...Cos with learning difficulties you know they get confused and you know sometimes they can't understand words if people am talking too quickly or if they use jargon, you know stuff like that..." RS

"[You need] someone that has good knowledge of both mental health needs and learning disability needs...." CS

Competence promoting support

Service users and staff made a clear distinction between supporting a person in a way that was helpful and allowed them to gain confidence and independence on the one hand, and input from staff that had the opposite effect, on the other. That is, competence promoting versus competence inhibiting support (27).

Service users appreciated staff members who:

"...are helpful, helping their client to do their job" SU

and

"...show you what to do instead of just telling you." SU

What they found particularly unhelpful was when:

"...they're on your case all the time, telling you what to do... they're putting more pressure on you..." SU

or when:

"They don't really listen to you. They just want to put you on a [college] course." SU

Staff emphasised the importance of putting the service users central to all decision-making and considering them as the 'experts', e.g. :

"Yeh, asking them what they want and what they need coz they often know better than anybody else....they quite often can tell you what they feel they need" CS

Awareness of link between past and future

Staff and service users considered it important that anyone working with a person with learning disabilities and mental health problems has the awareness that past history, and specific life events, may have a significant impact on mental health, and on how the service user is likely to react to any current and future events/interventions/approaches. For example:

"A fair number of people I work with have a diagnosis and that's often because of childhood experience. You've got to keep that in mind" CS

and:

" ...thinking back I think most men and women [with mental health problems] come from really dysfunctional families where they have perhaps been in care or their parents have had mental health difficulties or umm they've just come from very poor backgrounds really. You can see why they're so withdrawn or angry." CS

Moreover, it was considered bad practice if the workers were not provided with relevant background information, something that residential staff frequently reported e.g.:

"It's so important to know what they have been through but people come here and we are told very little about their background or what they find nice or scary...not much to go on really" RS

Service users also indicated they valued staff who had knowledge of their past:

"Someone who knows your background and knows what you are going through and has seen your files and things like that" SU

Good quality services

The themes presented in this section concern the qualities and operational policies of the relevant organisations rather than the personal qualities of the individuals working in the various systems. The participants of this study, although able to describe good practice in many instances, identified a number of problem areas in current services. They were most concerned about the, at times, inadequate interface between learning disabilities and mental health services, the lack of training in mental health issues and clinical supervision provided within services, and the pressures imposed on staff from higher managerial levels in their organisation resulting in, what they considered to be, inferior service outcomes.

Prevention and early intervention

This theme concerns the importance of a responsive service which service users can access at an early stage so as to prevent mental health crises. Both residential and community staff stressed the need for a flexible, responsive service and for good liaison between the various services in order to meet the needs of service users in a crisis:

"...we have a community nurse who's brilliant you know. He comes and gives us advice on how to do this and explains to us why this might be happening and we thrash out about what we can best do and that. Support from doctors and psychiatrists can be really helpful, to like give us some tips and hints and tools to work with to help that person and they're pretty quick to get here. They're only a phone call away, you can call up for expert advice coz we're not experts really here." RS

"If one of my clients their mental health deteriorated, I'd go straight to the consultant psychiatrist, seeking advice......And then hopefully this pre-empts a breakdown. That's happened, I've got a client who lives up the road in a residential placement and his mental health deteriorates on a yearly basis but the team there are very, very skilled in noticing deterioration. So they phoned me and then they phoned [psychiatrist] and then we assessed. You know with, with this quick action he hasn't gone back to [local psychiatric hospital] for about five years. That's success." CS

Although there was a general consensus that hospital admission should be avoided whenever possible, at least one respondent indicated that a stay in hospital may, on occasion, be helpful:

"... taking the person out of the situation for a while you know, over a period of time just to talk about things with them so they don't feel threatened in the environment they're in. Sometimes that's quite a valuable thing." CS

Service users valued a link person who could be easily contacted by phone, although many of their responses indicated that they were resigned to a delayed service response:

"I'd go to my social worker or a carer or a friend...If I have their number I'd call them and if they're not around I would make an appointment." SU

Regular reviews and liaison

This theme concerns the importance of people working together using good communication systems and avoiding 'passing the buck' scenarios, where service users who are on the borderline of a number of service are turned away, ending up as labelled 'ineligible' despite very real and complex needs.

For example, a residential worker spoke about the importance of using good care plans so that:

"...everyone sings from the same song sheet so to speak." RS

A community worker described the difficulties when a service user is considered to be on the 'borderline' of eligibility:

"We have been out and assessed people who in our view may not have a learning disability but they're still vulnerable and they still need help and so we try to sign post them to other services that will be able to help them. We as workers could pick up that case and work with that case but, you know, you don't want to label them when they haven't got a learning disability ...and there are a lot of vulnerable people out there. " [indicating that there is no capacity for the services to provide for so many people] CS

Team work and multidisciplinary collaboration was considered an essential ingredient of an effective service because otherwise the service users might experience inconsistencies in the approaches taken by the various workers and possibly conflict and an over-load of information given to them. E.g.:

"Yeh, good teamwork because people with learning disabilities and mental health issues, they often have a number of workers you know, they might be going to college and then seeing me [social worker], they might be seeing psychology, they might be having a support worker come out so there are lots of different people. It can make misunderstandings between the client and other people and myself. And I think that can create umm both frustration and uncertainty within the client so that can be a bit negative." CS

Both service users and staff participants appreciated the importance of regular reviews and meetings. E.g.:

"We have our annual reviews anyway and depending on their [mental] health we'll have more reviews, you know formal professionals' meetings." CS

There was an awareness that good teamwork must be considered in the context of client confidentiality and it was understood that for certain professions (e.g. psychology and counselling) to function effectively, the service users must be confident that what they say will be kept confidential unless there is an identified risk to them or others, or they request, or agree for the information to be shared. A community nurse stressed the importance of letting the service user know what will be kept confidential and what will not:

"So crucially it's about communication [between staff] on a day to day basis and passing on of information between each other. Now that can be a problem in itself , especially if, well I have a lot of people who say ' the staff are talking about me' and I have to explain what that actually means. It's up to the staff who support them to say what they'll need to pass onto the next..." CS

A service user who felt that confidentiality had been breached stated:

"I had this one worker and she said to me that it was private and confidential what I said to her and then she goes and tells my mum what I've said to her. So I like people who keep things to themselves and not tell everybody else..." SU

This last quote indicates that the limits of confidentiality had not been adequately discussed with the service user and that her trust in that particular member of staff had been broken.

