

PEER LED CRISIS ALTERNATIVES
 Creating a sanctuary in the community
 Dr. Jan Wallcraft - May 2009

CAPLAN'S CRISIS THEORY

- o Caplan's crisis theory: mental health crises usually relate to life events which
 - cannot be handled using the normal coping responses [e.g. accident, violence, bereavement, loss]
 - are prolonged beyond the person's ability to cope
 - happen to people who have not healed from previous trauma
- o Crises can lead to positive change instead of mental patienthood if the person receives the right help at the right time
 - Members of the community with professional roles, such as teachers and police, could learn more about how to intervene positively in crises

CRISIS IS ALSO OPPORTUNITY

- o Caplan suggests that a crisis does not automatically lead to psychological damage. It also presents an opportunity for personality growth, if the person is able to find the internal and external resources to handle the situation and resolve it. A crisis is, therefore, 'a turning point toward or away from mental disorder' (Caplan 1964 p.37).

TRAUMA THEORY

- Estimated 80% of psychiatric patients have experienced traumatic violence at some point
- Trauma, especially repeated trauma, causes wide range of psychological symptoms of distress
 - 'I feel I should have been given long-term psychotherapy help, counselling in which the abominations in my childhood would have been discovered. Instead I was given ECT against my wishes which I found inhumane.' (Rogers et al 1993 P.62)

CRISIS/TRAUMA THEORY AS ALTERNATIVE TO DIAGNOSIS AND PSYCHIATRIC SYSTEM

- Instead of diagnosis and medical treatment, who not start by simply finding out:-
 - Immediate problems – what is happening?
 - What is the social/familial context of crisis?
 - Relevant life history background
 - Existing resources and support
 - Immediate needs and wishes
- As far as possible provide what appears to be needed and what the person says they want
 - Build on what works and what people want towards more holistic and person-friendly services
 - People who have been through a crisis can often become skilled helpers for others

VISION OF CRISIS ALTERNATIVES

- Service users in USA, UK and other countries have argued for many years for practical solutions based on peer support and safe houses
 - 'I wanted to retreat to someplace inside myself for a while....I couldn't explain my need to withdraw - I couldn't find words for it. The more demands people made, the more frightened I became. Couldn't they see that I needed to be alone, to cry, to lie in bed and pull the covers over my head, to figure out what I wanted, what I needed?' (Chamberlin 1988 p.23)

ONE PERSON'S VISION OF SANCTUARY

o I remember clearly what I thought might exist, and what I desperately wanted to exist. I imagined I'd be passed on to a place where for a few days or weeks I could get away from the intolerable pressure of being alive. It would be quiet. There'd be a garden and perhaps you'd do some work and dig there or plant things. The people would be gentle and tolerant, and you'd slowly heal and evolve a life plan that might make sense' (Tomlinson 1996 P.5)

RESEARCH ON CRISIS – WHAT DO PEOPLE NEED IN FIRST TIME CRISIS

- o Hatfield et al (2000) showed that in one psychiatric emergency people experiencing a first time crisis (no previous or concurrent psychiatric contact) made up 41% of referrals to the psychiatric emergency service, and that of those, the largest group had problems that were related to stress or life events.
- o As many as 51% of people in a crisis seek or are brought into emergency services outside the 9-5 hours which most community mental health teams operate within
- o Services for people going into a crisis need to be re-examined - are they providing the right help at the right time?

DO WE KNOW OR CARE WHAT HAPPENS WHEN PEOPLE ARE ADMITTED IN A CRISIS?

- o Relatively little is known about exactly who are the people who stay on acute psychiatric wards and what happens to them while they are there.
- o There is a sense that hospital care is a black box, with people entering and leaving, and we have high but vague expectations about what happens in between.(SCMH 1998 p.11)

**RESEARCH ON ACUTE SERVICES
SUMMARISED**

- o The biomedical model approach to crisis is producing a service in which there is little attention given to patients' psychosocial needs.
- o Existing services are overstretched, which makes it more difficult for staff to find time to deal with patients' problems.
- o There is little therapeutic or socially-oriented activity on acute wards, and patients may be at risk from self-harm or violence.
- o Discharge procedures are unsatisfactory.

