

**Thinking, Feeling, Being: Critical Perspectives and Creative
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**The Dish of Your Discourse: A Carer's Perspective on Treatment,
Language and Empowerment**

By Tess Maginess

Exordium

As you all know, Saturday night ushered a new series of 'Casualty'. I am ashamedly and unashamedly addicted to hospital dramas (high class soaps). Mimicking the cinema vertite *technique* of ER, with a bit of Altmanesque montage cut in for good measure, we were obliged to focus on the first day of an F2 doctor. To say that he had a bad day at the office would be to understate the case wildly. I that Dr Toby had a lovely way with him (a refreshing departure from the derring -do risk taker heroes who always end up self prescribing cocaine or prosac, and the, elegant, chillingly efficient surgeons with their ironed hair and messy love life) Another person, more acerbic than usual (relapse indicator), was unconvinced by the Mr Bean follies of the first five minutes. Matters grew jerkily worse as the hapless hero, Dr Toby De Silva (dubbed Dracula by the 'oul hands), lurched from one screw up to the next. Hope was rising in my breast that he would continue upon this promisingly disastrous path and that what we were witnessing was, in fact, a nice big breakdown, a literal 'deconstruction' of the medical hero. And, of course, part of me wanted him to do something right, if only to relieve the monotony of a narrative of ridiculously recursive defeat. And, of course, in the end, Dr Toby triumphs; the boy is a bit special .The natural order is restored. Patients are put in their place, as 'feed' for the medical heroes, including the mildly subversive ones (the fugitive Hindu is not, in fact the suicide bomber, just an unhappy young man like Dr Toby, as Dr Toby says, alack alas, hustled into high achieving by their traditional parents. The Hindu (no names, no pack drill) comfortingly submits himself to the to the expert clinical gaze, is rebuffed by the modest doctor who says he is not a real doctor, presumably disappears into the safe hands of Abs, the psych liaison nurse as, meanwhile, after some gritty cityscapes, vertiginously filmed, Dr Toby, who is a great wee singer also, rescues a hypoglycaemic child from the arms of her psychotic father, beating down the door of a baton wielding Asian pharmacist , who, of course, also insists that the insulin titration is Dr Toby's call. Dr Toby riffles through MIMS (the Asian pharmacist being obviously illiterate) and, hey presto, pretty child opens eyes, sceptical paramedics welcome him to their inner circle of expertise and the irreverent Dracula tag is replaced by a restoration of his title as Doctor Toby, as if doctors could seriously be thought of as vampirish. But, that is only a frisson, all is well, we are returned to our natural state, comic resolution; a tad conservative, but oh so comforting.

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In these few short minutes I would like to, if I may, submit for discussion, three interrelated themes:

1. My personal experience of the Home Treatment and Crisis Response Service, including a comment or two on dishes of discourse¹
2. The ideologies behind Home treatment as demonstrated in the research and policy environment
3. The potential of a learning paradigm which could create a dynamic dialogic between users, carers, 'service providers' and the voluntary sector

(The longer version of this paper is a slim volume running, at present to about 60 pages, so what I am offering is a version so foreshortened that it makes Uccello's use of perspective look positively relaxed.)

1. Home Treatment and Crisis Response: A Carer's Experiential Perspective

'Are you a bit pressured, do you think?'

'No, takin' it easy, isn't that right, not pressured., chilled, great stuff that diazapam'

This non sequitur, or something like it, took place during a Home Visit. The clinician means 'pressured speech', indicating 'flight of ideas' within a manic episode. The 'patient's 'understanding of the word 'pressured' does not have this specialised meaning. There are two dishes of discourse; the closed system (hermeneutic) of the medical expert and the open system of the layperson.

The exchange was memorable because it was mildly ironic and because such synapses were, in fact, quite rare. And the reason for that was that the clinicians generally adopted the open system discourse of the patient. While I would not wish to go so far as to say that they became, as it were, like the Normans, 'more Irish than the Irish themselves', they did manage to avoid the more drastic forms of imperial domination, distinguished as they are by the imposition of an alien and alienating language.

It could be argued that this was rendered easier by the 'site' ; after all, this was the patient's home turf and everybody would naturally feel more informal and relaxed. But, prior to the Home Treatment and Crisis Resolution service, previous 'visits' by clinicians were not always so genial, sometimes taking the form of invasions, in which powerful forces, armed to the teeth with legal papers and sometimes backed up by police, enunciated in clipped, educated tones, their expert talk, took hostage the tenant - for his own good, and to the evident relief and guilt of the woman of the house.

¹ See Appendix A for a fuller account and recommendations

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So the locus of the transaction was not really the defining difference, but rather the *attitudes* of both parties. The awareness and willingness of the Home Treatment team to abandon their specialist language and to talk like the 'natives', including learning their specialist (professional) idiolects, was an index of their overall approach.

Beyond the question of vocabulary, the team were alert to other aspects of discourse. Where the traditional nexus tends to be the patient passively receiving questions and instructions from the expert, the team were more interested in the idea of a conversation. They spent a lot of time listening to us talking about our work and family and topics that were of interest to us; this is rarely possible in the appointment structure of a hospital or surgery. They were careful not to 'medicalize' the conversations by focusing relentlessly on symptoms and medication though they were very rigorous about that too. But they put a lot of time and effort into getting to know us as individuals who had skills, interests, families, networks (psychosocial approach) They also told us quite a lot about themselves (self-disclosure). Their tone was friendly and informal, in contrast to the stilted formality of the orthodox patient/doctor exchange. Humour was often used to defuse tension, (we do not usually share jokes or laugh in the presence of doctors). They also adopted a negotiative stance, working with us to agree visiting times that would suit us and so when more difficult issues had to be faced, the outcome was not imposition, but agreement.

