

## **Benefits of involving key cares in intervention plans... Cat Scofield**

Slide 1 – introduction

Slide 2 focus of presentation

Slide 3 –

Benefits of involving key workers & carers in intervention plans

In 1997 in the UK it was estimated that 40-60% of individual's diagnosed with schizophrenia on discharge returned to family members to live. The estimated cost of that 'community based care' was in the region of 3 billion pounds a year.

What has resulted for many family members is not feeling included but rather imposed upon, not included and taken for granted. Often the family is viewed as the problem.

This paradigm shift in the approach to providing treatment to people with a mental illness – de-institutionalisation didn't acknowledge or provide for the level of support and ? Training that would be required.

Slide 4 – Barriers to involving key workers & carers in intervention plans

Presumes that the clients themselves are involved in their management plans.

**In 2001 a study was undertaken in aged care looking at how to improve carers' involvement in decision making?**

Study was prompted because despite changes in Gov health care policy that prompted service providers to involve service users in the decision-making process. carers' organizations continued to highlight a gap between policy and practice in relation to involvement

This research highlighted four markers of satisfactory involvement:

- 1 feeling that information is shared;
- 2 feeling included in decision making;
- 3 feeling that there is someone you can contact when you need to;
- and 4 feeling that the service is responsive to your needs.

The majority of carers felt dissatisfied with the current level of involvement. A situation that has been echoed in other studies and I believe is still evident in Tasmania today. The study found that there were in all likelihood two main reasons

for the lack of inclusion of carers which were hospital systems and processes, and the relationship between nursing staff and carers. The assertion was made that it is the practitioners themselves that must notice and challenge these barriers if carer involvement is to be facilitated.

Value that we place on independence. In western society we strive to achieve independence.

Child and Adolescent psychiatry has a far better understanding of familial importance – takes a systemic approach from the outset – even if family therapy not the outcome.

Once into adult psychiatry a different approach – more individually constructed.

#### Slide 5 Cultural differences

The poetry no longer rhymes – taken from the title of an article published in 2007 about the experience of Somali Immigrants when accessing mental health services in the USA.

The Somali family system finds support in numbers. The greater the perception of illness, the greater number of family members, likely male, that will accompany the patient to the appointment.

Non-verbal behaviours definitely affect the climate of the psychiatric Interview, and are often interpreted differently by different cultural groups. In the Somali community, there are three people who are usually and consistently respected: a teacher, an elder, and a doctor. However, they are expected to give something in return (Mohamed, 2000). One Somali woman suggested offering coffee at the appointment to promote a genuine desire to be helpful as a caregiver. A relationship underpinned by equality and respect.

Being considered competent and maintaining pride are qualities that each Somali strives for. The acculturative transition of Somali immigrants to the USA has frequently been accompanied by pain and humiliation. Many types of psychiatric syndromes reflect the shattering of dreams, the sounds of a poetry that no longer rhymes in the heart and soul of these immigrants

#### Other cultural differences

In the Maori culture the western insistence on independence is viewed as a defensive attitude. Failure to turn to family in times of crisis is regarded as immaturity not as a sign of strength.

In India families are often present and active throughout an admission described by one relative as the “loving care was supplied by patients’ escorts, and the nurses were free to concentrate on the instrumental aspects of their role their actual nursing duties. It seemed that in the absence of kin escorts, hospital treatment on the whole could not have been very successful nor have there been many patients willing to be admitted. Observed this myself in 1986 where in a Delhi acute admission ward if there was no relative

there was no admission. Also visited a large psychiatric institution where this was not the case.

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#### Slide 6 – Historical perspectives.

- Scene from within the walls of Bethlem Hospital from the William Hogarth's *A Rake's Progress*.
- Eighteenth century Bethlem was most notably portrayed in this slide. This view of the time that madness was a result of moral weakness, leading to "moral insanity" being used as a common diagnosis.

I could find very little that mentioned the involvement of families from a historical perspectives – Dr Maharajh made the same observation in his dissertation on family involvement in the assessment and management of mentally ill patients.

Of one private facility Ticehurst it was written that it was the expectation by families that kin would be treated well by partaking in such activities as golf, hunting and cricket and that the families would merely be given reports and expected to foot the bill. It was noted that removing a patient from the home environment eased family tensions and it was this social need that the asylums fulfilled. There was at this time a lack of therapies for the mentally unwell - probably around the early 1900.

