

# Otago Regional Family Whanau Network Meeting Minutes

June 10th Thursday 2010.

Facilitated by Jo Ollerenshaw.

Minutes taken by Lisa Muir. Meeting started at: 1.30pm

Present: Jo Ollerenshaw, Lisa Muir, Fiona Panirau, Darcy Liddell, Karen Winkleman, Grant Donaldson, Sharyn McGlynn, Maryse Stanton, Rachel McAnelly, Ann Harrex, Lynley Claridge, Noleen Gott, Joan Paget, Chaz Forsyth, Pat Perkins, Joan Smith, Marie Roxburgh, Laurie Davies, Tanya Philips, Mary Bruce, Rosemary Diel, Adele Gott, Alix East

Apologies: Pat Perkins apologised for not being present for the previous meeting. Phillippa Winter, Ron and Joy Hollamby, Phyllis Lee, Nola Poulter, Alma Sheenan, Anne Parker.

Darcy Liddell introduced Jo as the facilitator.

Jo Ollerenshaw began by introducing what these meetings are about, i.e. that SF Otago has been given funding to facilitate these meetings. Jo also stated that people would be welcome to approach her after the meeting if they required reimbursement for transport.

*See below.*

Jo read specifically and directly from the contract and the terms of reference. So that the whole group was aware of what would be accepted in terms of reimbursement for travel, meals.

## **\*Provider Specifics Terms and Conditions\***

### 1. Otago Regional Family Whanau Network Meeting

Supporting Families Otago (SF Otago) will use this funding to set up and run the Otago Regional Family Whanau Network Meeting. The funding can be used at the discretion of SF Otago to pay for the venue and catering costs as well as to support families and Whanau financially by covering some of the transport's costs to the meeting's location.

Anne Harrex of SF Waitaki will host the next meeting with a date looking at September.

Jo opened it up to the group that if they had anything to discuss from last meetings' minutes.

Introductions of everyone who is present in this group.

What was raised in the introduction.

- Supportive Accommodation in Central Otago, 24 hour support (aim for this to happen soon)
- Strengthen the relationship between community teams/NGO's and DHB.
- Look to set up more services that meet community needs.
- Caring Communities advocate for 'Home for Life'.
- It was raised that people feel that families aren't being taken seriously, that they aren't being heard. It can feel that we are working in isolation; that the person with the mental illness is not being taken seriously. Families not being empowered.
- 'Mental Illness is a web that spreads out and affects the whole family.'
- Jail system – people with mental illness going to hospital, can be hard.

Jo is happy as facilitator to raise the points discussed today and also to assist with any ideas, strategies that can help with certain situations.

After a person leaves prison (with a mental illness) where is the health support out in the community, where is the rehabilitation? The idea that they have to achieve the correct number of points to be accepted into a programme i.e. Drug and Alcohol, Anger Management.

Alcohol related convictions could also relate to an undiagnosed Mental Illness, Alcohol and Drug assistance.

## PRISON SYSTEM & FAMILY CONCERNS AROUND MENTAL HEALTH

‘Families do not cry wolf’

