Submission to Senate Committee on Mental Health

The **Community Living Program (CLP),** auspiced by the Community Living Association, is a non-government community organisation based in Nundah, on the northside of Brisbane, that supports people with mild or moderate learning difficulties/intellectual disabilities to live in their local community. We focus on developing people's resources in the area of housing, skills, income and transport; developing personal meaning and a meaningful use of time therefore improving self-esteem; improving people's physical and mental health; improving safety and security issues as well attempting to make people free from sexual; financial, emotional and physical exploitation and bullying; and building people's community connections and relationships with family, significant others, neighbours, acquaintances and community members. Practice experience, research and analysis undertaken at CLP have generated significant knowledge and understanding of the mental health and well being issues that shape the lives of people with intellectual disabilities. In 2002, Community Living Association published a report outlining the findings of the CLP Dual Diagnosis Report which was done to research the knowledge and practice experience of workers from several Brisbane-based organisations whom work with and support people with a dual disability of mental illness and intellectual disability. This report will be attached to this submission.

Introduction

This submission discusses the impact of mental health issues and disorders on people with intellectual disabilities living in the Australian community, and the effectiveness of the Queensland mental health system in supporting this group of people in managing their mental health difficulties. People with intellectual disabilities experience an over-representation in many areas of social disadvantage such as marginalisation, isolation from society, poverty, homelessness, the criminal justice system, victims of crime, unemployment, physical health problems, psychiatric disability and experiences of violence, abuse, exploitation and victimisation (Community Living Prgram, 2002, 4-5). For people with intellectual disabilities, achieving the balance between the resources that they have to bear on the world and the pressures that the world is putting on them is a chronic and continual struggle. This is why the Australian National Mental Health Strategy identified living with an intellectual disability as a risk factor that would increase the likelihood that mental health problems and disorders will develop (CDHAC 2000: 15-16).

Our experience shows that a supportive family and community environment can protect people with intellectual disabilities from experiences of bullying as children and adults, abuse and exploitation, exclusion from the community, substance abuse, homelessness, unemployment, victims of crime, criminal justice system and a general lack of self-esteem and confidence. If a person has few supportive relationships in their life or if families can no longer cope or meet that person's needs, the struggle of living with an intellectual disability and all the challenges that daily life constantly provides, the resulting stress and anxiety can lead to the development of very significant mental health issues and disorders. It is our belief that there needs to be interventions at prevention, early intervention and tertiary levels of support, to people with dual disability of intellectual disability and psychiatric disability. Without this, these people have no option but to wait for crisis intervention from a mental health system which is ill-equipped to support people with intellectual disabilities. The issues of dual diagnosis of people with intellectual disability and psychiatric disabilities needs to be recognised at a federal level and programs need to be developed which provide a prevention and early intervention response in the community rather than purely a crisis response.

Background

There is no doubt that people with intellectual disability have higher rates of mental illness than the normal population. The prevalence rates vary within the literature from 10% to 90%, with variations according to whether people live in institutional care or in the community (Hudson & Chan 2002 :pp.32). White et al found that prevalence rates varied from 14% to 67% (2005:397). Other studies identified in other literature (Community Living Program, 2002: pp.10) support this. Lennox (1997:81) says that the prevalence rate of psychiatric disorders in adults with intellectual disabilities is between 30% and 50%. CLP's experience is that out of 34 clients that receive individual support (not including external clients who access some of our groups or intake clients) 34 clients experience mental health issues and disorders and out of those 23 are currently on some form of mental health medication. Therefore 100% of our clients are currently experiencing mental health issues and disorders while 68% are currently receiving prescribed mental health medication for depression, anxiety, mood and psychotic disorders and regularly see either a psychiatrist or GP for their mental health support. CLP is not funded to provide mental health services, but to support people with intellectual disabilities, and despite that it has become an integral aspect of our practice.