Working with carers

Staff participants but not service users often mentioned the importance of having a 'family centred' approach (28) when service users are in close contact or live with their family:

"There are some families who want a lot of support, there are other families who don't and so it's just keeping an eye on that really and umm, trying to help them in whatever way you can really." CS

A number of staff described the difficulties sometimes encountered when family members (especially parents) still consider their adult sons and daughters as 'eternal children' e.g.:

"We...work with families around decisions cos it's kind of getting people used to the fact that this is an adult now, this is a person with their own rights..." CS

However, it was widely acknowledged that the needs of the family as a whole must be considered and catered for whenever possible, as long as they did not clash with the identified clinical needs of the service user. Some workers spoke of negotiating with service users' families over long periods of time in order to achieve outcomes acceptable to all parties:

"...it took them years to accept that maybe she'd be better off living apart from them, it worked out, it worked out really well." CS

Looking after staff

This theme appeared frequently in staff member transcripts. Not surprisingly, the participants utilised the focus groups and interviews as opportunities to describe the challenges which their various jobs entailed. Most of their concerns related to excessive caseloads and paperwork (referred to by one community worker as "feeding the beast"), meaningless outcome measures, low staff morale, poor or absent clinical supervision and being prevented from doing the clinical work which they felt would benefit the service users best. For example:

"...this comes in and that comes in, oh well just give it to the workers. No one sits and thinks 'Now is that the best use of that individual's time?'..." CS

A number of community staff mentioned that they considered it their manager's role to protect them from the potential stresses imposed on them by the organisation but noted that good clinicians (particularly social workers) are often promoted into posts which are several steps away from clinical work:

" Well, there's the whole thing about social work in the news in the last couple of weeks...that people with more experience will stay on the ground rather than have to go up through the hierarchy..." CS

They observed that some of their managers appeared to have lost touch with the 'coal face' and were therefore less able to empathise with the 'hands-on' staff and were more responsive to the demands made by higher management than by their workforce. One the residential team leaders interviewed described the tensions which have to be managed:

"That's important for the staff, support when they need it. Whatever it is, the paperwork or whatever, issues that come up. ...They've got the people that live here, their issues and whatever needs doing for them will come on top of the list. The paperwork... what the organisation wants (coz obviously you do have to show that things are being done otherwise contracts can be lost. We're all inspected on a regular basis....) so it's trying to balance between both... trying to get the staff to understand that there is both. Both sides have to be done unfortunately but there is a lot of duplication [of paperwork]...sometimes it feels it could be better...." RS

One community worker described a 'protective' management style she had experienced:

" ...we get a lot of paperwork and things like that to do so it's about making things manageable for the staff... I think managers can talk about what's important to do and what's not so important to do and to prioritise things for staff ....and the manager I guess is just protecting them from like this barrage...just distilling the information and making it accessible." CS

Feeling protected from the media was another concern as workers were aware that when risk assessments go wrong, the individual clinician may be a scape-goat:

"I like things to be nice and safe for people and of course all you see in the media is where it's gone wrong and somebody's name on the front of the newspaper and that. I sort of joke with my colleagues and say 'Oh if this goes wrong I'm gonna be on the front of the Daily Mail'. It's in the back of your mind when you're making decisions you're gonna be absolutely hung if you make the wrong decisions. ...Our line manager, he's really experienced in this area and he's been really good. I can go in and talk through my concerns and he'll go 'Right, you've done X,Y,Z, you've done everything you can , legally you're sound, you're alright, you've covered every aspect you've had to.' Just having somebody to support you through..." CS

The community nurses who were interviewed for this study were concerned that, as they were managed in a social services context and were expected to take on care co-ordinator responsibilities, they were left no time to practice their nursing skills:

"The nurses have been very unhappy now for quite a while with regards to the fact that they're no longer using their clinical skills. They're not doing the nursing things they should be doing, they've all just ended up doing care management stuff..." CS

Service users were also aware that the staff members who support them need support themselves:

"They need a good gaffer." SU

and one service user participant suggested a 'payment by result' measure to improve the quality of their working practice:

"Being paid more if they do a good job" SU

Staff training and supervision that is relevant and ongoing

Service user participants considered it important that staff members receive training. E.g.:

"People should have the right training for the job so they can do their job properly. People don't always know what the job involves." SU

and that communication is an important area to provide training in:

"...training on how to communicate and help a bit more." SU

One service user noted that having students from the various professions on placement was a positive thing for everyone, perhaps noticing that having a 'learner' observing clinical practice, inspired everyone to 'be on their best behaviour':

"I think that we should be treated equal but we aren't...it depends on how they are and if they have students with them. [Facilitator: Do you find students ok?] Yeah, yeah because they have to go back and report to their boss." SU

All staff interviewed stated that they considered training in mental health issues essential for themselves and for colleagues at all levels of the organisations:

"...because of the high level of mental health problems amongst our [service users]...it should be part of the mandatory training and it's a shock to hear, even amongst my esteemed colleagues, how little they think they've had in terms of mental health training..." CS

"I've been banging on to my line manager for five years, in my supervision and appraisals: I want mental health training, I really want it! I feel this is what's lacking, this is what I feel I'd benefit from most." RS

Community team members stressed the importance of including support staff who work in residential settings, in training initiatives, as they considered them to be highly influential in the psychological well-being of service users:

"Where someone [with mental health problems] is living in a care home, they are reliant on those people who care for them and so if they're not caring for them properly, they need education..." CS

"...and to provide on-going consultation after that as well.... because I think some of the lower paid workers actually get the brunt of some of the hard parts of the work and they might be faced with something that's really difficult and identifying that at an early stage..." CS

Many were disappointed with the training opportunities available in their organisation. A number of staff reported that they were to a large extent self-educated in mental health issues:

"I live in [place] and there's a centre run by Mind. I go there quite often with my partner and they've got a big folder and any new information I needed, I would go to the receptionist and say 'Can I have a copy of this?' and they'd photocopy it for me or I see like the duty officer...or there's a carers group which I know I can get information from, or the internet." RS

Topics which were most mentioned as important aspects of their knowledge base, relevant to mental health include: diagnosis; psychotropic medication; basic counselling skills; psychology; relaxation techniques. Like the service users, staff participants were keen that training happened in the workplace and as an ongoing process with 'refresher' courses available on a regular basis:

"I think we constantly need to be having some training. Coz when you first start, you're new on the team...If you've got a caseload of about 50 clients it probably takes about 18 months to go full circle. With that many clients and to get to know them and know where they're coming from, the families and where they're living and things. So training is obviously... you've got to keep up to date. There's new legislation all the time. There's new understanding like dementia care. ...There's loads really and it's just part of the job, to have training." CS

Good clinical supervision separated from the management hierarchy was stresses by many of the staff participants. E.g.:

"I think supervision is the key one isn't it? ...we're working with sometimes quite complex people...supervision will sometimes answer some of those issues." CS

and

"...my line manager said to me at the time '[name] do you enjoy supervision?' And I said 'Well to be perfectly honest, no'. But you know...that was like the quality I was getting. Well, now I've got supervision with somebody else so, it's a lot better..." RS

Like this last respondent, a number of staff members did not feel comfortable receiving clinical supervision from their manager and preferred to receive supervision from an experienced clinician, not in a managerial position over them.