**FIRST EXPERIENCE HAS LONG TERM
IMPACT**

- o Goffman's (1961, 1963) influential sociological studies of asylums and stigma, and a number of autobiographical accounts of people's first experiences of psychiatric treatment indicate that the first experience of a crisis and psychiatric hospitalisation is a significant life event, which is likely to have a long-term impact.

**WHEN WE FAIL PEOPLE IN A FIRST CRISIS
WE MAKE THINGS WORSE**

- o *What is ignored is that, in addition to a basic objection to coercion, there are reasons why we may not comply with the authorities attempting to detain us. It may be our first crisis. I found myself, drugged and without explanation, in what I soon realised was a psychiatric ward. I ran out. I should not be there!*
- o *On being caught, I fought back - tooth and nail. I was fighting for my life. The injection to subdue me seemed to set me on fire and filled the room with bright light*
- o *...Later crises will be informed by past experiences - restraints, treatments, the trauma of being in a psychiatric unit. (Plumb 1999 p.460)*

ADMISSION IN CRISIS –THE PATIENT’S VIEW

o Typically, on admission to a psychiatric ward, you are interviewed by a doctor. Many people expect this to be an opportunity to tell all that is troubling them to an expert who will help. But much of the interview is wholly baffling. ‘Count backwards from 100 in sevens’. ‘Do you believe your thoughts are being controlled?’ There appears to be no space to say on your own terms and in your own words, just what are the difficulties that have reduced you to this situation. (Ross, Campbell and Neeter, 1993, pp.320-321)

MEDICAL MODEL CLOSES DOCTORS’ EYES TO PATIENTS’ OWN VIEW OF THEIR PROBLEMS

o Some psychiatrists (Briere 1999, Bloom 1997) have argued that psychiatric assessors often fail to elicit key information or to pick up vital clues to the patients’ real problems. This failure is argued to be endemic, and linked to absence of any coherent theoretical approach in mainstream psychiatry to mental health crisis.

LEADING UK SERVICE USERS CALL FOR ALTERNATIVES IN EARLY 1990S

o Campbell, a leading UK campaigner, voices a collective demand for alternatives to hospital:
o A feature of the user movement ...has been the consistency with which groups across the country have called for 24-hour crisis houses.(Campbell 1991)
o Despite 10 years of pressure for 24 hour, non-medical crisis services such facilities hardly exist in this country.’ (Campbell 1993)

SUMMARY OF WHAT SERVICE USERS WANT

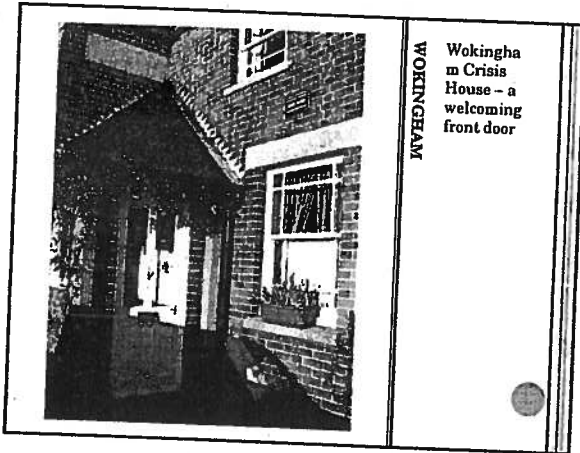
- o 24 hour services where they can find respite, peace and safety
- o Someone to talk to, or to offer counselling
- o Opportunity to express feelings safely, to reveal painful experiences and expect to be understood
- o Many reject a medical approach to their crisis and argue that psychotropic medication is unhelpful
- o Many argue that they want more control over what happens to them in a crisis
- o People seek more respectful treatment and opportunities to learn from their experiences