#### Slide 7 – Bedlam

- The **Bethlem Royal Hospital** of London is a psychiatric hospital in Beckenham, south east London. Although no longer in its original location and buildings, it is recognised as the world's first and oldest institution to specialise in the 'care' of the mentally ill. It has been variously known as St. Mary Bethlehem, Bethlem Hospital, Bethlehem Hospital and **Bedlam**.
- In 1330 it became a hospital, and it admitted some mentally ill patients from 1357, but did not become a dedicated psychiatric hospital until later. Conditions were consistently dreadful, and the care amounted to little more than restraint. The noise was "so hideous, so great; that they are more able to drive a man that hath his wits rather out of them." Violent or dangerous patients were manacled and chained to the floor or wall. Some were allowed to leave, and licensed to beg. They usually wore a tin plate on their arm as a badge and were also known as Bedlamers, Bedlamites, or Bedlam Beggars. Day to day management was in the hands of a Keeper, who received payment for each patient from their parish, livery company, or relatives.
- The Hospital became famous and notorious for the brutal ill-treatment meted out to the mentally ill.
- The residents were first called "patients" in 1700, and "curable" and "incurable" wards were opened in 1725-34. In the 18th century people used to go to Bedlam to stare at the patients. For a penny one could peer into their cells, view the freaks of the "show of Bethlehem" and laugh at their antics which were generally of a sexual or violent nature. Entry was free on the first Tuesday of the month. Visitors were permitted to bring long sticks

with which to poke and enrage the inmates. In 1814 alone, there were 96,000 such visits. By the 17th century, Bedlam was one of London's main tourist attractions and was considered one of the wonders of London and was a must for foreign visitors. It remained open to the public until the late 18th century, when visiting first became restricted to only "well-dressed" ticket holders, then finally to relatives.

#### Slide 8

This engraving shows the wards in the 1860s after efforts to make them more comfortable and cheerful. Patients were segregated and this engraving shows one of the women's wards. It was furnished with flowers, ornaments and bird cages.

- This building had a remarkable library as an annex which was well frequented. Although the sexes were separated, in the evenings, those capable of appreciating music could dance together in the great ballroom.
- In 1997 the Bethlem hospital started planning celebrations of its history on the occasion of its 750th anniversary. The service user perspective was not to be included, however, and members of the Consumer/Survivor/Ex-Patient Movement saw nothing to celebrate in either the original Bedlam or in current mental health care. A campaign called "Reclaim Bedlam" was launched by Pete Shaugnessey, which was supported by hundreds of patients and ex-patients and widely reported in the media. A sit-in was held outside the original Bedlam site at the Imperial War Museum. Historian Roy Porter has called the Bethlem Hospital "a symbol for man's inhumanity to man, for callousness and cruelty."

#### Slide 9–

Netherne Hospital – Comments taken from a web site – ex staff, patients and patient relatives posting comments and seeking information.

My Auntie was a patient at Netherne Hospital in the 80's back when I was young girl, I used to visit her with my family, I used to play the piano in a hall/games room and go outside and collect conkers in a pillow case in the autumn, and it was such a beautiful area to explore.

This really is fascinating stuff. I knew Netherne very well in the 1980's both as a patient in an acute ward and as an 'auxiliary' in a psycho-geriatric ward. I can't speak highly enough of the place, and although I understand the arguments in favour of closing large asylums, I think Netherne provided a vital place of respite and care for people in certain states of mental distress. It certainly saved me!

After searching for 7 yrs I have finally found what must be the final resting place of my fathers mother whose death cert I have at last obtained. It was and still is a very sad story. She was run over by a Dray in Islington circa 1926 after being raped by her brother and because of her injuries was sectioned and placed in several institutions, hence my father and brother lost all trace

of her. One of my fathers last wishes was for me to find what happened to her. Now I have traced her I just pray that he is looking down and now resting in peace. Her name was Ellen Phyllis Lee.

My great great uncle Ernest died aged 12 at netherne asylum in 1920 and i am trying to find out if he was buried there or whether his body was returned to my great grandparents. i contacted the Surrey history centre and they were very encouraging and helpful. i am hoping to come to visit netherne soon and i hope i manage to find the graveyard. It is amazing just how many people keep saying that Netherne was such a great place to work.

My wife is trying to find any info about her uncle, Derek Arthur Bateman, who died in Netherne in May 1978. Any leads as to why he was there or any memories would help us to find a sadly forgotten member of our family.

#### Slide 10 – The Athens Mental health Centre – Ohio

The Athens Mental Health Centre was an infamous facility that was used to house the criminally insane. Various stories exist of atrocities that occurred within its walls. Beatings, tortures, and other cruel forms of punishment were apparently the norm for its day and there have even been many reports of deaths and murders occurring within the facility's walls.

The institution was closed in the 1980's during the time when the Reagan administration closed many of the state's hospitals in order to realize budget savings. Many of the inmates were simply released on the streets and now account for much of Athens's relatively large homeless population.

Several of the buildings are open to the public where interested parties can take guided tours and hear of the atrocities and appalling treatment the hospital's inmates were forced to endure in particular during the 1800s.