This was our first experience of Home Treatment, since the service was only introduced in the Southern Trust in January 2007, and I would say the most valuable quality of it was that it was a genuine *learning* experience for all concerned. Indeed it was a learning paradigm. However, I think this could be greatly enriched and the objections of many users and carers as well as medics could be considerably reduced, if there were ways for all parties to participate in learning before crisis as well as in it. I will return to this a little later.

There were many other very positive features about our experience which I can only briefly summarise here; the management of the incipient crisis was coordinated proactively by the team, rather than the user or carer always having to pull professionals together, they came frequently (twice a day) and stayed for 'organic' periods rather than pressing us into appointment slots. They emphasised recovery but were not afraid to offer 'reality checks. They were solution focused, flexible and unbureaucratic, they worked effectively as a multidisciplinary team, displaying an admirable humility and awareness of each other's skills, and linked well with other parts of the service (CMHT and Consultant), agreeing between themselves as well as with us, when step up and step down needed to happen. Except for the service not yet being offered on a 24 hour basis, the delivery of it maintained 'high fidelity' to the best

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practice guidelines adumbrated by Heath, Smyth and the Sainsbury Centre for Mental Health.²

And the service worked; according to a range of evaluative measures of success; full blown mania was averted, (symptom reduction barometer) admission to hospital was avoided (impact on hospital admission barometer)³. User and carer were much happier with the process with its genuine emphasis on partnership, negotiation, empowerment (though these words were rarely used), the active participation of 'user' and carer in working towards recovery and the relative de-medicalization of the scenario as compared to hospital. A far greater degree of 'normalcy' was preserved not just because hospital was avoided but because the alternative succeeded (user/carer satisfaction barometer). It was hard work, but the prize was outstanding.

Many forests have now been hewn down in the rhetorical service of words like 'partnership', 'engagement' and 'choice' and how cynical these panjandruns have so often become. But here was an experience where these words had a shared meaning. And that was, I think, due to the commitment of the team to a set of goals that were shared by the 'patient' and carer.

2. Ideologies behind research on Home Treatment

In the debate which, even after 30 years of Home Treatment and Crisis Resolution, still rages⁴, it seems to me that the underlying issue is about goals. The basic argument runs that while clinicians tend to be focused on symptom reduction and behaviour modification, users and carers are more likely to measure success according to the degree of normalcy they can retain and the quality of the relationships established.⁵ Those who are critical of Home Treatment, notably Burns, Pelosi and Jackson⁶, tend to be dismissive of 'success factors' such as 'user and carer satisfaction (We are not here to satisfy patients, we are here to cure them, preferably in a paradigm breaking manner) and, critically, they rarely question their own motives, preserving an angry silence about the loss of power and authority

² D. Heath, (2004), *Home Treatment for Acute Mental Disorders*. London: Brunner-Routledge, p.128; M Smyth [undated], *Crisis Resolution and Home Treatment*. Birmingham: National Institute for Mental Health in England, p.13; Anon, 2001, *Mental Health Topics: Crisis Resolution*. London: Sainsbury Centre for Mental Health

³ See Appendix B for an indication of the prevalence of hospital admission as a criteria for success or failure

⁴ BMJ, 18 August 2007, 335, 311-312

⁵ M Godwin and G Wistow, 1997, 'The User Perspective on Managing for Health Outcomes: The Case of Mental Health', *Health and Social Care in the Community*, 5, 5 325; R Perkins, 2001, 'What Constitutes Success? The Relative Priority of Service Users' and Clinicians' Views of Mental Health Services', *British Journal of Psychiatry*, 179;9-10

⁶ T. Burns, '2000, 'Vigorous, Well-designed Trials are Needed, *BMJ* 321:177; A Pelosi and G Jackson, 2000, 'Home Treatment—Enigmas and Fantasies', *BMJ* 320: 305-309

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which concepts like Home Treatment draw, inexorably, behind them. Indeed Home treatment could be seen as a metaphor for the 'culture shift' exhorted in government policy here and in great Britain and through user/carer movements.⁷ However, the refashioning of the patient as consumer has obvious dangers, if Governments attend too slavishly to the Corporate model. Consumer choice may be limited to those who can pay for it and the tendency of Corpratism to measure success by volume may lead to pressure upon the small caseload of the Home Treatment teams (one of its most important features for achieving results) Corpratism also tends to favour centralisation and again, this runs against the decentered, localized, domestic character of Home Treatment. Cost is another key value and while there is some research to support a reduction in cost through delivery of Home Treatment, it is not, conclusive, since the indirect costs of inter agency and voluntary sector involvement is not always factored in.⁸ Government Ministers are apt to be susceptible to the panoply of corpratist pressures, though the new Minister for Health in Northern Ireland has backed Home Treatment. Let us hope he will be strong.⁹

And as Godwin and Wistow rightly point out, 'users' of mental health services are often captive recipients of care rather than free choosing consumers.¹⁰ One of the virtues of Home Treatment is surely its willingness to try and renegotiate that relationship, even in the face of sensational media stereotyping of community based care as leading to the presence out there of dangerous lunatics sure to commit shocking crimes.

Nonetheless, proponents of Home treatment are more likely to 'identify' with patients (users) and carers and thus to valorise the importance of

⁷ D. Bamford, Ed. (2005-2006), *A Strategic Framework for Mental Health Services*. Belfast: DHSSPS; DH (2005), *New Ways of Working for Psychiatrists: Enhancing Effective, Person-Centered Services through New Ways of Working in Multi-disciplinary and Multi-agency Contexts*. London: DH. DHSSPS (2001), *Informal Carers' Report*. Belfast: DHSSPS; DHSSPS (2004), *Valuing Carers: A Strategy for Carers in Northern Ireland*. Belfast: DHSSPS; R Hope, (2004) *The Ten Essential Shared Capabilities: A Framework for the Whole of the Mental Health Workforce*. London: DH and Sainsbury Centre for Mental Health; D Juriansz, D., P Lindley, P. and P O'Halloran, (2001), *The Capable Practitioner*. London: Sainsbury Centre for Mental Health; Department for Health and Children (RoI), 2006, *Vision for Change: Report of the Expert Working Group*. Dublin: DHC.