CRISIS HOUSES BEGAN TO EMERGE IN UK IN 90S – SOME HAVE SURVIVED, AND NEW ONES EMERGE

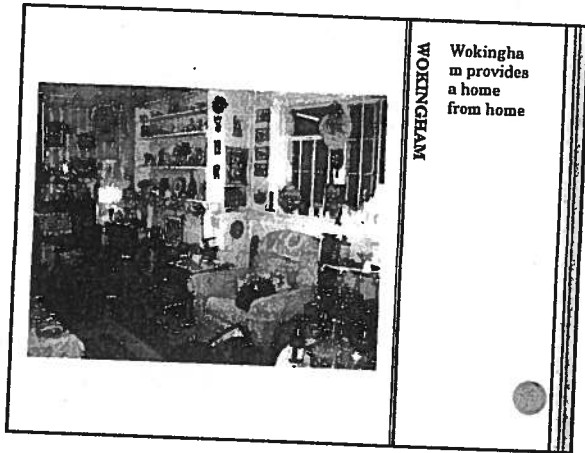
- o Wokingham Crisis House, long and short term community sanctuary – user led, based on volunteers -18 years old
- o Dial House, Leeds (user led crisis house) –short term, weekends – 10 years old
- o The Haven, Colchester, specifically for people with diagnosis of personality disorder – 4 years old
- o Kaya House, Barnet – weekend crisis house – user run – 2 years old

WOKINGHAM CRISIS HOUSE – 18 YEARS OLD AND THRIVING

- o *The great advantage of small community initiatives ...is that they have very low running costs because all their work is undertaken voluntarily. We get by on a tiny annual grant of £6000 from Wokingham District Council – augmented by an additional annual amount of £2000 from the local Mental Health Budget.*
- o *For this we provide five crisis beds, 24 hours, 365 days per year, a mental health drop-in centre, four days per week, drivers, a befriending scheme, and an advice / information service. (Pam Jenkinson)*



WOKINGHAM
Wokingham Crisis House - a welcoming front door



WOKINGHAM
Wokingham provides a home from home



WOKINGHAM
Pam and her team drink to their 15th year since opening - with the Mayor and Mayoress



WOKINGHAM

Cats have crises too!
Cuddles and Chloe came from the Cats Protection League in 2004

WOKINGHAM CRISIS HOUSE
A VISIT FROM THE MAYOR



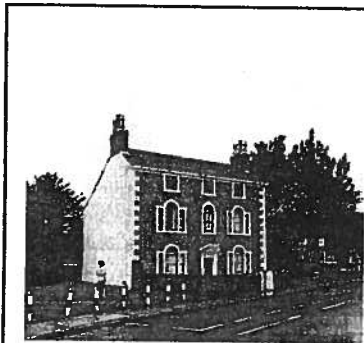
o From the numerous visits that we get from across the UK and beyond we are deeply conscious that everyone in the mental health world wants a user-run crisis house, but we are equally conscious that few achieve this and even fewer sustain the achievement.

o So what makes a successful crisis house? I believe that after fifteen years of running one I can pinpoint a few factors.

o The first essential is **COMMUNITY**. A community decides whether anything in its midst succeeds long-term. Crackpot schemes will not survive. The crisis house must genuinely serve the community and gain its respect.

WOKINGHAM CRISIS HOUSE

Pam Jenkinson on why Wokingham has succeeded where others have failed



Mental health service users in Leeds got the money for Dial House after 5 years of effort

DIAL HOUSE - LEEDS USER RUN CRISIS HOUSE

- o The Leeds Survivor Led Crisis House was set up in 1999 by a group of service users after 5 years campaign
- o Initially, it was a partnership with local authority, becoming a registered charity in 2001.
- o Dial House is a place of sanctuary, an alternative to hospital admission and statutory services for people in acute mental health crisis.
- o The service was set up and is still governed and managed, by people with direct experience of mental health problems.
- o 'We have our own unique perspectives on what it feels like to be in crisis and what helps and does not help'.