- What do people have to do to be recognised to be able to receive help in jail.
- Could there be a service like a forensic supported place that mentally ill could go to instead of going to jail.
- Mental Health services not listening to the families’ concerns.
- Acknowledging mild-moderate mental illness, because this could lead to a major mental illness.
- Pat Perkins raised that people with mental illness lose everything i.e. career, quality of life.
- Dual diagnosis – treat all including Alcohol and Drug.
- What assessment processes are there?
- For the person who is coming out of prison (or are still in prison) to be offered counselling.
- If the person in prison is taking the initiative to undertake rehabilitative courses in prison they should be encouraged to be allowed to take them.
- Families would like to understand the prison point system.
- Intervention to be provided at the mild-moderate level. A pre-admission protocol - Early Intervention plan/protocol is on each patients file, how can families be ensured that this is happening?
- When asking for help, i.e. when families can see the early warning signs happening, they are not being heard by mental health professionals and the police become involved and it can be destructive for families, relationships are affected.
- The Central Otago DAO spoke about looking at each persons’ mental health history and they will ask for police for assistance if they feel their safety is at risk.
- Family wanted to be supported immediately while their loved one is being assessed. If the need for EPS is called, could there be a team that assist the family until the appropriate services are ready to take over.
- Families do not want to feel isolated and left without support.
- Central Otago families contact EPS – if it is after hours the call goes through to Dunedin.
- The privacy of the person can become an obstacle in terms of safety and what families are able to know.
- Families and mental health teams/support to work together to create a safety/risk plan. This is best done when the person is mentally well. Copies need to be given to all who are involved i.e. case managers.
- Family packs should be given out to families from DHB. These are currently being updated.
- Families do not want the “wait and see approach’, they want help straight away, especially when the families are aware of the early warning signs.
- It must be better for the person with the illness to be treated at the mild to moderate stage and this could avoid a major event occurring.
- There are no respite beds in Central Otago and Waitaki.
- Jo made it clear that staff on the wards will only put patients in ICU (contained areas) if there is a safety concern, sometimes this might be a medication confinement – like a sedative.
- It was very clear that families in Central Otago and Waitaki are disadvantaged by being so far away from the mental health wards in Dunedin. Jo raised the fact there is a travel allowance that can be accessed for families to assist them with travel. Some families were not aware of this.
- Jo shared that SF Otago meet regularly with mental health teams to discuss the concerns around the person with illness and also to help with supporting the family better. Anne agreed that this works really well in Waitaki.
- Having family advisers on Community Mental Health teams.
- Social workers are available in both community mental health teams in Dunedin.
- Need a family support role in rural areas.

- There is not a rep from Central Otago on the family inclusion meeting – Jennifer was raised.
- Social worker based in central Otago to work solely with families.
- Perhaps SF Central, community mental health teams and maybe the police could meet quarterly to discuss concerns.
- Families raised that the person with the illness does not have psychosis in a “9am-5pm timeframe”.
- Families need clear communication from mental health professionals.
- Information packs need to be going out.
- Missing Link – how can we as families have better linkages to receive support when everything is stressful and my family member is really unwell. Using EPS can be frustrating.
- At entry point of person entering EPS for assessment the families should be given an information pack. Access to a family support role when a family is in crisis in an emergency outside hours 24/7. i.e. similar to victim support.
- Is there a programme to get a person back into society, for example a person coming out of ward 11 – looking at hygiene, motivation etc?
- Utilizing Maori Mental Health services, are these available in central Otago? i.e. Te Oranga Tonu Tanga (TOTT).
- Families find it hard that services shut down over the Christmas period in Central Otago.
- Prisons/Courts don't seem to be able to distinguish between “Mad People” and “Bad People”.
- More family involvement in assessments is what families want.
- Families to be involved in discharge meetings.

## POSTIVE FEEDBACK

- PHO initiative.
- Continued funding for SF branches.
- Joining together of DHB's.
- Family input into care plan and outcomes. Wanting this to happen to every service user.
- Neuro science research.
- Families feel empowered when involved in discharge meetings prior to leaving hospital.
- Great when families are listened to and involved.
- The Otago Regional Family/Whanau Network meetings are a great forum to raise concerns. (Central Otago meeting was great)
- Police have been outstanding in certain situations when they are required to transport people to EPS etc, they need recognition for how they treat families and consumers when in crisis.
- When there is collaboration between SF branches and community mental health teams it is fantastic.

Next meeting will be in September in Waitaki and will set a date and will let SF Otago know, so that they can inform everyone.

Meeting Closed: 3.45pm

## Otago Regional Family Whanau Network Meeting Minutes

May 4<sup>th</sup> Tuesday 2010.

Facilitated by Terry Ebeling.

Minutes taken by Lisa Muir.