The Commonwealth Department of Health and Aged Care (2000: 14) states that "single risk factors often have only a minimal effect on their own, but may combine to have a strong interactive effect and exposure to multiple risk factors over time have a cumulative effect". The exposure to multiple risk factors over time is a significant feature of life experiences for people with intellectual disabilities and explains why this population is so vulnerable to mental health problems. These risk factors include those identified by the Australian National Mental Health Strategy (CDHAC 2000: 15-16), as increasing the likelihood that mental health problems and disorders will develop such as individual factors, family/social factors, school context, life events and situations, community and cultural factors. Further risk factors identified by CLP for people with intellectual disabilities include abuse, exploitation and trauma; poverty and disadvantage, 'Care' and institutionalisation, separation from family, family dysfunction, medication and drug use, lack of purpose and meaning in life, biological or genetic conditions, physical health, social dislocation, poor relationships, unresolved grief and loss, education, inappropriate contact with mental health systems, constant change, lack of self-determination, poor self-esteem, self-harm, and learned hopelessness (Community Living Program, 2002 :18-20). These risk factors should be recognised and made a legitimate aspect of the assessment process.

Benefits of Prevention and Early Intervention Strategies

The benefits of using prevention and early intervention processes and programs are, that it can avert the pain and trauma of the experience of the mental health disorder for the person and the people and the people around them, as well as freeing up resources for other people in the community to access crisis response services. Our experience is that a person with an intellectual disability is so traumatised by their hospital experience that they either take several years to recover or they don't recover at all. They don't have the cognitive ability to process and deal with the trauma of the mental health experience, therefore they often don't recover and return to their previous self. Therefore their ability to be an active part of the community, to have relationships with others, to work in some part-time work and find their meaning and contribution to this life, is very limited. They often become recluses living in inappropriate and unsafe accommodation and in the process very vulnerable to those who can take advantage and exploit those people for their own ends. Specialist prevention and early intervention programs are a necessity for people with intellectual disabilities.

Difficulties in Accessing Mental Health Support before and during a Crisis

There are great difficulties for people with intellectual disabilities and their carers to get help for their family member or friend when they are in crisis. Often carers will only bring people to the hospital if they themselves have reached breaking point and don't know what to do with that person, particularly if that person is suicidal, verbally or physically abusive, and can't be left on their own. CLP workers have in the past taken a person up to the hospital because there behaviour indicated to us that they were extremely unwell and weren't safe to go home, where they would most likely live on their own. They were at risk of harming themselves or others. Yet these people are often assessed as not having a mental illness by nurses, not psychiatrists, largely because they take little notice of what the support worker tells them; they assume that it is a part of their intellectual disability, not a mental illness; and the person is a lot calmer as they have often spent most of the day with the CLP worker. We have found the only way to get a person into see a 'psychiatrist' is to get them into see a general practitioner first, who will phone the mental health service or write a letter stating that they feel this person is experiencing some form of mental health disorder and needs to see a psychiatrist, and only then will the person actually get to see a doctor at the mental health unit. Then that's when a treatment plan is worked out. This is appalling. How are ordinary people in the community, as well as people with intellectual disabilities, who don't receive any support from paid workers meant to access support with this kind of system.

We feel that there is an active process at the two mental health services that our clients access of blocking new patients and people who are extremely unwell from getting immediate support. The mental health workers at these services provide only one option for the family members or support workers to access some assistance, and that is a phone number to call for the next 24 hours to the Acute Care team. The fact is a person with an intellectual disability living alone are not going to ring a stranger to get help, or indeed not even recognise that they need help. The Acute Care Team at both mental health services are under resourced and not doing what they were set up to do. Its our perspective that the Acute Care Team have indeed become gatekeepers, rather than allowing greater access to mental health services in the community.

The following is a case study written by a CLP worker of a recent experience which illustrates the difficulties of accessing mental health services.....

P is not a client of CLP, but rather someone who was referred to us by the Prince Charles Hospital Mental Health Unit. His mother had taken her son there the previous *evening hoping that he would be admitted. He was assessed by a community nurse and sent back home with a 24 hour call access arrangement.*

She was terribly upset during the call saying that she could not cope with the situation her son was living in anymore, on her own. She could not take him home to live with her, as he was begging her to do, because she wouldn't be able to manage his behaviour and there was no one else to help. She said he was not managing living in his flat on his own, he often talked about suicide and all he wanted to do was sit at home and watch TV. She said he had , an intellectual disability, attention-deficit disorder and had become obsessive-compulsive. She said he had been receiving a lot of support from his step-father until he died about 18 months ago and since then his behaviour had deteriorated.

