

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.

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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.

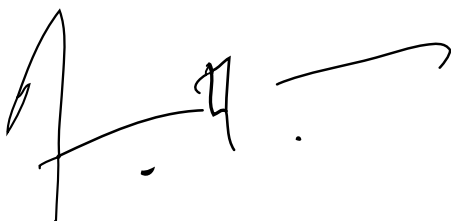
The Judith Trust customarily sets up a steering group to learn about and monitor the research we fund and we had an excellent experience with the Birmingham Group. The balance struck in the final report between ensuring users had access to the research and the quality of the work itself is evidence of 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.

A handwritten signature in black ink, appearing to read 'Annette Lawson', with a long horizontal stroke extending to the right.

Annette Lawson

Chair - The Judith Trust

ACCESSIBLE EXECUTIVE SUMMARY

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

ACCESSIBLE EXECUTIVE SUMMARY

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