Dial House, Leeds Survivor Led Crisis Service - how and why it was set up and how it is run.

DIAL HOUSE, LEEDS SURVIVOR LED CRISIS SERVICES

DIAL HOUSE - WEEKEND SANCTUARY

- o Dial House is a place of sanctuary open 6pm-2am Friday-Sunday. Visitors can access when they are in crisis. They can telephone to request a visit, or turn up at the door 6-10.30. We currently have 70-110 visits each month.
- o Visitors can use the house as time out from a difficult situation or a home environment where they may feel unsafe or that may exacerbate their difficulties. Visitors can relax in a homely environment and can also gain one to one support from the team of Crisis Support Workers.
- o Telephone Crisis Support line - well used

DIAL HOUSE – ONGOING SUPPORT


- o Coping with Crisis groups -6-10 week groups for people who are frequently in crisis, facilitated using a person centred approach to group work.
- o Coping with Christmas workshops -this is such a difficult time of year for people.
- o Valuable peer support happens between visitors and the idea of the groups is to bring people together to share their expertise and experience in coping with crisis
- o Social and Support Group, Thursday afternoons- provides social contact and support to people whose crisis is due to chronic isolation and loneliness. The idea of the group came from visitors and a Dial House visitor helped to develop the group.

**FIONA VENNER, CURRENT MANAGER SAYS
'THERE IS STILL A HUGE AMOUNT OF UNMET
NEED.'**

- o *Fiona has no doubt the service has kept many people out of hospital and gives them safety and sanctuary when they are at their lowest ebb. People often say to us: I would be dead if you hadn't been there'*
- o *Despite the volatile nature of many people's problems, there has not been a single violent incident in the service's seven-year history – People love the service and are very respectful of it and don't want to jeopardise it. The fact that we provide genuine kindness, warmth, affection and respect seems to mark us out as different from other services.'*
- o (From an interview with a national newspaper 2006 when Leeds user Led Crisis Service won an award for innovation and progress in customer service)

**LEEDS - PEER SUPPORT IN PRACTICE –
PEOPLE KNOW WHAT THEY NEED**

- o Between 30% and 50% of all clients who come to the service are suicidal - *'But if someone is here, there's always hope,' says Venner. 'Part of them might want to die, but part of them wants to live and that's the part that's with us'*
- o Most of the staff and volunteers have experienced mental health problems themselves. The therapeutic approach they follow is based on the radical notion that the users know what's best for them
- o The principle tenets of this philosophy are "unconditional positive regard", "actualisation" and "non-directivity". But, says project manager Fiona Venner, this simply means treating people with warmth, kindness and honesty. *'Rather than telling people what to do or giving advice or saying 'I'm the expert', it's very much about supporting people to bring out and develop their inner resources. People ultimately know what's best for them.'*



HAVEN, COLCHESTER

The Haven – for people diagnosed with personality disorder



THE HAVEN, COLCHESTER, ESSEX

Reg McKenna, service user chair

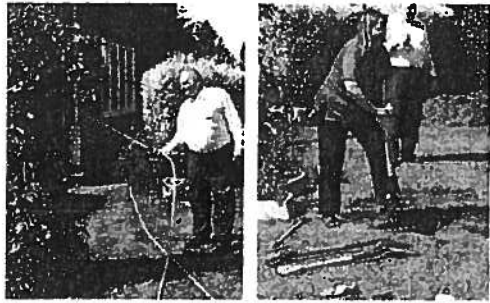
Reg was a leader in creating the Haven crisis house and support service

Specifically for people with personality disorder diagnoses

THE HAVEN, COLCHESTER

- o It is a 24/7 initiative for people with personality disorders
- o It provides a day service with practical help, support, friendship and therapies
- o It provides a crisis service with out-of-hours refuge and support
- o Originally set up as a 2 year experiment, as part of a Government initiative to create new services for personality disorder, the Haven has proved its worth, as in 2007 a third of its members went on to further education or employment