She had arranged to take P to see a doctor that afternoon who used to treat him for attention-deficit disorder when he was younger but she was anxious about how helpful that would be. I encouraged her to tell the doctor this same information and ask for his support. Then if she still felt concern she should take P back to the Prince Charles Unit. I offered to call Prince Charles to refer P and encouraged her to ring me the next day to let me know how things were.

I rang and spoke with a member of the Acute Care Team at Prince Charles. She assured me that P had been fully assessed and was not considered to have a mental illness. I asked if it was possible for him to be assessed by a psychiatrist. I talked about the effects of chronic stress and loss on a person with intellectual disabilities, leading to high levels of anxiety and depression. She said P could return again for a further assessment if they felt it was necessary.

The doctor assessed P as having some symptoms of mental health issues and felt he should be seen by a psychiatrist. He wrote a letter to the service advising that P should be seen by a psychiatrist and giving the service more information and detail concerning the condition. He recommended they admit him to hospital, monitor him and provide on-going medication. It was only then that the team decided to organise an assessment with a psychiatrist. A community nurse advised me the following day that P had had a full assessment with a psychiatrist and was going to have regular appointments with him at the Pine Rivers Community Mental Health Centre. I asked about medication and was told that some medication had been prescribed. I advised her that P's mother should also be notified about the interview times when they are planned because it was unlikely that P would get to his appointments without support. She said he would not be allocated a Case Manager with Community Mental Health because he did not have a mental illness, but rather an adjustment disorder.

From our experience with people with dual disability, it is important that someone supports the individual not only in attending their appointments with Psychiatrists or GP's but assisting them to communicate fully with these professionals in order to receive the best care. It is usual for people with dual disability to provide one-word answers to questions in these situations because it is too difficult to do otherwise for a variety of reasons. The support person's role is necessary and from our experience, welcomed by the individual to provide extra details, which can build a fuller picture for assessment. It seems to me that the Mental Health sector relies on an individual's voice and their story to their detriment at times when other views should be actively sought. The other important role in support is in relation to medication – purchasing and developing *routines around taking the medication, encouraging regular reviews with the Psychiatrist or GP and noting when there are differences in behaviour indicative of changes in their mental wellbeing.*

Issues of Post-hospital rehabilitation

There are few accommodation respite services for mental health patients in the community with intellectual disabilities. There are currently two services in Brisbane auspiced by ARAFMI for people with mental illness who have a direct carer. They will take a person who has an intellectual disability however the training for workers in dealing with intellectual disability is very limited and often requires the referring worker spending a large amount of time educating the workers. They also will not take people who don't have a direct carer, so all those people who live alone or in inappropriate supported accommodation aren't able to access these services.

Many people with dual diagnosis end up living in inappropriate supported accommodation with workers who receive little training; have poor staff ratios; they live with people who are equally or more unwell than they are which have a negative impact on the person's mental health; experience a great amount of boredom; isolation from the general community; lack of positive relationships; and poor physical health. The managers and workers at these hostels are poorly supported and don't have adequate resources to support these people more appropriately. It is a true tragedy to see how these people end up living in a country as wealthy as Australia.

Conclusion:

It is Community Living Program's belief that their needs to be a further focus on speciality interventions for people with a dual disability of intellectual disability and psychiatric disability in prevention, early intervention and tertiary levels.

Possible suggestions include:

Training – There isn't enough specialist research or practice knowledge in the medical profession around the treatment of psychiatric issues or disorders for people with intellectual disabilities. Many general practitioners, psychiatrists, nurses and other specialist staff have little understanding, experience or training in the area of intellectual and developmental disability.

1. Funding of further training from the Queensland Council of Intellectual and Developmental Disabilities (QCIDD) to mental health workers in government and non-government organisations providing support to people with mental health issues and disorders, around the issue of intellectual disability. One of the main difficulties with some of this process already is that while the local hospital will encourage and support QCIDD to provide training to its doctors, nurses and specialist staff, they will not provide the extra staff to cover the shifts that the staff have to take off in order to participate in the training nor do they make it mandatory for all staff who work in the mental health field.

2. The training of psychiatry in Australian does not provide specialist training in the area of intellectual and developmental disability, which they do in the United

Kingdom. As a result the UK has developed quite a range of specialist research and practice knowledge for psychiatrists in treating people with intellectual disabilities who have mental health issues or disorders. The knowledge and practice of treating anyone with an intellectual disability, no matter what the condition of the patient, needs to be addressed in the nation's medical schools.