Meeting started at: 5.30pm

Present: Joan Paget (Caring Communities), Jo Ollerenshaw (SF Otago), Sharon McGlynn, Lisa Muir (SF Otago), Marie Kelly (SF Otago), Joy Hollamby, Ron Hollamby, Katerina Miscewy, Glenda Fraser, Alva Sheenan, Phyllis Lee, Nola Poulter, Helen Ward, Colleen Howard, maryse Stanton, Grant Donaldson, Graeme Donaldson, Karen Winkleman, Angela Shea, Ann Harrex (SF Waitaki), Anne Parker, Chaz Forsyth

Apologies: Darcy (Manager of SF Central)

Terry read out to the group a letter from Kathryn Olcott (SF Otago Branch Manager).  
(refer to copy of letter attached)

- Note presented by Jo Ollerenshaw (SF Otago) on behalf of Darcy Liddell (Manager of SF Central Otago) *see below*

“Hi Kathryn,

We are in the process of setting up Central Otago’s Family/Whanau Network meeting. Because of the relationship we share with SF Southland/Wakaitipu - covering Queenstown area Sandy Dawson and I are scheduling the SF Wakaitipu meeting in early June and I’d like to run Central Otago’s around the same time either June 8<sup>th</sup> or 10<sup>th</sup>.” Darcy – SF Central Otago

- Terry has discussed that Kathryn Olcott welcomes anyone to make a submission to the DHB regarding thoughts on Terms of Reference for the next round.
- Ann Harrex (SF Waitaki) voiced that it (the group) was about discussing the concerns around family issues.
- Joan Paget (Caring Communities) voiced on behalf of Caring Communities that they as a group are not happy with a specific point in the Terms of Reference and they will be going forward to discuss this with Dan Mustapic about this. They are questioning a legality over a Term of Reference.
- Concerns raised over the historical issues surrounding the Family Whanau network and its legality.
- Joan Paget would like to see a special meeting be set up to discuss this concern over the Terms of Reference.
- Jo Ollerenshaw stated the contract is not negotiable, people are more than welcome to put in a submission to Kathryn Olcott. She also made it clear that she has had a guts full and did

not want to be here until midnight and that we (the group) have already wasted an hour on discussing the terms of reference, that are not even negotiable. Jo said that we (SF Otago staff) have worked hard in putting this forum together for families to have their say to the DHB and that as a group we need to need to move on, to move forward.

- Terry has proposed that if we either work with the Terms of Reference or that we close the meeting now, as it is not a place to negotiate the terms of Reference (Term 4 is in question). Terry is only obligated to facilitate the meeting in accordance to the Terms of Reference.
- It was voiced from the group to close the meeting, which was seconded.
- Discussion about continuing the meeting was raised by Karen Winkleman, who sees that if we stop a meeting then funding may stop in future if we can't continue.
- The definition of family has changed and it has lost its meaning.
- Karen Winkleman raised that we can't change the terms of reference as it is beyond our control.
- Joan Paget asked how can we move forward to work together as a group.
- Jo Ollerenshaw said that we need to have structure to this meeting to be able to move forward.
- Ann Harrex asked for clarity as she sees that the Terms of Reference are not open for discussion until next year – which is correct.
- Terry raised again that Kathryn Olcott and Dan Mustapic to discuss concerns.
- Term 4 is not clear for people.
- Terry proposed that Joan Paget organize the special meeting with Kathryn Olcott, Dan Mustapic and Brian Rouseau – Joan has accepted.
- Introductions of all who are present.
- Terry discussed that he was shocked to find that he had been accused of being rude at the last meeting, he asked all present to please tell him if they feel that he is being rude at all tonight.

#### Meeting begins

- Terry opened the meeting up to the floor to discuss there experiences
- Ann Harrex raised concerns about a lack of accommodation when people leave the Mental Health wards as there is none available. Anne has raised this on behalf of SF Waitaki.
- Accommodation for Mental Health patients ready for discharge – lacking.
- People staying longer in prison due to lack of community support or facilities.
- Jo Ollerenshaw raised on behalf of SF Otago families the lack of support for families prior to discharge.
- Karen Winkleman - no notification of discharge.