⁸ For, example, The Sainsbury Mental Health Centre document on Home Treatment does suggest that it is cheaper, but in addition to not showing what is covered under 'staff costs, their service model is 2-3 weeks, which would not necessarily be helpful to someone experiencing a manic episode, op cit, p.7. For a more subtle analysis, see, S Orme and B Cohen, 2007, *Researching Services Providing IHT as an Alternative to Admission.* In N Brimblecombe, op cit, p. 66

⁹ M McGimpsey, 2007, 'Health Minister Outlines Priorities to Assembly Committee'. Belfast: Northern Ireland Executive Press Release www.northernireland.gov.uk/news/news-dhssps-310507-health-mi, Accessed 4 September 2007

¹⁰ Op cit, 326

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user/consumer satisfaction. In so doing, they display a willingness, even a desire, to question their traditional value base, to risk the diminution of their traditional power, to exchange the dialectic of (powerful) self and (powerless) other for a more postmodern dialogology which acknowledges the validity of differing meanings, contradictory truths.

At the most radical end of the antipsychiatry and postpsychiatry spectrum, I hear invoked (music to my postmodernist, postcolonial ears) concepts such as the cultural construction of madness as an illness. Following Foucault (and a thousand poets and novelists), they would argue that this construction is but a thinly veiled attempt to segregate, alienate and emasculate and 'other' subversive critiques of hegemony. To construct madness as illness is but a soft landing to avoid calling it crime. The vernacular of Western thought since the seventeenth century has been to privilege and valorise the rational, thus to repress and construct as 'other' the entire Atlantis of the irrational and the unconscious.¹¹ Psychiatrists and their lesser satellites have huge power and prestige because they are the custodians of those who threaten the truth universally acknowledged and insouciant in the face to post modernism, that we are entirely rational beings.

So is it not a mite inevitable that the surfacing of the irrational is unlikely to take any shape other than the recursively sighted Loch Ness monster? Scottish Radio listeners were recently asked to 'vote for' the most Scottish person. Top of the poll was the 'Nessy' A similar exercise was conducted on Radio Ulster; according to listeners, the most Northern Irish person is Finn McCool.¹² M'Cool is another creature who 'transgresses' any notion of normality except the that which pertains in the literary form of the epic. Doubtless, the Jungians will be punching the air at this wonderful example of the collective unconscious reasserting its deepest beliefs over the paper thin surface of rationality. Given the abnegation of all else but the rational, madness is thus guaranteed to present itself as an illness to be cured, except, oddly enough, when it comes to people's collective self image, which would appear to comically disrupt the dominant ideal of the rational, real time, human being, engaged with society and functioning properly within it.

The will-o'-the-wisp of the 'paradigm breaking cure' is only too poignantly revealed in the noble quests of mad doctoring recounted in Sebastian Faluks' novel, *Human Traces*.¹³ And the difficulty of finding a 'cure' for madness

¹¹ See, for example, P. Bracken, 2001, 'The Radical Possibilities of Home Treatment: Postpsychiatry in Action,' in N Brimblecombe ed, *Acute Mental Health Care in the Community: Intensive Home Treatment*, London Whurr Publishers, pp.140-143 .

¹² Alan Simpson Show, BBC Radio Ulster, 4 September, 2007

¹³ S Faulks, 2006, *Human Traces*. London: Vintage

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might be, as Faulks' Dr Midwinter argues (deterministically but poetically), because it is 'hardwired' into our humanity.

However, it would be unfair and naïve to indulge ourselves in the quantum of our wanton, as Beckett's mad Murphy would have it. The actual experience of 'madness' for both user and carer is sometimes a deal; more ambiguous and the heroic figure of the mad lone voice (trickster, shaman or holy fool) inveighing against the evils of society, and presenting a deeper, moral truth, may also be something of a cultural construction. It is certainly a recursive literary construction. Madness is sometimes also wanton, grievous, cruel, manipulative, dangerous, irreparably incoherent, alienating, distressing, dehumanising, gargantuan in its self-absorption, imprisoning, meaningless.

While Home Treatment allows me to live in interesting times, I do not yet live in times interesting enough to enable us to fully square the circle of challenging paternalistic and imperial medical models, as well as the vacuities of corporatist models of 'consumer' choice in the problematised situation of people with mental illness, with attempting to cope in a humanising and empowering way with the less attractive but equally Promeathan manifestations of madness. So no matter how Foucaultian our own dispassionate and radical 'gaze' may be, there is still some sense in which we have a responsibility to collude with some of the orthodox goals of mad doctoring .

Home Treatment and Crisis Response is a microcosm of the transitory, borderline, liminal and experimental nature of the current relationship between mental health/illness establishment and the so called user and carer. Its potential for acting as a model for the kind of 'whole systems' approach evident in the Cavan-Monaghan model is immense.¹⁴

I would also wish to humbly make the point that while I have by now ingested a hefty titration of research on Home Treatment, I have come across very few articles or books written by users, and even fewer by carers (to date, none). It may well be that I have not yet drunk deep enough of the Pierian Spring, or it may be that there is plenty of evidence, but it does not find its way into the 'mainstream' of published research, or that google only searches among medical sources, or it may be that there is, in fact, a paucity of evidence from carers and users.