3. There is little information currently available for carers or support workers to determine which General Practitioners or other medical professionals have done further training in the area of dual disability of people with intellectual and psychiatric disability. This makes it difficult to seek out the most appropriate care for the person involved without putting the potential patient through a stressful process of finding the most appropriate doctor for that person's needs.

Advocacy – Queensland is the only state in Australia that does not have a peak body to advocate purely for those people who have an intellectual disability.

1. There are some peak bodies in Queensland that advocate for people with disabilities, but this particular group of people, meaning those with 'mild' or 'moderate' intellectual disabilities who are considered to have some capabilities because they are able to live in the community in some capacity, are often ignored by the mainstream disability groups. There needs to be funding and support given to the development of a peak body that can advocate purely for the needs of people with intellectual disabilities, and therefore the issues of dual disability of psychiatric and intellectual disabilities.

National Mental Health Plan

1. Intellectual disability needs to be identified as a priority under the National Mental Health Strategy as opposed to simply being categorised under the realm of 'complex conditions' with only a service delivery focus (Commonwealth of Australia 2003:19). It needs to prioritised as a significant area of need within mental health services with a focus on prevention, early intervention and tertiary responses.

Prevention - An overall awareness of the possible risk factors in the development of mental health symptoms and disorders for the person with the disability, the carers, family members and significant others and any support workers is essential. A particular focus should be placed on children, particularly those placed in foster care or those who have experienced some form of trauma.

1. Any care plans put in place should incorporate this awareness as well as general practice interventions (Community Living program, 2002, pp.48) such as

- General support work
- Physical health promotion
- The further development of the person's networks and supports by supporting existing relationships and building other positive and mutual relationships
- Supporting and encouraging the person to build on their strengths and on existing resources by engaging in some skill development

- Looking at ways in which the person can reduce the stress and anxiety that they live with such as engaging in relaxation processes and building supportive and positive relationships.
- Increasing their sense of safety and security in their local community by improving relationships with neighbours etc.
- Supporting the person to access appropriate medical interventions
- Support person to access or work with person using appropriate therapeutical interventions
- Work with person in promoting self-value and worth and challenging pre-conceptions of person in regard to own sense of self.
- Supporting the family or significant others to support the constituents.

2. Appropriate education processes should be provided for parents, family members, teachers and school staff and foster carers caring for children with intellectual disabilities around the possibility of and the risk factors for the development of mental health issues and disorders. In particular the effect of bullying of children within schools and in the community should be addressed as part of this education.

Early Intervention – This is very important because if we can prevent a person's deterioration into a crisis and therefore prevent more traumatic experiences of being unwell and possible hospitalisation, then the person has a greater chance of rehabilitation and return to their normal selves.

1. Family members, carers, support workers, school teachers etc need to be given the opportunity to learn about the warning signs (Community Living Program, 2002, pp.48) for the development of mental health issues or disorders for a person with an intellectual disability. These include:
    - Sudden changes in behaviour or routine
    - Erratic Behaviour
    - Irrational behaviour
    - 'Acting out' behaviours
    - Anti-social behaviours
    - Internal preoccupation
    - Decline in self-care
    - Physical complaints
    - Obsessive / Compulsive behaviours
    - Hallucinations
    - Overwhelming worries
    - Scattered thoughts and behaviour
    - Depression
    - Sadness
    - Stress symptoms
    - Change in level of activity
    - Loss of skills and capabilities
    - Presenting as 'up', 'hyper', 'manic'
    - Addictions
    - Self harm and suicidal ideation
    - Disturbed sleep patterns

2. Improved access to mental health support is necessary for person with disability with support of carers, family members, and support workers at this stage.
3. Better training of General Practitioners and mental health workers in recognising the warning signs for people with intellectual disabilities and knowledge dual disability is a necessity for access to improve for people. Also the acceptance of the fact that a person with an intellectual disability can indeed develop a psychiatric disability.

4. Queensland Health and Disability Services Queensland should develop specialist dual disability resource units within their services that can support children and adults with a dual disability of intellectual and psychiatric disability. It would certainly aid this process if paid positions were established which allowed the specialisation of these services, instead of the current practice of adding it to the worker's already overloaded workload without any formal position description and support.