Training methods preferred by staff, other than standard classroom teaching, included mentoring schemes; peer supervision; having a clinical lead post alongside the manager; reciprocal secondment/shadowing schemes with colleagues in mental health services; a clinical information group on mental health; and through joint work with mental health colleagues.

For example:

" I think we could learn a lot from mental health colleagues... I was trying to run a bi-monthly sort of clinical information group which brought together mental health [and learning disability] nurses to speak regarding their experiences and that seemed to help the [community]team. It had a good response." CS

One residential team leader reported an induction procedure which appeared thorough and was followed up with a mentoring scheme:

"If [new staff] haven't worked with people with mental health [problems] and learning disabilities before...they go on an induction. I think it's three or four days and they go through absolutely everything. You know different mental health [problems], the different risk assessments we've got, umm policies and procedures. We go through all that with them and then finally when they do come to work here, they always have a mentor. So if like say if a new person comes in I'd mentor them for six months and I'd work closely with that person. And I'd make sure they, you know, worked with each individual client...We have to make sure they know..." RS

Interface between learning disability and mental health services

Although a number of staff respondents were able to report on positive experiences of working together with generic mental health services:

"[I've]been able to work with the mental health team and I even sat down with the manager of that team the other day and she was offering to put some of her workers into working with one of our people who has a learning disability and mental health problems... " CS

the majority of descriptions of the learning disabilities/ mental health service interface concerned problematic issues.

FINDINGS

First, the referral systems, as already mentioned above, often resulted in negative outcomes for service users and their carers and supporters, leaving them in some instances without a service or with a disjointed package of support:

"I would say she has sort of mild learning disabilities but mainly Asperger's syndrome. And umm, she also has , she can have psychotic episodes but it's never been diagnosed and can get very depressed from her awareness of her position....she's a very vulnerable person ... I think there needs to be a sort of senior manager level decision of who works with who so that there's not this drift." CS

Another problem described by staff participants concerned hospital admission where the mental health nurses are unprepared for the specific needs of the service user, resulting in less than adequate care:

"...people with learning disabilities being placed with [psychiatric] hospital staff that haven't got the knowledge to work with them or might even find it quite frustrating to work with somebody with a learning disability if they haven't done before.... In an ideal world you'd hope that something's more there and that services would be more accessible...maybe someone, a liaison who could work with the individual, somebody in the middle who could bridge those gaps." CS

Sometimes mental health workers seemed to under-estimate the ability of a patient with learning disabilities admitted to a psychiatric ward:

"I would see him as quite a mild chap who's in a very rowdy ward and it would be the same for anyone else really...but they're [ward staff] putting the learning disability in a place that I wouldn't ...they're underestimating him, both in terms of what he can do for himself and they're assuming he won't be able to report how he's feeling..." CS

Moreover, liaison with Community Mental Health Teams did not always result in good care co-ordination and mental health colleagues appeared to be unwilling to remain involved long enough to ensure effective interventions:

"Well, I think the mental health team, a couple of times they were going to say 'We're not getting anywhere, he's not answering the door. You know we're going to have to close this case. We've got a lot of other cases on' which I understand but for us to see the guy we need mental health to be good." CS

Finally, some of the learning disabilities care co-ordinators noted that some mental health services were not accessible for their service users:

"I suppose when you look at dementia and access for some of our people, accessing things like memory clinics, I think that's really quite poor in [locality] where they just aren't allowed to access the memory clinics and therefore they're not able to access the drugs...I think that's quite a travesty really." CS

> ***"Staff need good supervision and on-going training and they need to be treated well themselves."***

The Judith Trust

IMPLICATIONS FOR SERVICE DELIVERY

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IMPLICATIONS FOR SERVICE DELIVERY

Implications for service provision

A wealth of innovative and constructive suggestions was put forward by all the staff groups as well as the service users. They are summarised below and grouped into cohesive areas for service planning.

The personal qualities which were perceived as desirable in people who work with adults with learning disabilities and mental health problems included a genuine interest in people and specific interpersonal styles and skills. This suggests that staff selection, supervision and training are important in recruiting and retaining a workforce which possesses the attributes, experience, knowledge and skills needed to work effectively with this group of service users.

Ways in which this may be achieved:

- Include well-defined personal qualities in Person Specifications and appoint service users on interview panels in order to rate candidates according to those qualities
- Provide new staff with induction programmes which include shadowing of, and mentoring by more experienced colleagues
- Provide regular and ongoing individual supervision for all by an experienced clinician/clinical lead in order to review competency in interpersonal skills

As working with adults with learning disabilities and mental health problems requires knowledge and experience in not just one but two complex areas of clinical expertise, appropriate and ongoing training is essential if workers at all levels (including at managerial and professional levels) are to be, and feel confident that they are, adequately equipped. The findings of the audit of university teaching (see appendix) indicates that professional courses do not include this topic to any great extent. Services must therefore prioritise:

- Regular training in order to 'top up' knowledge and skills in mental health issues such as counselling skills, relaxation techniques, symptoms of mental distress, impact of bereavement, abuse and trauma, and the application and monitoring of psychotropic medication
- Training to be prioritised and presented in a variety of ways (not only classroom teaching) such as regular clinical seminars/journal clubs/clinical information groups organised by and for clinical members of staff
- Learning disability and mental health staff groups to share training events and exchange their knowledge and expertise by reciprocal secondments and joint information/journal clubs
- Liaison with local universities in order to ensure that clinical training courses such as nursing, medicine, social work and clinical psychology include adequate training in the mental health needs of people with learning disabilities

Many respondents described their workloads as excessive and some of the tasks expected of them irrelevant to the psychological well-being of the service users. Suggestions for service development to address these problems are:

- Implement clinical activity level records for staff which are more meaningful (not just 'head counts') and not too time consuming in order to allow more time for face-to-face contact
- Separate the care management and nursing role, or alternatively allow community nurses who have a dual role in this respect the time to practice both aspects of their job description so that their clinical skills can be utilised

Regular reviews and good liaison between professionals was seen as an important determinant of service quality by both users and staff. In the field of physical health, there is now evidence that regular reviewing is highly effective in early detection and thus prevention of more serious health problems (29). It is, therefore, suggested that:

- Mental health is included in the standard health checks and relevant primary care staff is trained in the symptomatology of mental health problems in people with learning disabilities
- Such training is also given to residential support staff in order for them to detect mental health problems at an early stage and to have the knowledge and confidence to refer these to, and discuss them with, colleagues in psychiatry and psychology