¹⁴ See The Cavan Monaghan Project: A Model for a new Community Mental health Service, www.monaghanmodel.com/directory.htm accessed 5 September 2007; M Fleming, undated, unpublished, 'Cavan Monaghan Mental Health Service

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Might I suggest that while the very existence of Home Treatment and Crisis Response services reflect a policy shift from a dominant 'medical model' to a nascent 'social model', or more riskily, to a corporatist model, this advance has not yet been accompanied by the logical development of it into user and carer based 'emancipatory' research based on a learning paradigm in which a genuine exchange of expertise between the professionals and the users and carers is enacted.

4. A learning paradigm

I referred earlier to the potential of the shared learning approach which underpinned the Home Treatment team's orientation and to the negativity which has been expressed by users and carers who may well feel that this is yet another form of psychiatric surveillance and control, involving recursive invasion, a pitiless refusal of asylum for the distressed individual and an intolerable burden on people on exhausted carers. Medical professionals who have had no real knowledge of Home Treatment are more likely to deprecate it and defend that beleaguered territory that they have battled hard to colonise.

But, to date, there is still very little training for users or carers on mental health and mental illness generally, and even fewer high quality learning paradigms which incorporate users and professionals.¹⁵ Though some excellent examples are evident at this conference, for example Anne Matthews' study of Foucaultian models among mental health nurses, Liam MacGabhain. Action research involving inpatients and nurses as co-participants and the work of the Recovery Alliance Theorists.¹⁶

I would like to propose that the potential of Home Treatment as a working model of how the culture shift towards multidisciplinary, partnership, choice and empowerment could be maximised by extending learning about it. The most important principle of this learning would be that it is facilitated by a *combination* of users, carers, clinicians, academics and voluntary sector organisations. The training should be accredited, it should take place in non-clinical settings and it should be timetabled to suit users and carers. Programmes would include:

Training for Trainers programme.

¹⁵ See Appendix C for an indicative list of programmes I have uncovered

¹⁶ A Matthews, 2007, 'Foucaultian interpretations of risk, gender and power and gender in mental health nurses' descriptions of managing aggression and violence in their practice' DCU, *Health4Life* Conference paper; L MacGabhainn, 2007, 'Discovering intercultural meanings and mutual understandings in a hostile place' DCU, *Health 4 Life* Conference paper; E Shanley, 2007, 'Recovery Alliance Theory: A Fresh Look at our common humanity' DCU, *Health4Life* conference paper

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This would offer an embodiment of the negotiative partnership based value system of Home Treatment

The training for trainers programme would in itself be an important forum for reflection and evaluation of practice which could in turn influence future evidence based practice and indeed identify areas for further joint research between professionals, users and carers that would be more emancipatory in its approach from the outset.

Learning about Home Treatment : users and carers

The training would be delivered by cohorts who have gone through the training for trainers programme. It should be repeated until all users and carers in the area who wish to avail of it have done so.

CPD

At the other end of the spectrum, the training for trainers programme should also develop a learning paradigm for professionals. To encourage multidisciplinary working, CPD sessions should include a range of professionals in both primary and secondary care settings.

Embedding of a learning paradigm in current university and professional training

More radically, I would like to propose that the training for trainers programme would also be offered in universities and other training institutions to all disciplines who could in the future be involved in Home Treatment. By embedding this kind of learning paradigm in professional training and delivering it, ideally, in cross-disciplinary cohorts, familiarity with the values and practices of Home Treatment would be achieved.

This kind of training would also help to sponsor more innovative multidisciplinary and team based approaches in relation to other aspects of mental health service.

Co-negotiated emancipatory research involving users, carers, professionals and the voluntary sector

Even when researchers are more willing to understand the implications of a user focused model in terms of the importance of actually voicing the opinions and arguments of the user and carer, the voicing tends to be contained by the authorial voice of the academic or clinician. Jim Walsh and Paddy McGowan's critique of the dangers and limitations facing user researchers is condign; they sardonically observe, the spectacle of 'some individuals reaching the dizzy heights of becoming authors of academic papers and books.'¹⁷

¹⁷ J. Walsh and P McGowan, 2007, 'I Had a Dream (but got committee membership): Authority, Representativeness, Collusion and Protest in the Service User Movement' , DCU, *Health 4 Life* Conference paper.

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The absence of user and carer voices as 'authors' is, of course, not unrelated to the dominance of quantitative over qualitative research, especially in the field of mental illness and behind that, the incorporation of the academy as an intellectual factory producing high volume, high quality, internationally significant research 'product' to meet the globalised demands of incorporated government whose return on their investment is the eldorado of the paradigm breaker which solves the greatest number of problems for the greatest number of people.

And since values like 'quality of relationships', tailored approaches, small caseloads, microsystems rather than macrosystems, are so fundamental to high fidelity Home Treatment work, it is not surprising that the research tends towards the qualitative and that academics and clinicians may feel obliged to assert whatever authority they still have within the research factory, rather than diluting it further by sharing authorship with users and carers. Users and carers may, as a result, find any research they do manage to do, disregarded by the very medical journals where it needs to be read by the experts.

Nonetheless, the main problem is more basic; most users and carers are not academics or clinicians and are likely to be unversed in the languages and methodologies of constructing research. So again, there is a power imbalance which needs to be addressed.¹⁸

I am suggesting, therefore, that there is a need for a training programme, again facilitated by the cohorts who have come through the Training for Trainers programme, in association with academics and voluntary sector scholars, familiar with models like qualitative/inclusive research methodologies and user based service monitoring.

The resulting research would be able to combine the experiential with a wider knowledge of policy and academic research and would also enable direct authorship and genuine co-authorship for users and carers.