5. Disability Services Queensland should promote more flexible funding and resources to support more effective responses to dual disability issues, such as more of a flexible use of funding packages to support prevention and early intervention plans.

6. Greater funding of speciality respite services for people with a dual disability of intellectual disability and psychiatric disabilities which not only provide respite for the carers, but also for the clients as many live in inappropriate supported accommodation which only increases the level of stress and anxiety for the person at home. Currently only two located in Brisbane and both with very long waiting lists with requirements that they have a live-in carer.

7. Supporting the existing family and friend relationships in supporting the person to get the help that they may need and know how to manage the issues and behaviours that may occur.

Tertiary

1. Improved training of mental health professionals in understanding the issues of dual disability of intellectual disability and psychiatric disability in assessment, diagnosis and treatment planning. For instance the assessment process should take account of the above mentioned risk factors and warning signs of mental health problems for a person with an intellectual disability.

2. Improving the process of assessment and diagnosis so it takes into account the fact that a person with an intellectual disability may communicate in alternative ways and may present symptoms very differently to a person who doesn't have an intellectual disability, such as asking clearer and simpler questions of the person and using the advice of the carer or support worker who accompanies that person to the hospital. Recognising the impact of incidents of sexual abuse on a person with an intellectual disability and how this can be a very significant cause of the development of a mental illness.

3. If a person is clearly experiencing some mental health issues but the assessment person is unable to clearly assess or diagnose the issue, an appointment with a doctor within Mental Health should still be made so the family member or carer knows there are some options and possible therapies can be discussed.

4. During the initial assessment process, the nurses need to listen to the carer or support worker about the changing behaviours and what their concerns areas they know the person far better than assessment team, particularly if they are a new patient and not known to the service. People with intellectual disabilities present mental symptoms differently to other patients and often have great difficulties communicating their symptoms as often they don't know what's happening and can't understand the questions, even if they have verbal abilities.

5. Improving access to mental health services for families and carers supporting the person with the intellectual disability, who are very unfamiliar with the system.

6. If the person is in hospital, it is important to include carers, family members or support workers in case conferences and planning as a matter of course, as they are the one who knows the person best and understands their behaviour and communication.

7. People with intellectual disabilities often have a great amount of difficulty managing their medication as they often have difficulty organising their day, remembering when to take tablets and even how many they have taken. They need support to develop routines around taking medication. Several people have had relapses because they couldn't manage taking their medication. This is often not recognised by mental health workers and options for dealing with this issue are not provided to the patient, support workers or carers.

8. A range of hospital and non-hospital respite options are needed for when people's needs escalate and their illness becomes acute that are accessible and appropriate. It isn't going to help their recovery to be put into the general mental health ward at the hospital where they don't understand a lot of what it happening and there are a lot of very unwell people acting in a way that most certainly will frighten them. Funding towards creating specialised wards in the hospitals to cater for people with dual diagnosis is a necessity.

Recovery – Recovery is as important as early intervention because if appropriate support is not provided through the recovery period, a person may easily end up back in hospital.

1. Extending the services of the Mobile Intensive Support Teams to the development of life skills and general support to reintegrate into their community, rather than just making sure a person is taking their medication.

2. An important aspect of a person's recovery is the focus on the improving the existing relationships and building new relationships and support networks in that person's life, so they have more support in their local community.

3. More appropriate supported accommodation to be made available to people with dual disability of intellectual and psychiatric disability. There is little appropriate supported accommodation available for any person who has a mental illness, and cannot live on their own and support themselves. These places usually hinder rather than support a person's recovery, in fact making it worse for the individual.

Community Living Program is deeply concerned about the lack of appropriate mental health services for people with intellectual disabilities, and the general lack of recognition by government decision-makers and funding bodies of the needs of this sector of the population. Many of the problems that we are currently seeing can be prevented, however the general focus on crisis response by government means that there is entire sector of the population who are generally being ignored and are living a very low quality of life. The number of people with dual disability is only going to grow as they are an aging population, and mental health services, which are already stretched for resources, will come under further pressure to meet the needs of this population. There needs to be some action on this issue. The Australian government and community can't continue to ignore the mental health needs of people with intellectual disabilities.

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