

MENTAL HEALTH AND LEARNING DISABILITY REVIEW

News Letter No 2 – February 2004

FROM THE REVIEW CHAIRMAN

The Review is now well into its second year, and substantial progress has been made. Scarcely a day passes without a Working Committee or sub-committee meeting. The collective energy generated across all of our deliberations is quite remarkable. In particular, I wish to pay tribute to the crucial contributions made by service users and carers. Their influence has been fundamental.

Two Working Committees – Learning Disability and Adult Mental Health - will have detailed documents ready for consultation with stakeholders by summer this year. All committees are well under way and I would continue to urge all those wishing to contribute to the Review to make contact with the support team to facilitate the necessary arrangements. These can range from use of our freephone, website, by letter, one off informal meeting, formal consultation with one or more convenors, as well as presentations to a particular committee. Your voice can be heard and will be listened to.

This Review is in reality not a single review at all. The Steering Committee has long since accepted that here are several important reviews going on under one umbrella title. There are of course numerous interfaces and overlaps too obvious to mention; suffice it to say that the management of this entire process is complex!

As well as the Steering Committee, a key ingredient in holding the Review together is the regular convenors meeting. These

help to generate and maintain a unity of purpose.

The Review is maintaining close contact with Government. One important example of this is our participation in the current review of workforce in mental health and learning disability. While our overall vision is a long term one, it is gratifying that both DHSSPS, other relevant Departments and key stakeholders are now actively taking note of the direction the Review is taking.

I thank everyone for their sterling efforts.

David Bamford

ADULT MENTAL HEALTH – A NEW FRAMEWORK

The goal of the Review of Adult Mental Health is the preparation of a new service Framework, or blueprint, for adults with mental health needs. This work is progressing well and we have completed our initial review of evidence. Members of the Review Group have begun a series of consultation meetings with stakeholders to consider our findings and receive comments and advice.

Our work has been grounded on a need to recognise and promote the personal dignity of adults with mental health needs and their carers. We are also paying careful attention to the evidence base for best practice, including local examples of good *(continued overleaf)*

practice. While there are deficiencies in the comprehensiveness of the population level information about mental health needs and service provision, the available evidence strongly suggests that mental health needs in Northern Ireland are greater than in many parts of these islands and nevertheless service provision is significantly less. The message is clear.

The Review Group in its development of a new Framework for Mental Health has considered the service requirements at three levels: community and primary care, secondary care services and specialist services for people with particular needs.

Community and Primary Care.

There are significant opportunities for strengthening the contribution of non-statutory and community based services through care-based mental health service provision. The planning and development of primary care services can be facilitated by greater participation of users and carers. Primary care services need access to mental health expertise and there needs to be seamless provision between primary and community care. There is scope for improvements in both the availability and quality of medical and psychological treatment in primary care.

Secondary Care Services

The Review Group have considered in great detail the service needs for adults with more severe mental health needs requiring the skills and facilities of mental health services. The proposed reforms of current services should ensure a major shift in the centre of gravity of secondary mental health

services over the next 10-15 years. With appropriate development of the full range of community based services it is anticipated that the need for admission to hospital will be greatly reduced and the duration of admissions much shorter. The magnitude of community based services, the skills and capabilities of community mental health teams and the range of available service options should enable the great majority of service users to be treated and cared for entirely within community settings.

The Review Group have considered a person-centered approach to service planning and provision as fundamental. Mental health services need to reflect the multi-dimensional nature of service user and carer needs. This includes mental health needs but also such issues as employment, training, accommodation. Services also need to consider the need of carers and families. Modern mental health service consists of a complex set of activities and functions designed to meet the needs of individual service users.

Following a person-centered approach the Review Group have found it helpful to consider mental health services in three complementary aspects: the ongoing needs of people with mental health needs, needs at times of crisis and those aspects of provision necessary to promote recovery of health, personal functioning and self-fulfilment.

Specialist Services

The Review Group are also considering service user groups whose needs often cannot be fully met without specialist services and expert skills. This includes people with severe brain injury with enduring mental health problems,
(continued overleaf)

people suffering severe sequelae of psychological trauma, deaf people with mental health problems, people with eating disorder, people with severe personality difficulties, people suffering from Autism Spectrum Disorder.

