

**Presentation to the Mental Health Review Board  
Carer & Consumer Forum  
by Penny Lewisohn, carer and Co-chair Inner South Parents & Friends  
22<sup>nd</sup> October 2008**

**I've been asked by the Carer Network to provide some carer views to the review**

**It is an unhappy message from Carers**

With twelve year's experience of the Victorian mental health system, I've canvassed the views of other families in preparation for today. Their message should make the mental health 'industry' ashamed!

**What is the message?** There is desperation amongst carers that nothing seems to have changed in the twenty years since de-institutionalisation. Families have borne the brunt of a system, heavily under-resourced, which has all but ignored them.

**What should be the response? - Family Inclusion!**

- **Meaningful, not tokenistic, inclusion of families and carers is long overdue**
- **Research worldwide supports** linking families with services and involving them in decision-making because it leads to better outcomes.
- **Other jurisdictions acknowledge our existence:** The NZ Mental Health Act requires that carers be consulted, except in certain justifiable circumstances. The Scottish Act is inclusive of families or an alternative advocate to support the consumer.

**Why should families be consulted?**

**1. Family members may have information critical to the decision making process:**

- **Often the treating clinician has a quite limited knowledge of the patient:** One consumer had 11 different treating psychiatrists in 6 years and not infrequently the doctor has seen the patient only once prior to the hearing.
- **Patient presentation at the Board hearing may be misleading**  
Sometimes the consumer presents as being well, but beneath the surface the situation might be quite different. Family support will be critical in providing this information to the Board.
- **Early intervention and relapse signals** – families can usually detect specific early warning signs of relapse but without collaborative procedures they are not heard.

- **The history of the illness has to be taken into account both on appeal or review** – it is not confined to professional records and opinions. Family members can provide a useful historical perspective.
- **Social circumstances must be considered** – the lifting of a CTO needs to be much better linked to the provision of ongoing care whereas often it can signal imminent discharge from services.

## 2. Advocacy

- **No one other than family stands up for non-compliant consumers.** Non-compliance is often construed as ‘bad behaviour’ particularly where substance abuse is involved. Services can become impatient with lack of progress and discount the mental condition of someone who is seriously unwell. An alternative diagnosis of ‘personality disorder’ is sometimes applied and services withdrawn. Strangely the ‘bad behaviour’ can miraculously disappear when, with perseverance, the right treatment is found.
- **No-one else really advocates for dual diagnosis patients either:**
  - Everyone sidesteps dual diagnosis issues yet unsympathetic, poorly co-ordinated services can lead to some absolutely shocking outcomes.
  - In practice, current Drug & Alcohol services are too rigid for mental health patients.
  - Carers think substance abuse should receive concurrent treatment. It seems illogical for a CTO to require medication to be taken without helping to address addictions, which exacerbate the illness.

3. **Failure to consult or notify family can be disastrous:** One family believed their mother was still receiving treatment under a CTO until she tried to kill their father with a cricket bat. Only then did they discover that the CTO had been lifted two years earlier. No one had bothered to inform them of this, or that her treatment was no longer being monitored.

### So why are families not included?

- **Autonomy** – When someone is seriously ill the concept of autonomy can be pushed too far shutting families out. When someone is seriously unwell is it not unfair to their long-term interests to expect them to function autonomously? Surely they need the support of their family or some other advocate.

- **The adversarial element clouds** the issue of where ‘best interests’ truly lie. I know a case where a young Legal Aid advocate secured the release from HDU onto the street of someone who was seriously unwell whom he’d met two minutes prior to the hearing. She was readmitted within the week but the stress for all involved was acute.
- **Traditional attitudes toward the families of the mentally ill** lead to a tendency to demonise families as part of the problem.
- **Some mental health workers characterize carers as control freaks.** In fact families generally just want to achieve the best possible outcomes. Everyone would benefit if families were presumed innocent until they prove themselves guilty.
- **Perhaps it is all just too difficult?** The lack of mention of families in the Mental Health Act does not preclude their inclusion. - it has simply allowed for lazy practice on the part of hard pressed service providers and avoidance of awkward situations on the part of the Review Board
- **The thorniest issue is probably Confidentiality** – Speaking with carers need not mean invading privacy or breaking confidences. Psychiatrists should be expected to have interviewed them and then report relevant information to the MHRB at hearings.
- **Is there an inherent predisposition towards lifting CTOs?** – some families believe that lifting a CTO is used as a significant measure that ‘treatment’ has been successful. There is huge demand on services and a need to achieve throughput – without their family to protect their interests many consumers fall through the cracks. Indeed unless on a CTO these days, specialist mental health services for the seriously unwell are few and far between.

**So how can the Board better include families? – Some Suggestions:**

- **Families should always be given notice of hearings and outcomes unless there is good reason not to.**
- **Focus on being more family friendly** - Most families are completely at sea when a family member becomes mentally unwell. They need to be supported and included in decision making because they can be valuable members of the therapeutic team and provide vital continuity.
- **Enhance education for all participants including Board members:** Communication skills are needed far beyond the level normally required in average family interactions. **The Carer Network is keen to join with the Board in a pilot project to assist in such training.**

- **Require a thorough examination of ongoing supports when reviewing a CTO:** During the recovery phase lifting the CTO should be conditional on rehabilitation and relapse prevention plans with special attention to accommodation. Treat family liaison as essential because quite often they are left to co-ordinate fragmentary services as well as to provide ongoing day-to-day support.
- **Work on the most appropriate way to receive family input:** the issues surrounding confidential information are too complex to cover now, but for example, VCAT seems to manage quite well in the case of Administration Orders.
- **Find a mechanism to avoid reimposing involuntary treatment in the emergency department of a Public Hospital each time there is a relapse.** To allow acute episodes to develop repeatedly, at great cost, is dispiriting for everyone and delays recovery.
- **Adopt a more collaborative approach instead of our adversarial system –** Incidentally, enhancing access to legal representation will not, in the view of families, lead to better outcomes. More mediation, perhaps combined with a more collaborative model may be the answer.
- **Advance Directives -** Preferably assume from the beginning that the family will be participants rather than that they won't.

#### **Some final points:**

**Complaints** – there is great need for a better process for complaints. There should be a role for say an **Independent Mental Health Commission for** when treatment isn't working.

Families don't want to see further direction of resources to an expansion of legal process and believe that better collaboration would negate the need.

**I hope that I have emphasised sufficiently that the Board should consult with families!**

Legislative change is necessary and there are good overseas precedents in NZ, the UK and Scotland. In cases where, for good reason, a particular family cannot be involved then an advocate (preferably not a lawyer) should be provided, as is the case in Scotland.