The added advantage would be that the outlets for this kind of research would be much wider, not restricted to the academic arena, but accessible in

¹⁸ Godwin and Winston, op cit, embrace the importance of qualitative research and record interviews with a large number of users. Some of their comments are recorded, but it is clear that the users are not the authors; Premila Trivedi and Til Wykes offer an account of their experience of undertaking research with users See, P Trivedi and T Wykes, 2002, 'From Passive Subjects to Equal Partners: Qualitative Review of User Involvement in Research.' *British Journal of Psychiatry*, 181: 468-472). It is an admirably candid report and contains some very good recommendations based on their experience.

See Appendix D for an indicative list of research on user involvement.

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language (deploying both open and closed systems, experiential and expert idiolects) and format to users and carers.

A Learning paradigm for the community

While there is a great deal of rhetoric about educating the community,¹⁹ no sustained and structured approach is evident, certainly in Northern Ireland. There is the beginning of some work to engage the wider community in education about mental health/mental illness, for example the recent television advertisement campaign in Northern Ireland. However, much of this 'community awareness' tends to be focused on the more dramatic manifestations of mental 'health', such as teenage suicide. In relation to work with young people, this seems to be somewhat preoccupied with devising programmes to react to 'bad, mad and dangerous behaviour in schools'²⁰. I acknowledge this is a very crude characterisation, but there is, I believe a certain ghettoisation of these 'special programmes' in that they tend to be targeted at deprived areas and at remediating individual behaviour so that it subscribes to an unchallenged societal 'norm'.. So far as I am aware, no strategic programme involving all schools or targeting all communities, is in operation. The deficit present in the wider society merely reflects the deficits present in the narrower 'clinical' world.

So I would propose a schools programme that would be much less narrowly focused, available as part of the curriculum and embedded into it, and a community programme that contextualizes Home Treatment within a wider agenda of citizenship and civic participation, empowerment and social inclusion.

Appendix A unedited account of Carer response to Home Treatment and Crisis Resolution Service and Recommendations

Life before Home Treatment

I had the great honour last year to be involved in the creation of a manual for users and carers experiencing mental distress. (T. Maginess, ed., 2006 *And Never Dared Ask: A Manual for Individuals, Families and Friends Affected by Mental Illness*: Armagh: Out and About Project) The manual was produced through a series of accredited formal and informal workshops and was part of an ongoing partnership between Queen's University's Open Learning Programme/School of Nursing and Midwifery and a voluntary sector pan-disability group based in Armagh, called Out and About. What we were at, though we did not know the fancy name for it at the outset, was emancipatory

¹⁹ See, for example, K Weare, 2007, 'Linking Education and Mental Health – A European Priority'. *Health Education*, 107, 3, pp.245-249)

²⁰ (See, eg G Noam and C Hermann, 2002, 'Where Education and Mental Health Meet: Developmental Prevention and Early Intervention in Schools.' *Development and Psychopathology*, 14, 861-875).

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research. (T. Maginess, 2006, Are Ye Mad...). I will return to this subject a bit later. In the manual, we identified the main problems encountered by individuals and their families and friends experiencing a crisis as:

- Poor information about who to contact, how to contact them and when to contact them
- Severe lack of co-ordination between the different parts of the mental health services
- A related failure to track the individual through ongoing updating of information relating to the crisis
- The lack of a pro-active and co-ordinated approach on the part many of the professionals, leaving the individual and the carer stranded, having to carry the responsibility for co-ordinating the crisis response
- A weak culture of engagement and negotiation with the individual and carer (despite all the policy documents, advocating and acknowledging the 'culture shift' to a person centered model and psychosocial approaches), with an associated tendency among professionals to patronise the individual in crisis and to ignore the expertise of the individual and the carer
- Lack of common sense on the part of some professionals in planning ongoing crisis response, both between professionals and with those directly affected
- Arbitrary judgements about risk management

I would now add to this:

- Excessive strain placed upon the after hours emergency service. While, my personal experience of this service was, on the whole, positive, and while the personal 'capability' of individual staff members was, almost without exception, of a very high calibre indeed, the small team was simply stretched to breaking point. The constant pressure to 'triage' led to a situation where crisis was being answered by an often pressurised service which allowed little opportunity for in depth assessment, sustained care and proper negotiation involving the individual in crisis and their loved ones.
- The existence of two languages which seldom enjoyed mutual intelligibility; on the one hand, the *experiential* language of user and carer, characterised by vivid narrative, vigorous debate, comicality often of a sharply ironic nature, and collusive or resilient silence - to name but a few of its moods and registers, and on the other the *expert* language of clinicians, characterised by specialised vocabulary, lack of narrative fluency, artificially calm tonality and notably infrequent humour.

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The Home Treatment Service: A Personal Account

Until the introduction of the HPCR Service, my -- what will I call him, now, in an august, academic context such as this, considering that we are not supposed, really, to even use the first person, (there goes that rule) and ethical questions of 'confidentiality' ? (See the latest ding dust on this old chestnut in *Sunday Tribune*, 2 September 2007) . - the/my 'user, the/my 'consumer', the/my 'patient, , the/my 'loved one' the/my 'main man', the/my 'subject' (read object), 'our boy', 'the boss', the 'Free State butterfly-soul-psyche (Vision for Change) type person, 'A', 'I' (mememe), 'Al', 'John', 'Seamus', 'Gordon'? All 'packing' as we used to say in Northern Ireland. To say nothing of the Postivist research model rearing its sartorial hydra head. Dishes of discourse, how are ye. I will nominate him as Brian, completely unsatisfactory as a solution but I like the sound of that name.

To continue, Brian has, on every occasion, been hospitalised. This was, in my view, due to the factors outlined above and the resulting bottom line that when he was no longer able to trust and negotiate, with myself as carer and, consequently 'blew' into mania, I had no alternative but to hand over responsibility, since there was no alternative 'service' or even a concept of 'crisis resolution' (C Flannigan et al, 1984, A. Beck et al, 1997, cited in N Brimblecombe, ed., 2001, *Acute Mental Health Care in the Community: Intensive Home Treatment*. London: Whurr Publishers, p.192).