- Joan Paget raised that she has heard that the Psychiatrists are frustrated at the lack of housing.
- Joan Paget would like to see “housing for life’.
- People having to stay longer in prison due to lack of community support.
- It was raised that in situations where there is no accommodation for people with a mental illness it can then become a burden to families.
- Discussion was raised about the fact that families have rights.
- Everyone is concerned, needing to work together to air views so we can help each other.
- Jo Ollerenshaw stated that we all want the same thing and that is why we are all here.
- Grant Donaldson asked where does the ground lie for someone (a person with a mental illness) to be able to make a decision.
- How to we assess a persons’ competence to make a decision.
- Medication can be a factor to a person being incompetent in making decisions
- Glenda Fraser raised that there is a “blame culture” where some staff treat patients as problems and not as people.
- Maryse Stanton discussed that the person takes responsibility for their health.
- Question decision to prosecute patients unwell in hospital for their behaviour.
- Jo Ollerenshaw discussed that the last thing you would want is for your loved one to be under risk management as it is extremely difficult to come off – it would be good to clarify what the process is for a person to be taken off risk management.
- Karen W. raised that staff in the hospital need to listen more to the families, she finds that the ‘Aides – Mental Health Assistants’ are great, finds some nurses do not communicate very well with her.
- Many senior staff could improve listening to family.
- It was raised that families should have a say and they (the person with the illness) should not be given a choice about where they live.
- Grant Donaldson discussed that we need to be wary of this issue as there are laws governing choice, rights of the person.
- DHB could follow up support in DCC flats – quality of work.
- Maryse S. discussed that sometimes it feels as though families are fighting for rights whereas consumers are having their rights met.
- Karen W. said that it feels as though we are sometimes ‘bashing our heads’ trying to fight.
- The group would like to highlight the lack of follow up on physical health issues.
- i.e. the Metabolic condition or diabetes.
- Dual Diagnosis – Psychotic Asperger’s – not supported, not fitting under certain groups.
- People fall through the gaps between services dual diagnosis etc.
- There appears to be a lack of respite places/beds in Dunedin, including planned respite.
- Ann H. raised on behalf of families and clients who are not allowed to smoke on the wards i.e. the acutely unwell, who are in the DHB wards, it is seen as being unfair.
- People who have a loved one with a mental illness under the age of 18 years and over the age of 65 have no family support. There is a huge gap here. No funding.
- What happened to the exemption around the non-smoking on DHB grounds, for mental health consumers.
- Terry asked if he had been rude at all so far – everyone agreed whole heartedly that Terry has been very pleasant, very enjoyable.
- During the break there was discussion that Carroll st. Trust is doing extremely well.
- Joan P. made it clear that Caring Communities has been misunderstood and that people have seen there group as wanting institutions like Cherry Farm back – this is not true at all. She sees that places like Carroll st. Trust are fantastic.
- Melbourne St. accommodation is another great services.

- Jo Ollerenshaw asked if families were involved with setting up a plan to alert families about early warning – answer was that all were not involved.
- Karen W. said that this is good until you come across someone who takes the wait and see approach even though all the early warning signs were being met, again families not being heard. Sometimes mental health teams are slow to react/respond.
- Organised multi disciplinary team meeting (family, in-patient, community mental health teams) very helpful.
- It was agreed that the aides in the wards are fabulous – very caring other staff are pretty good too.
- Ann H. stated that if they are mentally stable they should have the right to be able to make their own choices.
- Maryse S. asked that SF Central utilise there community paper to advertise the next meeting.
- Joan P. stood up and said thank you to Terry for tonight, she was very appreciative.
- Terry Ebeling is unavailable to facilitate at the next meeting.

Next meeting will be in Alexandra on Thursday the 10<sup>th</sup>, meeting to start at 3.30pm. meeting place for rides will be at SF Otago at 12noon, contact SF Otago prior to this day if you require a ride to Alexandra.

Waitaki will be host the meeting after that and Ann Harrex has confirmed with Terry Ebeling that he will facilitate that meeting.

Meeting finished at 7.30pm.