In the areas we sampled, the ways in which services respond to people in crisis appear to be adequate and involve minimal delay in most cases. Moreover, how the various professionals work together in MDT (Multi-Disciplinary Team) settings is appreciated by residential staff. However, when a service user with learning disabilities is admitted to a generic psychiatric ward, the expertise of ward staff was said to be at times inadequate and it would improve the continuity and quality of services if:

- Psychiatric nursing staff, psychiatrists and other mental health professionals who are involved in the care of patients with learning disabilities receive training and supervision in aspects of learning disabilities in order to enable them to recognise and meet the needs of these service users; or alternatively to have the input of a learning disability specialist worker available to them (a similar role to the Health Access Nurse in physical health services)

IMPLICATIONS FOR SERVICE DELIVERY

Other ways in which the interface between learning disabilities and mental health services can be improved are:

» Carry out joint assessments when a service user falls in the 'borderline' of learning disabilities, mental health, substance abuse and or forensic eligibility criteria so that a joint care co-ordinating approach can be adopted by the relevant services

» Create 'virtual teams' around service users to allow professionals to cross service boundaries and work together by each providing their particular area of expertise, thus avoiding unnecessary and time-consuming 'battles' between the services which result in exclusion or delay

Generic mental health services appear to be, in some instances at least, inaccessible to service users with learning disabilities. Examples of inaccessible services include memory clinics (30) and the 'Improving Access to Psychological Therapies' initiative (IAPT; 31). The latter remains closed to service users with learning disabilities in most areas, despite a recent DoH publication directing that services ensure that barriers to accessing IAPT are removed for this population (32)

» Local referral policies must therefore be revised to ensure that the Disability Discrimination Act is not breached.

The Disability Discrimination Act
The Disability Discrimination Act (DDA) gives disabled people important rights of access to health service and social services...(33)

Finally, a number of staff respondents emphasised the conflict of interest that often occurs between the clinical needs of the service users and those of their families and paid supporters. Possible ways of avoiding such conflict are:

» Adopting a 'family centred approach' (28) by which the needs of the family as a whole are considered as important factors in determining positive outcomes for an individual service user and therefore must be considered or 'signposted' to other services such as local carers support organisations

» Using a systemic therapy approach (34) adapted for people with learning disabilities when working with families, in order to avoid simplistic explanations of psychological distress which attribute cause within one individual only, rather than acknowledge the importance of interpersonal and organisational factors in the occurrence and maintenance of distress. Systemic approaches can also be used when providing training and consultancy services to residential staff groups

> *"Regular reviews and good liaison between professionals was seen as an important determinant of service quality "*

6

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Learning disability organisations

- Mencap http://www.mencap.org.uk/
- Respond -Supporting people with learning difficulties, their families, carers and professionals affected by trauma and abuse www.respond.org.uk/
- MIND http://www.mind.org.uk/
- Scope www.scope.org.uk/
- British Institute of Learning Disabilities (BILD) www.bild.org.uk/
- Ann Craft Trust safeguarding disabled children and vulnerable adults www.anncrafttrust.org/
- Foundation for people with learning disabilities www.learningdisabilities.org.uk/
- The Tizard centre www.kent.ac.uk/tizard/
- Valuing people support scheme http://valuingpeople.gov.uk/index.jsp
- Department of Health http://www.dh.gov.uk/en/index.htm
- Association for Real Change http://www.arcuk.org.uk/

Dual diagnosis and Mental health organisations

- Estia Centre www.estiacentre.org/
- The Mental Health Foundation www.mentalhealth.org.uk/
- Clear Thoughts- knowledge centre on mental health for people with a learning disability www.clearthoughts.info/
- The National Association for the Dually Diagnosed www.thenadd.org/
- Royal College of Psychiatrists www.rcpsych.ac.uk/
- Sainsbury Centre for Mental Health www.scmh.org.uk/info/mental_health_information.aspx

Gender and women’s rights organisations

- Women’s Resource Centre - www.wrc.org.uk
- Rights of Women - www.rightsofwomen.org.uk
- Women’s Health Concern - www.womens-health-concern.org
- UK Disability Forum women’s committee - www.edfwomen.org.uk

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APPENDIX ONE: AUDIT OF LEARNING DISABILITIES TEACHING AT BIRMINGHAM UNIVERSITY 2009/10

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APPENDIX ONE

AUDIT OF LEARNING DISABILITIES TEACHING AT BIRMINGHAM UNIVERSITY 2009/10

The University of Birmingham has a student population of around 16,500 undergraduate and 8,000 postgraduate students, making it the largest university in the West Midlands region. Birmingham has departments covering a wide range of subjects. The university is structured into five 'colleges', which are composed of numerous 'schools':

» **Arts and Law** (Archaeology and Antiquity; Birmingham Law School; English, Drama and American & Canadian Studies; History and Cultures; Languages, Cultures, Art History and Music; Philosophy, Theology and Religion)

» **Engineering and Physical Sciences** (Chemistry, Chemical Engineering; Civil Engineering; Computer Science ; Electronic, Electrical and Computer Engineering; Mathematics; Mechanical Engineering; Metallurgy and Materials; Physics and Astronomy)

» **Life and Environmental Sciences** (Biosciences; Geography, Earth and Environmental Sciences; Psychology; Sport and Exercise Sciences)

» **Medical and Dental Sciences** (Cancer Sciences; Clinical and Experimental Medicine; Dentistry; Health and Population Sciences; Immunity and Infection)

» **Social Sciences** (Birmingham Business School; Education; Government and Society; Social Policy)

Teaching relating to people with Learning Disabilities is included in a number of different courses. A survey of courses by the Centre for Excellence in Interdisciplinary Research identified teaching in the following courses. Significant efforts were made to gather information from academics responsible for pertinent teaching programmes. While the returns received may not be fully comprehensive, they do offer a guide as to the amount of teaching relating to people with learning disabilities who have mental health issues at a large university.

The teaching can be split into two broad categories:

» Courses that are provided as part of a professional qualification (ranging from Bachelors to Doctoral degrees) aimed at practitioners who will be working within human service settings.

» Additional courses (generally up to Masters degree) that do not result in a professional qualification but do provide evidence of further personal development.

APPENDIX ONE

AUDIT OF LEARNING DISABILITIES TEACHING AT BIRMINGHAM UNIVERSITY 2009/10

PROFESSIONAL QUALIFICATIONS

Social Sciences

Within the college of Social Sciences there is some teaching on the Social Work BA and MA programmes. For example, the BA Year 1 Module on Social Contexts for Social Work contains material on Learning Disabilities and Health (in general) with some information on mental health in particular. There is an optional Learning Disability Elective which is taken by a minority of students that contains relevant material, but teaching on the issues of mental health and learning disability is not covered in detail. The elective focuses more on acknowledging this as an area of service need which is often hidden and marginalised. The 'Adults Pathways' on the Masters and Bachelors programmes include one half day on 'Learning Disabilities and Health' (in general). No specific teaching is included on the 'Child Pathways'.