HAVEN, COLCHESTER - GARDENERS





HAVEN CLIENTS VIEWS

- o *The Haven is my safe place.*
- o *It feels that you are a replacement Mum and Dad that I never had.*
- o *You can stay overnight for a while under this fantastic roof. I feel everyone around me hated me, until I came here. There's always a smile and a kind word.*
- o *I think how far I have come, things that happened to me while I was in care and on the street, it wasn't my fault.*
- o *I haven't touched alcohol for almost two years.*
- o *I haven't self-harmed for almost nineteen / twenty months.*
- o *I haven't been in psychiatric hospital since I've been registered with you*
- o *I'm clean and have stayed clean. .. I could have gone back to using without even knowing it was wrong, which I have done in the past, whilst I've been psychotic still. Kind of like instead of popping a pill, I come here.*

MORE HAVEN USERS' FEEDBACK

- o *The Haven is completely different to any other service I have ever used. In every other service you don't actually have an opinion or your voice isn't heard. At The Haven your voice is heard and your opinions taken into consideration, and everyone is treated individually here and you're not a number anymore here, you're your own person.*
- o *Seeing the people who have moved on to college, you can set yourself a little goal then can't you. They've done it so, you know, maybe there's a chance.*
- o *This is a magical place where miracles happen. I owe my life to these special people. People with personality disorder frequently reach crisis point and the Haven Crisis Line offers a unique service.*
- o *When you are given a diagnosis of personality disorder you become a long-term nuisance - a drain on resources. But those of us who fall into the Colchester catchment area are so lucky to have The Haven Project.'*



Helen Blackwell died in October 2007 after a long struggle with distress and self-harm. She was a freelance trainer, researcher and consultant, with particular interests in self-harm, recovery and user-led services.

At Barnet Voice for Mental Health, a local service user-led organisation, she helped to establish the user-led crisis house, Kaya House.

Helen was committed to improving services for people who self-harm, to genuine user involvement and to recognising the strengths in all of

HELEN BLACKWELL - SERVICE USER WHO HELPED TO SET UP KAYA HOUSE

KAYA HOUSE, USER RUN CRISIS HOUSE

- o Funding was obtained from several large national charities in 2005.
- o The plan was then approved by the local authority approval and some state funding was offered.
- o Kaya House offers a weekend crisis service with 4 beds, and a mid week support group.
- o 85% are self-referrals though many are encouraged by state services to refer themselves because of the ethos
- o Kaya House is based on Caplan Crisis theory.
- o They believe to be effective a crisis house needs to be very much more than a safe place or a refuge.
- o It needs to offer the person in severe distress an opportunity to focus on their issues, enable them to plan the best possible coping and growing strategies and to begin putting them into place - and to offer this quickly and in a context that provides the highest levels of respect and acceptance.

KAYA HOUSE, KITCHEN



KAYA HOUSE, NORTH LONDON



KAYA HOUSE, BEDROOM



KAYA HOUSE, BEDROOM



KAYA HOUSE, ROOM



KAYA HOUSE – USERS VIEWS

- o *Because I felt so cared for during my stay it felt natural to begin to care for myself when I left"*
- o *"Before I came to Kaya House I didn't feel like a part of life and now I have my sense of self back and I feel able to participate in life"*
- o *"I wanted to tell you how much my stay at Kaya House meant to me..... The weekend was so helpful in giving me a safe haven in which to have a silent scream and be supported in wonderful surroundings and with understanding, dedicated staff. I would definitely go again. I felt better just not being on my own and not having to be a burden to family and friends when I was frightened of going into crisis, trying to prevent myself from having another relapse."*

KAYA HOUSE – HELPING PEOPLE REGAIN A REASON FOR LIVING

- o *"Over the last 10 years I have had 19 hospital admissions; I have got more from staying at Kaya House for 6 weekends than I ever got from those admissions. Staying at Kaya House has helped me to move from a place of darkness and wishing to end my life to having a vision of my potential and purpose."*