## Otago Regional Family Whanau Network Meeting Minutes

March 11<sup>th</sup> 2010: Scenic Dunedin City Hotel

Facilitated by Terry Ebeling. Minutes taken by Lisa Muir

Present: Lisa Muir (SF Otago), Jo Ollerenshaw (SF Otago), Harlow Brundell, Marie Kelly (SF Otago), Alva Sheenan, Maureen Humphreys, Sandra Cameron, Denise Cameron, Gabrielle Mills, Ruth Wheeler, Kaylene Holland, Ros Murrell, Ann Harrex (SF Waitaki), Grant Donaldson, Naili Lim, Phyllis Lee, Jan Beatson, Anne Parker, Patricia Perkins (Caring Communities), Chaz Forsyth, Joan Paget (Caring Communities), Kathryn Olcott (SF Otago)

Apologies: Colleen Howard and Graeme Donaldson

This is your time to express what you want, Terry will organize what your thinking will be as accurately as possible.

- Introductions of everyone who is present at tonight's meeting.

Formulating an Agenda:

- Everyone wants to see a good outcome tonight.
- It was agreed that the group would not break up into smaller groups, but remain as one and discuss as a whole.
- Encourage all attending to share their experience.
- "I'm not alone", mutual support.
- Quality of life.

P.Perkins – discussed how this group originated and started to give an historical overview.

J.Paget – asked that we discuss the Terms of Reference.

\*\*Terry initiated the discussion on the Terms of Reference.

\* What does "Safe Environment mean"? This was raised by Ros Murrell.

Safe Environment – Ground Rules

- What is said in the room stays in the room.
- Respect for each other's story: De-identifying
- As minutes are being taken it was agreed that this was acceptable.
- Respect privacy as we share our stories.
- Share stories without using real names.
- When someone speaks, common courtesy should be used so one person speaks at a time.
- All have a chance to speak, no one will be allowed to dominate.
- Terry reiterated the importance that everyone has a chance to speak.

Terry then reviewed aloud what was discussed and asked if everyone agreed, all agreed out loud.

What is the goal of this meeting, is the goal personal or for an overall i.e for SF or for other organizations, as at times it can be out of our control.

How can we achieve a goal? What is the way forward?

Meeting as a group supported by ODHB.

- what area of ODHB are we talking about i.e. provider arm.
- Clarify who we are reporting to, i.e. provider arm
- In future perhaps inviting guest speakers.
- Planning and funding to receive these minutes.

Focal point

- Maybe we would link in with the Carers Society. M.Stanton
- We need to remember that this is about Mental Health, it has to be clear that this is about this, not anything else. J.Ollerenshaw
- This group could be a conduit of information.

Network

- It is about where the person with the Mental Illness is living.
- What does it have to do with this group?
- If a Consumer lives in Auckland for example, family members who live in Dunedin are eligible to attend these meetings.
- "Family" has a large definition.
- Should we leave it?
- It could be seen as being discriminatory.
- The group is very confused about this.
- The next meeting we arrange for someone to address this issue, someone who can explain what this means.
- All agreed.

Research

\* Discussion on the confusion over past terms of reference, in accordance to today's terms of reference.

\* It is non-negotiable, as this has been constructed by Dan Mustapic, this is the minimum of what we can do, as it has already been signed off.

\* K.Olcott discussed that everyone was notified, she talked about the contract. There was money ready to be distributed for this such purpose. This had come out of a National SF contract and it was to be used for training.

\* It was to provide this conduit for this group to be able to report back to the ODHB planning and funding arm.

\* We want access to research.

Major issue over why certain aspects of the previous Terms of Reference have been left off.

P.Perkins asked what happened to Canterbury, K.Olcott said that we do not have anything to do with them, the money when to lower south island.

There is \$3,000.00 available for these meetings

From a family perspective. This is what we need to focus on.

Make everybody work together.

In the past it was all families, there were no participants from NGO's etc.

Need consistency.

Support workers and members from NGO's.

In the past the group also was available to people who did not officially belong to other groups. That is why now hospital services are involved in such groups as this.

Group consensus on family perspective.

Support workers and other mental health services are part of this group as representatives of this group. We cannot exclude these people. People who advocate for families.

J.Paget asked how can a family advisor advocate? If they aren't allowed to advocate? M.Stanton said that she only advocates as a whole not for each individual.

Reporting and Advocating are different.

Terry opened the group to discuss their experiences. So we have information to be able to feed back.