On the Social Work Post-Qualifying Award in Specialist Social Work with Adults, parental learning disabilities and parental mental ill-health feature in the 'Assessment and Risk' module because these are often prominent in care applications and safeguarding. However the topic of Learning Disabilities and Mental Health is not specifically addressed.

Placements are available that involve working with people who have learning disabilities. However, these are optional.

Nursing and Medicine

In the College of Medical and Dental Sciences a professional qualification (BSc) in nursing is offered which includes general adult, child and mental health branches. Learning Disability Nursing is not offered as an option. Possibly as a result of this, no formal teaching on mental health for people with learning disabilities is provided. However, they may gain experience of this in clinical practice.

On the MBChB – undergraduate medical degree there is limited teaching on Learning Disabilities in general and some aspects of learning disability are covered in the MBChB Psychiatry course. Within the MRCPsych – Psychiatry there is a module on Learning Disabilities in Year 3, including lectures on Treatment Methods relating to Drugs and Psychological Management.

Clinical Psychology

Within the School of Psychology as part of the Doctoral Course in Clinical Psychology there is an eight day module in Learning Disabilities which runs over two years. One half day session is specifically on mental health and there are other related sessions e.g. challenging behaviour. Trainees have to spend at least six months on placement in a Learning Disability service setting and they have to produce a 5000 word clinical practice report of their work during this placement.

OTHER QUALIFICATIONS

Social Sciences (Education)

The college of Social Sciences the School of Education offers a number of courses, at the Certificate, Diploma and Masters levels in: Learning Difficulties/ Disabilities (Severe, Profound and Complex); Inclusion and Special Educational Needs and Autistic Spectrum Disorders. The first two of these areas does include training on learning disabilities and mental health for example, units on specific health needs, challenging behaviour (3 units) and lifelong learning which covers issues such as dementia.

Nursing and Medicine

Medical and Dental Sciences offer an MSc / Postgraduate Dip / Postgraduate Cert. In Intellectual (Learning) Disability Studies by Distance Learning. This programme does not provide a professional qualification but is a continuing professional development programme and is aimed at experienced professionals who might be from any background and involved in care of people with learning disabilities. This includes teaching on mental health and learning disabilities in the module entitled 'Health and Healthcare for People with a Learning Disability'.

Psychology

There is an elective third year module on Learning Disabilities in the BSc Undergraduate programme in Psychology. The elective is popular and a large proportion of the students will elect to take the course. Other courses consider different learning disabilities particularly Autism and Asperger's syndrome. However, there are no sessions specifically designed to address the issue of learning disabilities and mental health.

Conclusions

While this survey only involves a single university and there may be some gaps due to not all course tutors responding to the survey, it is clear that the amount of teaching in Learning Disabilities is not extensive and that there is relatively little focus on the issue of learning disabilities and mental health. Some courses do seem to feature specific sessions, particularly psychiatry and psychology. There are also opportunities offered by the university for further education in this area up to Masters degree level. However, these are optional courses and staff will have to elect to take these, often at significant personal cost, both in terms of finance and time.

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PART II

Gender, Mental Health & Learning Disabilities

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Gender, Mental Health & Learning Disabilties

Gender and mental health

In the general population large gender differences are observed in the prevalence of the most frequently reported mental health problems such as depression, anxiety and somatic symptoms (1). One of the most robust epidemiological findings in mental health studies is that in most countries depression is suffered more by women (2), for whom the condition is more persistent (3) and has a higher incidence of relapse than for men (4). Women are also more likely to suffer from post traumatic stress disorder (PTSD; 5). Alcohol dependence and antisocial personality disorder, on the other hand, are more likely to be diagnosed in men (6).

The World Health Organisation's document 'Gender Disparities in Mental Health' (WHO, 2006; 7) stresses the importance of socio-economic determinants in explaining gender differences in mental health across the globe. For depression and anxiety these include lack of access to resources such as pay and property, status, valued roles and options for self expression and personal development. Women are said to be the largest group of people affected by PTSD as traditional gender roles engender women to be passive and dependent and domestic violence and sexual abuse are endured by large numbers of women. Moreover, male stereotyping may suggest to many men that aggression and violence are not only acceptable but also desirable means of achieving goals and resolving interpersonal conflict, further contributing to violence and abuse against women and thus higher levels of mental health problems.

The socio-economic factors which have been associated with mental health problems in women are also frequently experienced by adults with learning disabilities. Men and women with learning disabilities, compared to other adults, are more likely to be exposed to poverty, poor housing, unemployment, social exclusion, abuse and overt discrimination (8).

Because of methodological problems, especially problems with self-report, prevalence figures for mental illness for adults with learning disabilities have varied widely across studies. Nevertheless, there is strong evidence for higher rates of psychological and emotional difficulties. The findings of a recent study, which assessed a sample of over 1000 adults with varying levels of learning disabilities, suggest that, if challenging behaviour and autistic spectrum disorders are included, over 40% of the adult population with learning disabilities have mental health needs (9).

This same study found that both men and women with learning disabilities had higher point prevalence than observed in the general UK population and that women were more likely to suffer mental ill-health (43.2% versus 39%), especially affective and anxiety symptoms.

Gender specific service responses

The WHO (2006) report concludes with a number of recommendations to reduce mental health problems in the general population, particularly the overwhelmingly high global incidence of depression amongst women.

They include:

- Collect further evidence on the prevalence and causes of mental health problems as well as on mediating and protective factors for women and men

- Promote the formulation and implementation of health policies that address gender specific needs from childhood to old age

- Improve the competence of primary health care providers to recognise and treat mental health consequences of domestic violence, sexual abuse, and acute and chronic stress.

Awareness of gender specific causes and consequences of mental illness for the general population remains an under-researched area. Much research has been driven by academic health researchers and a dominant biological paradigm. Yet when women themselves have been asked to comment on possible causes of their mental ill-health they stress heavy workload, the gendered division of labour, financial insecurity and unremitting childcare responsibilities (e.g. 10). Lack of research relevant to causation of mental illness and effectiveness of clinical interventions and staff training means that gender specific mental health service provision is as yet not evidence based.

Services for people with learning disabilities are no exception in this respect. Although clinical practitioners have become more sensitive to psychological needs and the dire consequences of impoverished and segregated institutional care (11), when people with learning disabilities experience mental health problems, service response is still lacking in terms of co-ordination, accessibility, and essential knowledge and experience in gender specific issues on the part of both mental health and learning disabilities policy makers and staff.