KAYA HOUSE – MORE VIEWS

- o *"Feeling insecure and vulnerable after a night in Accident and Emergency the idea of a house I could stay at for the weekend filled me with great relief. Having had hospital admissions in the past Kaya House couldn't be more different."*
- o *Kaya house offers a clean, safe environment which is tastefully decorated. Kaya house encourages rest and relaxation and the staff also encourage the guests to learn coping strategies and are at hand to find any information which maybe useful for them at their time of crisis."*
- o

USER LED – BUT DUTY OF CARE CREATES A DIFFERENCE BETWEEN STAFF AND 'GUESTS'

- o *Kaya House has a difficult balance to achieve. It is run, led and managed by service users or former users, and uses this fact as a key element in its therapeutic interventions, by underpinning its work with the high levels of respect and empathy that Kaya House 'guests' would expect."*
- o *But at the same time staff are paid, volunteers are managed, and both have a clear duty of care directly towards guests and towards the maintenance of an effective service."*
- o *This clearly creates a difference in power between staff and guests."*

KAYA HOUSE'S CHALLENGE AT THE END OF ITS FIRST YEAR

- o Evaluation of the house in 2007 showed a very high level of client satisfaction - 98% in most areas
- o The report argued however that the acid test is whether Kaya House is providing value for money.
- o Research needs to be carried out to examine whether it is meeting its stated objectives of providing an alternative service for people who would otherwise be at risk of hospital admission, and/or reducing the degree of statutory mental health service input.
- o The second test would be to see whether the effects of a stay at Kaya House make measurable and quantifiable improvements to peoples' quality of life.
- o The report argues that commissioning such research would be worthwhile for the local services and could also make a significant contribution to the national and international knowledge base.

THE EXPERIENCES OF THESE CRISIS HOUSES VALIDATE FINDINGS FROM PREVIOUS RESEARCH

- o 'Being There in a Crisis' report (2002) summarised findings from 8 crisis services, the majority of which were user led.
- o Dial House was one of these, several of the others no longer exist.
- o All of the services showed high levels of client satisfaction, the key issue being the nature and level of interaction with staff - having someone to talk to when in a crisis
- o Most were emphatic that they would not have had the same level of support in a hospital, and many said they had been enabled to recover in a way they had not previously experienced.

WHERE TO GO FROM HERE?

- o It is frustrating that despite the hard work of service users/survivors in lobbying for and creating peer support-based services, there are still so few, and some have been short-lived. This is often because they exist in an environment which does not value or support their work.
- o Learning from crisis houses could enlighten the rest of the mental health services rather than remaining locked up in these small enclaves of good practice.
- o Research to test and possibly validate the peer support model needs to take into account key factors, including the reliance in these services on committed individuals who set up these places. It may be hard to create a standard model.
- o We should accept each service will be different and should be different as it needs to respond to local situations and needs.
- o Quality of life cannot be measured statistically, however the measures are designed. We need to look at people's stories

CONGRATULATIONS TO THESE PIONEERING SURVIVORS WHO MADE THEIR VISIONS A REALITY!



Pam Jenkinson
- Wokingham

Terry Simpson
- Dial House

Reg McKenna
- The Haven

Helen Blackwell and Elsie Lyons
- Kaya House

AND TO THE MANY MANY MORE PEOPLE WHO WORK IN THE HOUSES AND USE THEM

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- Wallcraft J. and Michaelson J. (2001) 'Developing a survivor discourse to replace the "psychopathology" of breakdown and crisis' in *This is Madness Too*, eds Craig Newnes, Guy Holmes and Caitzie Dunn, PCCS Books. (with John Michaelson) pp177-190

FURTHER INFORMATION ABOUT THE SERVICES

Wokingham Crisis House

mailbox@wokinghammentalhealth.org.uk

Leeds Survivor Led Crisis House (Dial House)

<http://www.lslcs.org.uk/index.html>

The Haven, Colchester

<http://www.thehavenproject.org.uk/Contact.html>

Kaya House, Barnet

kayahouse@bvmh.co.uk