Infrastructure

The proposals for a new framework for mental health services depend critically on a number of underpinning elements. These include appropriate funding, provision of suitably trained and skilled staff and good information on the needs of the community, the services being provided and their impact on the mental health of the community. The Review Team with the help of experts from the Department of Health and Social Services, will over the next few months be giving detailed consideration to these issues as part of our preparation of a new Service Framework for Adult Mental Health.

Roy McClelland

CONFERENCE: MENTAL HEALTH LEGISLATION – DO WE NEED IT?

This well-attended conference at the Dunadry Inn, Templepatrick, on Friday 16 January 2004, opened the debate within the Review on whether a revision of legislation on mental health was required; and, if so, what principles should underpin new legislation.

Organised by Dr Maria McGinnity's Legal Sub Group, and chaired by Roy McClelland, the conference heard initial stimulating and thought-provoking presentations from Professor Bill Fulford (Warwick University) and Dr Tony Zigmond (Royal College of Psychiatrists) on differing perspectives

on mental health legislation, and their experiences of the review process in England and Wales. The importance of the interface between Incapacity legislation and Mental Health legislation became clearer.

Bernadette Hamilton, one of the organising committee, then spoke about work to date on values and principles within the Sub Group. There seems no doubt that legislation needs to be revised. This led into workshop sessions, to begin the process of identifying the key principles, which should underpin legislation here. Members felt that these must include equality, partnership, reciprocity, risk, justice, and autonomy.

Finally, delegates heard from Dr Madeline Osborn (Mental Welfare Commission, Scotland) on the principles underlying the review of mental health legislation there. She also had some very pertinent reflections on the process of review, the importance of developing a Code of Practice in tandem with legislation and the difficulties of implementation.

The conference is only the start of the process. The work to develop a set of principles is now being taken forward by Dr Maria McGinnity's group, with the aim of providing a report by the summer.

Roy Keenan

NEEDS AND RESOURCES COMMITTEE

The Needs and Resources Committee has been concentrating on costing the recommendations which are being developed by the Adult Mental Health Working Committee and by the Learning Disability Working Committee. We will be assisting these Committees to look at the financial implications of the options (*continued overleaf*)

which they are considering as well as costing their final recommendations.

Our costing sub-committee, chaired by Sean McKeever, has decided to increase its membership to allow it to manage the considerable amount of work which it needs to complete over the next few months. Approaches are being made to secure volunteers from Trust Finance Departments!

For the period during which we are working on costings we have arranged for members of committees making recommendations to become members of the Needs and Resources Committee. Seamus Logan is already representing Adult Mental Health and Tom Smith will join us on behalf of Learning Disability. We are also delighted to have been strengthened by Delores Ferran from the Housing Executive and Angela Meyler of CAUSE for Mental Health is representing carer interests.

Karen Campbell of DHSSPS has been leading on another strand of our work – identifying the resources committed to meet the needs of people with mental health or learning disability by DHSSPS and other Departments of government. This should allow us to make comparison between the resources available in Northern Ireland and those elsewhere.

Brian Dornan

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A separate news letter produced by the Learning Disability Working Committee is also available.

CHILD AND ADOLESCENT MENTAL HEALTH COMMITTEE

The Child and Adolescent Mental Health (CAMH) committee commenced in October 2003. The membership of the committee is presently addressing how to involve the carer and user perspective with invitations for involvement. The CAMH committee is working to the terms of reference as set by the Mental Health and Learning Disability Review.

The principles that have been adopted by the CAMH committee are:

- Child-centred
- Family-focused
- Community-based
- Multi-system
- Culturally competent
- Least restrictive/least intrusive

The CAMH committee have formed three working groups and are seeking nominations to each group to bring forward the work of the committee, as follows:

- Tier 1/2 services working group
- Tier 3/4 services working group
- Marginalised and at risk working group

The remit of each group will be the scope of the mental health terms of reference.

Planned work includes:

- Mapping exercise regarding services for tier 1/4 across the four Boards in Northern Ireland.
- Meet the four Board CAMH Commissioner regarding current and projected business objectives.
- Meeting with the drug and alcohol working committee March 04.

- Meeting with the forensic group soon
- Planning a seminar event for early June 04 to receive presentations from different stakeholders and their view on what they believe needs to inform a future strategy for CAMH service education and policy agenda for Northern Ireland.