The WHO recommendations provide a framework for researchers and clinicians to tackle gender specific mental health problems more effectively and the current study is a modest initial attempt to explore the current views and experiences of services by service users and staff.

> *"The WHO provide a framework for researchers and clinicians to tackle gender specific mental health problems more effectively."*

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THE STUDY

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THE STUDY

Aims of this study

The case for more service user and other stakeholder involvement in research concerning people with learning disabilities has been made (12) yet in the area of mental health and learning disabilities these voices are rarely heard. Therefore, as part of a larger study (13), the views of women and men with learning disabilities and mental health problems as well as those of their support and professional staff on gender issues were sought. The aim of the current study was to gain insight into their views and experiences regarding:

- Gender differences in cause and presentation of mental health problems
- Whether current services respond differently to men and women with mental health problems
- Identifying areas in which services can become more gender sensitive

Method

For the purpose of the larger study the authors met with a small steering group which included clinicians, academic staff and a service user, to discuss the project aims and how best to achieve them. Ethical issues were addressed by gaining ethical approval from NRES and the Ethical Committee of the University of Birmingham and adhering to ethical principles regarding informed consent and confidentiality.

It was agreed that service users from urban and rural areas would be asked to participate and that they should have personal experience of having a learning disability and additional mental health problems. Service users were approached via local managers and clinicians and were provided with accessible information leaflets about the study before they were asked for their written consent. All service user participants were deemed to have the capacity to consent.

It was also decided that staff participants were to include a wide range of staff drawn from urban as well as rural areas, residential as well as community settings, and qualified professionals as well as unqualified staff. All staff participants were recruited through the relevant local service managers who were asked to distribute information leaflets to their staff and pass on potential participants' (i.e. individual members of staff who had expressed an initial interest in the study to their manager) details to the lead researcher. Members of staff were then contacted to ask for their written consent and to arrange a convenient time and venue for the interview to take place. Participants were aware that they could withdraw their consent at any time and any data relating to them would then be destroyed.

As the research focussed on the personal experiences of the participants, it was deemed important not to use standardised questionnaires but to employ an open-ended qualitative methodology in order to influence as little as possible the choice of topics discussed and the criteria utilised to judge the quality of the services and the people employed within. For this purpose, semi-structured interviews were designed to prompt discussion.

Two different methodologies were used to collect the qualitative data. First, a stakeholders' event was organised during which a number of focus groups were conducted with service users and a variety of staff, all of whom had had experience of the services under discussion. Subsequently, individual interviews were conducted with staff members employed in residential and community learning disability services. The responses of a total of 54 participants (16 service users and 38 staff) were included in the qualitative analysis. The methodologies are discussed in more detail below.

Stakeholder focus groups

A stakeholders' event was held during which four focus group discussions were facilitated and recorded. It was decided to have same-sex groups in order for the participants to feel they could discuss experiences relevant to their own gender as openly as possible. It was known that a number of female service users had experienced abuse from men and their current mental health problems were closely linked to these experiences, making open discussion about gender and mental health services in the proximity of men difficult.

The four focus groups were: female service users (N=8), male service users (N=8), female staff (N=10) and male staff (N=6). All service users were known to have learning disabilities and also experienced mental health problems. The staff groups included staff with a variety of roles in supporting adults with learning disabilities including support staff (N=7) , a team assistant, nurses (N=2), an assistant social worker, a counsellor, psychologists (N=3) and an advocate.

All groups included no less than six and no more than ten members. Group discussions were limited to one hour. All four focus groups were co-facilitated by two experienced professionals and the two service user groups also had a co-facilitator who was a service user. The discussions were digitally recorded and transcribed verbatim.

The questions which related to gender issues were:

» What are some of the mental health problems men and women have? Are they the same?

» Do staff treat men and women the same? Sometimes, is it easier if a staff member is a man or a woman?

Individual interviews

One-to-one interviews were conducted with a broad range of staff members who worked directly with adults with learning disabilities and mental health problems including support workers and team leaders from residential services and professionals working in multidisciplinary community teams for adults with learning disabilities. Staff who took part in the focus groups were not included in this part of the study. The interviews were digitally recorded and transcribed verbatim.

The residential staff members (N=12) were sampled from urban (N=6) and rural settings (N=6) and from a range of statutory, private and voluntary services. They included two team leaders, one senior support worker and seven support workers. Their ages ranged from 20 to 52 years (mean=38) and ten participants were female and two male.

Qualifications included NVQ 1, 2 and 3, BTEC, and one RNMH (highest qualifications ranging from 2 to 4 award levels;14) and four staff members had received in-house training in at least one topic relevant to the mental health needs of people with learning disabilities (including Mental Health, Bipolar Disorder, Autism, Challenging Behaviour).

The peripatetic professionals (N=10) were drawn from a number of teams covering urban (N= 4) and rural (N=6) areas. They included five community nurses, four social workers, and one assistant psychologist. Their ages ranged from 24-64 (mean=43) and seven participants were female and three male.

Qualifications included a Master's degree in Social Work, a diploma in Social Work, first degrees in Sociology and Psychology, RNLD and RNMH (highest qualifications ranging from level 5 to 7 award level; 14) and four staff members stated they had received in-house training in topics relevant to the mental health needs of their service users (including Mental Health and Learning Disabilities, Drugs and Alcohol, Dual Diagnosis).

Staff participants were invited to be interviewed on a single occasion for no longer than one hour at a place most convenient to them (usually a quiet office at their place of work). They were also asked to complete a brief questionnaire detailing their age, gender, employment and qualifications.

Similar questions to those asked in the focus groups were used and in order to prompt thought and discussion, brief digital recordings (15) of the experiences of people with mild learning disabilities and mental health problems were presented before the interview commenced. These brief (one minute) anonymous audio recordings, spoken by actors and accompanied by still photographs, were shown on a laptop and provided typical scenarios for staff to remind them of the impact of mental health issues on the lives of people with learning disabilities.

Data analysis

Thematic Analysis (16) was applied to the transcripts. The responses to each topic raised by the interviewers and group facilitators were grouped together on the basis of similarities. The concepts expressed were then summarised. This resulted in a number of initial themes which were then collapsed into wider themes. It was thereby possible to identify commonalities and diversity with regard to reported views and experiences of staff and service users.

Care was taken to ensure that the content of the emerging themes was grounded in the original data. An audit of two of the focus groups and the initial three interviews was carried out in the form of independent analysis of the transcripts by two of the researchers who then compared and discussed in detail their emerging themes. Good agreement was found. The first author then completed the analysis.