This was on every occasion, an extremely difficult river to cross, both for Brian and myself. There was often anger and blame on his part and a feeling of guilt and anger on mine.

So how did we get involved with the Home Treatment Team? Brian had experienced a number of manic-depressive crises over the years and so was 'known' to the system and the referral was made through the Community Mental Health team key worker, in this case a CPN in liaison with the Consultant Psychiatrist.. I will address the issues of referral and tagging a bit later.

Brian was adjudged by the CPN, the Consultant Psychiatrist and myself as carer as marking the onset of a 'relapse crisis' in a number of ways, Brian himself recognised that he might be becoming unwell, though this was a very difficult recognition, since he felt 'great' . The markers were recursive behaviours outside the framework of his individual 'normal' personality traits. He was thus 'at risk' of being hospitalised. The introduction of this 'intervention' was agreed and negotiated, and that is significant in itself as a process, but also, because this was the first time that we had any real alternative route to hospitalisation for 'crisis resolution'.

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The stigma associated with hospitalisation for users has been amply documented., E Goffman, *Asylums...* ; M Smyth, date *Crisis Resolution and Home Treatment*. Birmingham: NIMHE (E) and Centre for Community Mental Health, UCE, P.27, M J Hyland. . .) The secondary stigmatisation for carers perhaps less so, though see M Ostman and L Kjellin, 2002, 'Stigma by Association: Psychological Factors in Relatives of People with Mental Illness', *British Journal of Psychiatry*, 181: 494-498) This is, for many commentators, the result of the 'cultural construction' of madness , not only in terms of medicalization, but also in terms of a much broader societal fear of the 'otherness' of the mad. I will take this up again, but I just wish to note, at this point, that Brian himself, like many people affected by mental distress, was himself 'colojnised' by the sense of stigma and criminalisation associated with how the 'service' dealt with his distress – or in the case of the manic 'presentation' dealt with his sense of increasing control and well being. The lanuage Brian used reflected his sense of being crinalised. He objected to people reporting on him (me), talking behind his back , 'shopping him' to the system. I was seen as an informer betraying our inner world; a term extremely loaded within a Northern Irish context. There were allied aspects of this subversion/compliance axis, which I will try to return to.

May I state here that our current CPN has been outstanding in her practical, compassionate, humorous and firm approach and in her thoroughly internalised application of psychosocial, person-centered and recovery model approaches. The Consultant Psychiatrist has also been, in the best sense, a critical friend, treating both my loved one and myself with respect and compassion.

Within a few days, the Home Treatment Service was in place. Smyth and Heath, among others have emphasised the importance of Rapid Response. (Smyth, Heath, p. 128) Smyth notes that carers are more willing to respond to Home Treatment as an alternative to hospital when they know that help is at had quickly. (Smyth, p. 27)The CPN introduced the service and team members to us at home. This was, I believe a very comforting and also intelligent approach. We knew the CPN well but did not know the Home Treatment Service, as such, so it was a very reassuring to have this 'hand over' and also this was very 'good practice' in creating a co-ordinated approach between the Community Mental Health team and the Home Treatment Service. (see Smyth and Hoult..., Smyth, p.6).

It became clear that the Home Treatment Service was going to be co-ordinating the situation completely. Each of the three teams in the Southern Trust operate between 9.00am and 9.00pm. One of the teams is also available between 9.00pm and 1.00am on a rota basis. I will discuss the additional value of a 24/7 service shortly.

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So instead of having to constantly repeat information and make connections, , between the Community Mental Health Team, the Consultant Psychiatrist, the after hours emergency service, and sometimes, also, the GP out of hours service, we were clear about who to contact, and indeed, we did not have to do the contacting because they offered a sustained and proactive service. We were also encouraged to contact them if we had any difficulties between visits. This was very easy as we had a direct number and indeed a mobile number also. (I have read of one service where clients who did not have a phone were given a mobile by the Home Treatment team, Brimblecombe?). So the major problem of coordinated action in handling crisis was being addressed.

And, this team was going to be proactive. As a carer, I did not have to keep contacting them, feeling bad about pestering them, feeling angry about having to wait for hours for someone to come, feeling unsure about whether I was overreacting, unsure about whether I was under-reacting, rudderless about risk management and how to be positive about it or filled with worry that I was being irresponsible in not preventing some action that could be dangerously risky. Most of all, I had previously felt very isolated and insecure and became exhausted from lack of sleep and the sheer volume and variety and relentlessness of demands being made by my loved one, his remoteness from me, and the unnaturalness of having to 'police' him.

The Home Treatment Team assured us that, if we were agreeable, they were going to come every day, twice a day, and more often than that, if we thought that this would be beneficial. (Smyth and Hault, 2-3 times, Sainsbury?)

It was also our first experience of Psychiatrists visiting us at home. It was beginning to register with me that this was a '*multidisciplinary team*'. Both psychiatrists were most respectful and down to earth, markedly different from the more traditional 'top down' medical model attitudes we had experienced in the not too distant past. It was evident that these professionals had embraced the 'culture shift'.

So what did they do, how did they do it . . .and why did they do it?

What did they do?