Moira Davren

WE HAVE A DREAM

Messages from people with a learning disability to the Review.

How many of my close friends have a learning disability? That's the question I was left with after reading 'We have a dream'. The clear message to the Review is 'We are people too, you know!'

The directness of the report made we aware that I can be extremely patronising to people with a learning disability – and when that happens I rob that person of their human dignity.

'Why do we not have a choice?' is a constant plea in this report. *'Can we not decide where we live, at home or with friends?'* People with a learning disability experience others talking about them rather than talking with them. *'Doctors don't talk to us but to the people who come with us. They should talk to us.'* People who use wheelchairs said that the community often ignored them. Those who have been in employment often found it very difficult, with employers having no understanding of learning disability and worse, people with a learning disability told of experiences of being bullied and picked on by other workers. Support staff working with those with learning disability are no different from the rest of us, *'Some are bossy'*; and then again *'My support is just right.'*

The world described in this report can be a very lonely place; for many people with a learning disability, their only friends are relatives or staff members.

This report was written by The Equal Lives Group, who describe themselves as people with a learning disability. With three support workers they have met with others in different locations throughout Northern Ireland about what is good and not so good with their lives. They summarize what they want to say to the Review in the following points:

- Everybody should have a choice where they live and if they want to stay in their local area then they should be supported to.
- If people want to live on their own or with friends they should get the help they need to do that.
- All staff who work with people with a learning disability should get special training so that they understand how to respect people and know what to do to support people with a learning disability
- Any time people are making decisions about services or support they should have to listen to people with a learning disability.
- We hope that the Review will make sure that there are more advocacy groups and more chances for people to speak out and be listened to. We do not think this happens enough and that is why things go wrong.
- People with disabilities should have the same opportunities as people without a disability.

Trevor Williams



Focus on Families – Messages from family carers to the Review

Most families who care for a member with a learning disability don't want to be called heroes. They want support. They want someone who will listen to what life is like for them, and when support is offered to have a say in what kind of help would be best. After all they are the experts.

The stories in this report show that the voices of the carers are not being listened to. As a result the services that are being offered are not as effective as they could be, and the difficulties carers face are often made worse by those who are seeking to support them.

Many of the family carers told horror stories about the manner in which they were told that their child had a learning disability. But that's not all. Time and time again, the concerns of carers were dismissed by professionals and the carers were made feel that they were just being neurotic, obsessional or hyper-anxious.

More information was needed. As one carer put it *'Please show us the respect by giving us the information we need to do our jobs as parents and carers.'* Another person said *'I am 84 and I have been caring for my brother on my own for years. He is 74. I did not know until the last few weeks that I was entitled to help with benefits and that there was such a thing as respite. A nurse sees my brother now every fortnight and arranged a 3-day respite last week for the first time'*

They also know what they want – an information pack. The contents should include information on:

- Child assessment
- Carers assessment
- DLA and other benefits
- Statementing

- Schools options
- Respite provision
- Name and contact details of key staff e.g. social worker
- Charities that can help
- Local support groups.

This information exists. What a great first step to put it together in an information pack.

In the early years more help is needed from speech therapists. And life would be so much better if professionals communicated better with each other. The Wraparound Project in SHSSB was commended as an example of good practice where this problem had been addressed.

In this report it is interesting to hear carers discuss whether 'special schools' were best or if it was better to integrate people with a learning disability into mainstream schools. The support, understanding and skills of special schools was greatly appreciated. But then the advantage of children with disabilities *'going to school with their brothers, sisters and neighbours'* was also important. *'This will educate the whole population about disability because there will be no segregation'*.

On support, the provision of out of school activities and respite, one quotation in the report should alarm us all when they say *'I did not get any break at all until I threatened to take my own life'*.

Clearly the selection and training of staff is of the utmost importance. As one carer put it simply *"Who will or can understand my son?"* Skilful and sensitive staff can transform the quality of life for carers. Here's just one quote from the report *"My life has been totally changed lately. I got a new social worker a few months ago and suddenly I am getting a lot more help in the house. I got my first break ever a couple of weeks ago'*. This person's daughter is in her 30's. She has been a long time waiting.

Trevor Williams