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RESULTS

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RESULTS

The themes derived from all the data sets were combined and will be presented below. The major themes which emerged from the group discussions and the individual interviews are summarised under each of the questions asked.

WHAT ARE SOME OF THE MENTAL HEALTH PROBLEMS MEN AND WOMEN HAVE? ARE THEY THE SAME?

Compliance versus challenge

Many staff respondents indicated that in their experience women with learning disabilities present as more compliant than their male counterparts, a tendency which results in depressive symptoms as an expression of psychological distress. In contract, men with learning disabilities were said to have a tendency to challenge rather than be passive and compliant when they experienced psychological distress and thus presented with "behavioural problems". For example:

"Women might have greater expectations to comply....women may be having more depressive illnesses whereas umm, men might more challenge in that climate and therefore that gets into the behavioural realms." (female staff)

Vulnerability

Female service users and a number of staff members described the ways in which women are more vulnerable to abuse. For example:

"...I believe that women might have experienced more abuse and that's the direction you might take in supporting and helping..." (female staff)

whereas men's psychological problems were associated with addiction:

"Theirs [men with learning disabilities] is more tangible, they want something... It could be alcohol, cigarettes, that, that sort of er..., those sort of things, seeking gratification. " (male staff)

and one female service user's more radical opinion:

"Well, women have different problems to men...men are the cause of the problems. It's like with my partner, he tried to kill me and put the fear of God into me..." (female service user)

Some staff appeared to indicate that women were inherently more fragile and therefore more likely to experience mental health problems. For example:

"And so with female clients, they're usually more emotional." (male staff)

and that hormonal cycles played a large role in women's mental health:

"With the women you've got hormonal issues as well. You've got all the menstrual issues that could maybe affect the balance of their hormones that might affect them worse." (female staff)

Expression of emotion

A number of respondents spoke about a perceived difference between men and women in how they expressed their emotions and that in their experience women found it easier to talk about their problems. For example:

"...women will be more likely to express anxieties or umm problems with their mental health than men." (female staff)

This was linked to the observation that suicide deaths are higher amongst men in the general population:

"You know, they say that suicide rates in men are higher than women you know. I mean is that because women talk more about their problems and men don't ? [laughs] Who knows, you know!" (female staff)

However, not all staff agreed that women are more able to talk about their problems:

"I've known some women who are quite [pause] they don't really show their emotions, they're just... you'd think they were like really butch [laughs] as they say. You wouldn't expect it from a woman but that's what I've seen and that's why I treat them both the same when I'm working with them."(male staff)

Do staff treat men and women the same?
Sometimes, is it easier if a staff member is a man or a woman?

Equality

Both male and female service user focus groups discussed gender equality in service delivery and both concluded that the opposite sex was treated better:

"I think we should be treated equal but we aren't ." (male service user)

"I think women are treated differently sometimes because they can knock on a door and they can just come in and talk more to them [staff]." (male service user)

"Women don't get picked on as much" (male service user)

"Well, I think there's more help out there for men than there is for women because they think that us women, well, we can cope with it and men can't. But it's wrong…." (female service user)

Most staff perceived the services to provide equally to both sexes, regarded gender as irrelevant and stressed individual needs as determining service response:

"I treat them all the same cos I think they are a person. I don't look at sex or whatever. I…if I'm working with a male then I talk to them and then if I'm working with a female, then exactly the same. I don't differentiate… " (male staff)

and some referred to legislation:

"…because at the end of the day it's equal opportunities and you don't discriminate against anybody,umm whether it their gender, colour, race, religion." (female staff)

Man to man and woman to woman

The majority of respondents commented that in certain situations it was preferable if a person with a mental health problem can have the input of a member of staff of the / same sex, particularly when issues relevant to relationships, sexuality, inappropriate behaviours and sexism are dealt with:

"…if it was anything sexual regarding a male service user and obviously the same with a female, you know, they feel more at ease talking to their own, really." (female staff)

and the need for suitable male role models for male service users who have sexist attitudes to female staff and service users:

"He [a service user] sees women in particular roles and it must come from his family, you know. He doesn't see that he should wash up for example." (male staff)

"Male clients need male staff because the way they treat female staff. " (female staff)

Often the respondents then went on to state that male workers are not always available:

"…and again with the males here, they might overall prefer to have males working with them and if you can accommodate then that's obviously better but it's not always possible, is it?" (female staff)

A number of staff observed that some male service users perceived male staff as more authoritative and therefore were more likely to respond to their requests:

"…you'd have a job, you know, just getting them out of bed. But a guy would just come and say 'come on ' and someone who has been screaming for the last ten minutes just to get them out of bed, you know, and when the guy comes it's 'alright, alright'. Like nothing happened, you know? So, yeh, I do think they do respond differently to male and female, yeh." (female staff)

Staff stressed also the importance of safety considerations for female workers:

"Particularly if you have to do lone working with male clients who perhaps have a history of, you know accusations of inappropriate behaviours for female staff….I have in the past had a male colleague to come out with me or you know take over or whatever." (female staff)

"There's times when er, males, male workers [should work] with particularly, maybe violent men. They can be threatening" (male worker)

Caring qualities

Male and female service users identified female staff as "easier to talk to" and indicated that male staff do not always show as much understanding of emotional issues or are not good at listening. For example:

"…I can talk to a woman easier as they understand more." (male service user)

"I just go to lady staff because they listen to you and men don't listen all the time. I prefer women staff." (male service user)

"I've had a man worker but he doesn't really understand and because I got raped…. and I felt he thought it was probably my fault so I changed my worker and I talked to a woman instead….she knew where I was coming from." (female service user)

"A lot of ladies have been in the same situation that we have so they know then what we're feeling" (female service user)

One male service user observed that in his experience male staff can at times "have attitude", suggesting that there is a competitive element to the service user/ staff relationship which is absent where female staff were concerned:

"Yes, because one or two men workers, if you say something sometimes as a joke, they say they don't really want to know that and you end up having one on you because they don't have the right attitude. Women don't have attitude problems like some of the men" (male service user)

One male service user indicated that female support workers are at times able to be more caring because they are less squeamish:

"When I was in hospital and had to have a tube in me, the men staff were a bit afraid and the women didn't mind. They do things different to men, they don't mind things like that" (male service user)

A number of the women who contributed to the focus group discussion attended a women's community psychology support group and described the benefits of peer support:

"…we all meet up and go to each other's houses and it just gives us more confidence. Before I was on my own but now the group has brought me out and I've made friends and everything and I know there is people out there that need help." (female service user)

and being in an all-women environment:

"Sometimes when you're with men you just clam up but when you're with women you can get on. They can understand what you're going through and we all sit down in a circle and we all say our problems and everything. Then at the end of the day you're more relaxed and at ease now and if you have any questions or need help the staff are there if you need'em" (female service user)