They came, they stayed, they came back. They did not wave magic wands. They mostly listened, they asked questions, gently, wittily, sometimes with a hint of warning, they talked, we talked. Some of the team emphasised the

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importance of trying to preserve as much of my loved one's 'normal life' as possible, (Heath, Smyth), while others emphasised that Home Treatment was about simulating the conditions within hospital, where people would not be working or running around shops or being unsupervised about medication; like a hospital on wheels. My own observation is that, while potentially, these two views could be confusing, and that, superficially the 'normalisation' model is more attractive to some users and carers, the alteration of them was, in practice, useful and flexible. When my loved one was in agreeable and enthusiastic frame of mind about Home Treatment, the 'normalisation' model worked well. When he was in danger of taking on too much and 'blowing', the hospital analogy was more condign.

And, as you can see, the *dialogue* between family and professionals and between clinicians themselves, reflected the acknowledgement by the team that the patient's goals were primarily about control, continued integration with family and community and 'normalcy' while their frequent reviewing of the impact of medication and the recourse to the analogy of the 'hospital on wheels' was clearly inspired by their own more clinically driven goals of symptom reduction. The point is that they managed to narrow the gap between these traditionally divergent goals by a process of listening, negotiation, suggestion, and agreement.

And, equally importantly, they understood deeply rather than superficially, because they were observing and negotiating every day twice a day and for quite long periods of sometimes an hour or two hours, the protean nature of the drama they were participating in. This close and sustained scrutiny enabled us all to adjust 'treatment' and attitude with far greater rigour and precision than might be possible in other contexts. The flexibility of the management was, by an apparent paradox, the result of sustained work (Heath, principles).

My observation is that this is much more difficult to achieve in a ward situation where the sheer numbers of patients renders this kind of tailored approach impractical. A patient may only be seen for very brief periods, though the situation is, admittedly, immeasurably better than the experience of Dr Midwinter's patients in Faulk's novel, *Human Traces*, who were hastily diagnosed and then not seen for perhaps a year (S Faulk, 2006, *Human Traces*: London: Vintage) If the patient is 'out there', being seen on a weekly or even daily basis by the Community Mental Health Team, changes in behaviour, even quite extreme 'deterioration' can be masked by plausible presentation to professionals. I myself have locked horns with a certain psychiatrist who archly responded to the question why did you not admit him, by telling me that she saw nothing wrong and accusing me of overreacting. Within 24 hours he was sectioned. And, as noted above, the after hours

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emergency service was so overstretched that they sometimes unwittingly carried a crisis to the crisis.

Within the sustained and ongoing process of engagement with the loved one, the Home Treatment team, building incrementally on their knowledge of us and preserving good communication between themselves also, were able to respond much more positively and expertly to risk.

Risk was carefully weighed and agreement arrived at concerning what could be considered negative risk. So the car keys were surrendered after some discussion, bank cards were handed over to obviate the negative risk of wild overspending (though this did prove a slightly tricky process, given that the team had not yet developed a protocol for the safe keeping of such items and I had to make some suggestions about how this could be managed!).

Positive risk management was also very evident. Each day we would discuss what my loved one wanted and 'needed' to do. Only when his mood became such that concentration was seriously threatened, was there advice to cut back and then stop work for a few days.

In relation to medication management, discussions about dosage and types of medication were only introduced well into the conversation rather than at the outset, thus establishing a non directive and non inquisitorial environment. The 'patient' was asked for his views about what he felt to be the effect of the medication, as was I as carer. As the curve of the mania began to rise after an initial stabilisation, we were asked if increased doses of largactil be acceptable and would my loved one be agreeable to me overseeing the taking of medication since his concentration was not great. (Smyth, p.27)

Each day we discussed and agreed what the plan was. And while this did not always work out, a lot of it did work out. Work was reduced, stimulus was reduced, increased medication was taken.

Occasional tensions between Brian and myself over what the appropriate course of action would be or over the account given by one or other of us about the previous few hours, were acknowledged and seen as a natural part of the process. This gave me, as carer, an important licence to disagree with my loved one and at other times to act as advocate for my loved one.

How did they do it?

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To me, the most striking aspect of the service was the *negotiating* (*daillogical*) approach. In clinical terms (some of us 'collusively' learn that language for bridging purposes and to be taken seriously by the 'experts)), he was, for the best part of seven weeks, hypomanic; which I understand to be, not completely manic; exhibiting ' overactivity' ' pressured speech', 'flight of ideas', loss of judgement', 'inappropriate comments and behaviour', dark thoughts', aggression', 'self absorption', tendency to spend, 'increased libido', 'disturbed sleep'.

Underneath these medical model typologies, I would say he was 'talking ten to the dozen' (which he does not usually do), deaving me with very loud music played late at night and early in the morning, critical, alert, full of fun, full of information, drinking loads of coke, eating for Ireland (junking), wanting to buy stuff he would not usually buy, wanting to go places, wanting to do loads of jobs, holding it together, losing it, getting paranoid, being remote from me, demanding, self-absorbed, subversive, critical of authority, funny, scary, silly, profound.

The team negotiated. They listened to him, they listened to me, they gained agreement, so he began to settle He 'rose again of course, if not quite in the third day.. They tried different approaches, they learned what was possible at particular times and depending on 'how he was' The team displayed great *flexibility*, tailoring their 'intervention' to the individual as a dynamic individual.(Heath) A weekly plan seemed like a good idea, but proved impractical. Brian insisted on drawing the lines for the calendar and managed to do so with far more precision than the team member, but then lost concentration and we were left with a beautifully ruled blank page. The team member offered a good humoured, if slightly rueful smile and wisely abandoned so ambitious a grand design. So the team realistically opted for planning a day in advance, maybe even a few hours in advance. This was, in fact, more in tune with the normal 'working habits of my loved one. While he would keep a 'bookings diary', the reality of his job often entails responding to calls at very short notice. By contrast, academics or clinicians may be much more accustomed to weekly and even monthly planners. So this was also a nice little example of how, as they got to know my loved one, as an individual, and got to know about the rhythms of his life, were able to adjust their practice. No 'advance directives' were in place, and this may have helped with the resolution of more tricky issues (For the positive effect of these mechanisms on 'sectioning' of patients, see C Henderson , C Flood, M Leese, G Thornicroft. K Sutherby, G Szmukler., 2004, ' Effect of Joint Crisis Plans on Use of Compulsory Treatment in Psychiatry: Single Blind Randomised Controlled Trial, BMJ, 329:136)