- Respect and happy with how staff support our loved ones who have mental illness, as well as how they treat families.
- Positive sharing of information
- Trauma of when you see your loved one in a psychotic state and then to see them well in hospital and wanting them not to give medication.
- Feelings of powerlessness.
- Having glimpses into the downsides of mental illness, can help towards understanding the positives.
- The costs over a lifetime of looking after a person who has a mental illness. What can be done?
- J.Paget stated that they have been advocating for 20 years for "homes for Life", where will their family go when they (parents die).
- A.Harrex mentioned that the families she supports have the same concerns.
- P.Perkins stated that quality of life is important.
- They haven't chosen to have this (Mental Illness); we didn't choose this for them.
- Such places as Carroll Street Trust are great as they are able to provide accommodation for those who have a mental illness.
- \*\*\*We need responses about Care for chronically mental ill people, looking for accommodation and the aged. Also for those who are waiting for accommodation.
- Inadequate housing, funding.
- Some families are struggling to cope.
- M.Stanton said that we need another service for aged Mentally ill.
- MOH is now using the term "Homes for Life" J.Paget
- J.Ollerenshaw – Discussed that she hears from her families that it is easy to diagnose and be given medication, what they also need is counseling on their diagnosis (when they are well) and taking responsibility for their situation.
- Holistic, Wrap Around Services, Follow Up, Quality of Life.
- P.Perkins said that it is well known that people who have mental illness are ending up in prison, she does not agree with this. What can we do about this?
- Dual diagnosis – what are the support services for this group.
- J.Ollerenshaw stated that nurses and psychiatric doctors administer meds, prison staff are trained and supported.
- It can be very difficult when people who are psychotic, they need appropriate support i.e. if transferred to prison.

- A. Harrex believes that those who are mentally ill need to be placed elsewhere not in prison if they have committed an offence).
- What are the alternatives to prison for those who have a mental illness.
- M. Stanton would like it known that we should be looking at Teenage mental health.
- Earlier Assessment and Support for young persons.

## PLAN FOR FUTURE

- Local issues

Continuity of care ie. change of staff, not looking at the persons file, they do not follow set plan. They come in with different plans. A person can go through for example 3 doctors in a year, it can be good for getting a different opinion. But for being able to build up a therapeutic relationship can be difficult. Mental Health workers should listen more to the families. Mental Health workers hide behind the Privacy Act, Code of Family Rights is working towards becoming a legal document.

Where can families go for help? Within the ODHB what are the lines of being able to make a complaint? SF Otago has a memorandum of understanding with the ODHB, where they meet with the wards on a regular basis. SF Otago also advocates strongly for families.

Privacy can be seen as a major issue.

As a family you have the right to know who your loved ones Clinician is, and their contact numbers, you have the right to be heard and if you are not being heard you should reach out for support from a family advocate.

If you are not happy with your loved ones key worker, you can contact their manager to make a complaint. MS

## NEXT MEETING?

\*\* Next meeting to be held in Oamaru and Ann Harrex will need to be helped to arrange this. Ann will also ask Dan Mustapic if he would be able to speak. KO also reminded everyone that there is money available for travel. MS asked if we could use Community newspapers to advertise, and yes we can.

\*\*\*\*\*It was changed and the next meeting will be NOW HELD in Dunedin in May. Once we are established we will hold meetings elsewhere i.e. Oamaru, Balclutha, Southland (meet with them once), Central Otago. KO has offered the SF Otago rooms as a donation to the group to hold the next meeting. Tuesday May the 4<sup>th</sup> at 5.00pm at the SF Otago rooms, 34 Prince Albert Road, St. Kilda, Dunedin.

- Focus of next meeting?

The group would like Terry to come back to facilitate the next meeting. This decision was unanimous.

- Frequency/length?
- Drivers/leaders?

## REVIEW OF TONIGHT

It would be great if we could all work together. We have can have a stronger voice we can make their lives better as well as ours. When things go wrong “no one is accountable” accountability. Collaboration all NGO’s and DHB for discharge meetings.

Meeting Closed at 9.30pm