#### Slide 11 & 12 the Royal Derwent

Used this historical perspective to illustrate why the institutions were closed – not a local issue but a global movement.

Own experience in St Clements Ipswich Uk.  
80 year old and cake – I wish my mother could have seen this.

Patients tied to chairs with their own clothes  
An alcoholic charge nurse – chlorpromazine  
Staff leaving the patients and just going up to the local pub for the evening  
No go areas for staff  
Sex for cigarettes  
Threats made against those of us who spoke up – tyres slashed of our clinical educator

Little accountability

Very little contact by relatives – diminished over time if the patient became a long term resident.

Slide 13 –

Absence of carer involvement while not being responsible for the atrocities that were committed in the large institutions can provide a huge protective factor in us not repeating the past.

Benefits of carer involvement.

Slide 14 Adolf Meyer

70 years ago Adolf Meyer 1866-1950 highlighted the challenge for clinicians of dealing with the social aspects of their patients. Adolph Meyer was born in Switzerland and emigrated to the United States in 1892 after he qualified as a doctor. He worked in New York State Hospital Service Pathological Institute, where he was involved with the training of psychiatrists. He met Sigmund Freud and Carl Jung and was appointed professor of psychiatry at Johns Hopkins University and director of its Henry Phipps Psychiatric Clinic, which became an internationally renowned training centre for psychiatrists Meyer became so influential in his adopted country that he was known as "the dean of American psychiatry," and his work has had a wide influence on psychiatric theory and practice. In Meyer's view, the diagnosis and treatment of a mental disorder must include a thorough understanding of the patient as a whole person. This approach, which would today be termed "holistic," involved studying the patient from various perspectives-medical, biographical, educational, and even artistic. It was this goal that led him to introduce the use of the individual case history, bringing together in one place information about a patient's physical condition, past history, family life, work situation, and other facts that could be relevant to treatment. Meyer also pioneered in promoting visits to the patient's family in order for the psychiatrist to understand the environment in which the patient lived, and to which he or she would return when treatment was completed.

Dr Maharjah's would claim that we are still grappling with that concept today and I do not think that he would be alone.

**Slide 15 - Current situation a state of transition**

The Tasmanian MHS Strategic plan 2006 -2011 also highlights the need for participation as well as consumer & carer involvement. Adoption of recovery principles in delivery of care.

The Consumer participation framework 2006 – 2007 outlined the direction for MHS in Tasmania with regards to the involvement of both consumers and carers. It was developed following extensive consultation during 2003 – 2004 with a representatives form a number of key consumer and carer groups.

The impetus for this framework was:- the global movement in this direction which was underpinned by:-

- The belief that participation by C&C was beneficial
- Evidence that C&C involvement reduced the frequency and severity of admissions
- As well as improved the quality of life for all family members and significant others.
- The financial aspects.

There was a national focus well over 15 years ago that MHS should reform and move away from institutionalised care to being far more consumer focussed.

The aim of the Tasmanian C&C framework was to learn form other work that was being undertaken in this area, connect with our own rich experiences in Tasmania and produce a document that focussed on practical measures to improve the experience of consumers, carers and service providers within our local MH system.

The document provided a good starting point for MHS to challenge and change the culture of care delivery.

#### Slide 16 – Flawed structure

Not really understood – developed and distributed but not well implemented or promoted.

The recent review found that the implementation of the C&C framework had not progressed. While there is widespread support and for the implementation of the framework there are a range of different views on this should progress.

#### Slide 17 – The barriers that were identified as preventing effective participation were identified as being:-

- Lack of clarity & information
- Feedback did not reach the right people
- Knowledge & attitudes of some staff
- Ability to participate influenced by wellness
- Strong opinions = trouble maker
- Expert knowledge more valued than lived experience
- Tokenistic involvement
- Lack of feedback
- Confidentiality

#### Slide 17 – confidentiality – very confusing for some clinicians.

Can be seen as a symptom of our failure to fully engage the client in participation. If we were more supportive of the client and their involvement in care planning it may be much easier to be collaborative and inclusive of significant others in treatment planning and ongoing management.

What we don't do well – Individual Service Plans

Recovery principles – some clinicians see that recovery and acute care are not connected statement by Dr “this is acute care not a rehab facility”

Slide 18 the future

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- RECOMEDATIONS
- Staff Development Program MHS & CSO
- Policies & Protocols be developed & systems established to monitor & evaluate
- Benchmarking
- Adequate funding
- Remuneration for C&C reps

Slide 19 – not exactly rocket science but it is confusing and challenging for MH staff as is evidenced by the reports and complaints that are received on a regular basis relating to rudeness, non inclusion, and frustration at being able to access help, refusal to share information or even be asked for information.

Slide 20 – hope that within all this confusion some that something more effective will result from ongoing commitment to change and respond.

Cat Schofield