Boundaries

Several staff members observed that for young female workers it is, at times, difficult to support male adult service users as their presence could be sexually arousing. For example:

"I think certainly with some of the younger men I'm working with at the moment… They have a lot of issues with sexuality and umm, a lot of difficulties around umm, having a female worker….Quite often the sexual language that comes out. It's almost, you're almost giving them sort of a reason to, not a reason that's the wrong word, but presenting yourself as a young female when a lot of their language and behaviour is often directed towards young females, it's making the situation a bit more difficult " (female staff)

"…young men with hormones that are raging that have lots of difficulties, a lot of their risk is around inappropriate sexual behaviour and risk to children or women around them umm and so I feel that, yeh, absolutely, I think that myself going into the situation umm, I don't know how they'll perceive me…" (female staff)

One person commented that older women may be more suitable as support workers for some male service users:

"[community support for men]…it's often whether the support can come from someone who's boundaried enough and therefore it can be men or women [staff]. In my experience, it's often older women or men that support men." (female staff)

One of the male service users in the focus group discussion indicated that he is aware of the importance of 'boundaries' where female staff is concerned but that this was not easy for him:

"There's a new girl who has just started and she's only 22 years of age but she is a good worker. She treats you really well, she reminds me of my ex-girlfriend. I wouldn't do anything about it though as she's a member of staff and I'm a client at the end of the day. But I think about her in my room." (male service user)

Male staff spoke of the delicate line between providing good and sensitive care and support to female service users and being open to accusations of being intrusive or even abusive. The working life of these staff is complicated by these potential problems and one respondent compared the public's trust in male medical staff with the, at times, suspicious stance taken with male support and nursing staff:

"I think as a male member of staff you're kind of umm, sort of put in this rotten basket…for the women I'm not allowed to go in their room, some of them cos of their history, some of it's like 'oh you're a man, you can't do that job'. That can be really frustrating cos I'm a professional person…I think if you was, if I was a doctor in a hospital or whatever…I'd be expected to still treat females, you know. And there'd be no kinda question about it, I don't think." (male staff)

Female service users and female staff stressed the importance of having female to female support for women who were vulnerable to abusive relationships, not just for the sake of the service user but also to protect male members of staff from false allegations:

"If it was a woman who was perhaps very vulnerable and looking at the vulnerability of the person offering the support as well…so sometimes it's quite clear that it should be umm a woman for a woman." (female staff)

> *"Female service users and female staff stressed the importance of having female to female support."*

The Judith Trust

DISCUSSION

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Discussion

The respondents' narratives have provided a wealth of information about the experiences of female and male service users with learning disabilities and mental health problems and the staff which support them. This paper reports specifically on gender issues and the themes which emerged from the qualitative analysis throw light on a number of areas in which gender plays an important part in determining service quality and outcome.

Differences between male and female presentation of psychological problems were commented on mainly by staff, some of whom perceived women to show 'passive', depressive symptoms and men 'active', challenging symptoms. These descriptions closely match the epidemiological evidence, reported in the introduction of this paper, which according to the WHO report on 'Gender Disparities in Mental Health' (7) is due to socio-economic factors which give women a disadvantage in terms of protecting their mental health. Staff also noted that women are more vulnerable to mental health problems because they are more likely to have experienced abuse, again echoing the global evidence presented in the WHO (2006) report. Other reasons given for why there are differences in presentation between the genders and why women may be more vulnerable can be described as biological explanations, such as hormonal changes.

A number of staff observed that women found it easier than men to express their emotions and talk about their problems, although exceptions were also mentioned. Some staff participants appeared to be aware of the finding in the general population that women are better at seeking help for medical as well as psychological problems (17).

Both female and male service users described how gender inequality in service responses put their sex at a disadvantage. In contrast, the staff respondents reported that, although they acted in a gender sensitive manner, they did not perceive their service to treat either gender better or worse.

At least one female service user perceived all her problems due to men and indicated that mental health services for her would only be effective if provided by women. Having input from same sex support and professional staff was perceived by most respondents as desirable where personal issues such as relationships and sexuality are concerned, although a number of male service users indicated that they preferred female staff to support them in such situations.

Linked to this, a dominant theme which emerged is the importance of the personal qualities of male and female staff. The latter were often described as better at listening and being more gentle and understanding whereas some male staff were viewed as having less empathy. On the other hand, many female staff respondents noted how male staff often had more authority and they emphasised the value of having male staff act as appropriate role models to combat disrespect and sexist behaviour towards women and as guardians when male service users were thought to be violent or aggressive. Most staff noted, however, that there are too few male workers available for these roles as the workforce is predominantly female.

The difficulties experienced by young female workers were described in this context and their attractiveness to male service users was seen, at times, as problematic (and unfair?) as their presence was regarded as potentially provoking inappropriate sexual behaviours in some male service users.

Male staff reported their own specific problems caused by gender. That is, male staff described (in emotional terms at times e.g. "put in this rotten basket") how they were prevented from working with female service users on a one to one basis for fear of the risk of inappropriate behaviours on their part or false allegations on the part of the women in question. Although there is evidence that male carers constitute a significant percentage of perpetrators of reported sexual offences against women with learning disabilities (18), being treated as potential abusers is obviously a cause for resentment for male workers.

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DISCUSSION

As the present study is small scale and exploratory, no firm generalisations or recommendations can be made on the basis of its findings. Nevertheless, the authors consider it appropriate to suggest a number of areas for future research which may then provide an evidence base which can inform future clinical practice:

» Collect further evidence for the adult population with learning disabilities on the prevalence and causes of mental health problems as well as on mediating and protective factors specific to gender so that interventions can be designed to meet the needs of both men and women most effectively.

» Research the manner in which men and women with learning disabilities express their emotions and seek help for emotional problems in order to identify possible sex differences which lead men with learning disabilities to be less likely in receipt of timely support for mental health problems.

» Evaluate the benefits of same sex support groups for men and women with learning disabilities and mental health problems, particularly groups which adopt a community psychology approach (19) i.e. the use of psychological methods to enrich the lives of the powerless, with a focus on change and action to improve well being and tackle the causes of health inequalities.

» Educate support staff in the socio-economic causes of mental illness and improve their competence to recognise and treat mental health consequences of domestic violence, sexual abuse, and acute and chronic stress.

» Investigate the effectiveness of group and/or mentoring interventions for adults with learning disabilities and mental health problems to encourage respectful relationships between the sexes by exploring differences and similarities between men and women.

» Investigate the effectiveness of training and supervision aimed at supporting both male and female staff working with adults with learning disabilities and mental health problems in developing the interpersonal qualities (traditionally considered female), relevant to listening skills and expressing empathy.

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