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From what I observed, a *psychosocial* approach was very much in evidence; combining negotiation about medication with an awareness of the individual's own personal situation and the broader social realities; including helping with practical issues like benefits or money problems or even shopping or getting meals organised. This awareness of 'social systems (or lack of them) can be just as important as managing the symptoms of the illness, ensuring that medication is taken or managing 'risk' and ensuring safety, since all these aspects affect how an individual can cope at home. This is repeatedly emphasised in the research on models of good practice (McGlynn, pp 41-51,

The approach was, to put it another way, very much person centered. The team used their not inconsiderable interpersonal and communication skills to find out about the person they were working with, and beyond that to the 'social system' of the carer and the broader family and social context. Team members had a good way with them, they were able to find common points of interest and connect with the individual and the carer very skilfully.

We were not just consulted, but asked about what times were suitable for visiting, the team were apologetic about interrupting us at mealtimes, were respectful and friendly (Planning of visits (p. 5, Smyth),

The 'recovery model' , again, so often referred to in the research, was explained and invoked, mostly in a very accessible and non-patronising fashion. I think this also was reassuring; the team were very strongly focused on working with us to get through the crisis to recovery. This kind of positive attitude was continually reinforced and I think that we all began to have faith in it and so we all worked at it. There was a very definite sense of a goal; to see if we could avoid hospital and, between us, get over the crisis. Both the loved one and myself were very affected by this dedication and the challenge of working in a far more active and shared atmosphere. And I say, 'working; because that is what it felt like; we were all working on a project, and the odds were sometimes not good, but everybody was very determined. And this was true *empowerment*;(again one of those Health Service mantras); realistic and sustained

Because there was a common goal, the individual team members were more inclined to work as a team. They demonstrated an admirable awareness of each other's strengths and a willingness to consult one another. I saw little sign of tension or 'silo' thinking among them. Several commentators have emphasised the importance of this team approach, oh so much easier said than done when there are so few 'working examples' of how this policy

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imperative would actually happen, given the persistent rigidities in the workforce practices of the health service. Bruce Cohen offers a candid analysis of some of the difficulties of getting this to actually happen (B Cohen, 2001, in Brimblecome, ed, op cit, pp163-186), though there is hope from such 'whole systems' models as that developed in the Cavan Monaghan Mental Health Service (www.monaghanmodel.com/directory.htm; M. Flemming, undated, unpublished paper ; telephone interview with Margaret Fleming, 6 September 2007)

Finally, language was an important factor. Most of the team were very expert at talking with us in non medical language. Where they did have to use jargon, they explained it. Beyond that, they were nearly all very good conversationalists, and while linguistic skills and a creative, imaginative, witty attitude to language may seem a very unimportant, even trivial part of the repertoire of a health care professional, it is, in my view, central to success or failure. For if the professional cannot communicate with the service user and carer, how is negotiation to take place? Too often, professionals have hidden behind language as one aspect of a more generalised 'closed system' (hermeneutic) designed to ensure their power over the patient; which implies imperial relationship between colonising expert and colonised subject/patient: I will speak to you about the subjects I choose and in my language) knowing that you know it not., and on my territory, to which you are summoned. So the skill of the clinicians in using ordinary language, listening and talking about subjects the 'patient' and carer are interested in, are indicators of a tone and an attitude that is about valuing the expertise and uniqueness of the people they are working with (rather than at or on), and is much more likely to result in an identification between the team and the family and hence an engaged relationship relaxed enough to enable negotiation.

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Why did they do it?

The team were very highly motivated to prove that this kind of new service could work. And, perhaps, because this was the first 'manic patient' they had worked with, there was a very strong drive to prove that the service could deal with the particular challenges that this presented. The importance, and dangers of enthusiasm have been documented, eg Cohen, Pelosi and Jackson...). They were also committed to a more radical view of what their own function was as health professionals, and while they may not have been totally 'postpsychiatry' in their approach(see P. Bracken, 2001 in Brimblecome ed, op cit, pp139-162), nor as yet, fully skilled and knowledgeable about the ambitious goals of citizenship adumbrated in the Monaghan-Cavan model, their ability to interrogate traditional clinical approaches and to respond to the goals and meanings of mental illness/wellness sponsored by the 'user' and carer, was very stimulating and supportive.

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An evaluation of the HPCR Service: summary.

Advantages

1. It is *co-ordinated*
2. It deploys a *'step up, step down'* approach which recognises the importance of intense intervention to prevent escalation (Heath, p.91)
3. It provides *rapid response*, again preventing escalation (Heath, p. , Smyth, p.27)
4. It is *proactive*, in keeping with Government ideology about 'consumer rights', choice and 'customer service'
5. It is *person-centered*, thus fulfilling current policy imperatives and is, thus better at engaging the 'client' and family (see, eg, Killapsy, REACT study)
6. It is genuinely *empowering*
7. Because it is empowering there was *significant symptom reduction*; a full blown hyper manic crisis was averted
7. It is *flexible* and tailored to individual need.
8. It is *psychosocial* in both theory and practice, combining medication with an awareness of 'social systems' and the particularity of the individual (Heath, p.91, Smyth, p.28) Geddes criticism is not borne out by my experience

There is very little evidence that psychosocial interventions are effective in mania. . . Very little evidence currently supports the use of psychosocial interventions in acute depressive episodes in bipolar disorder (John Geddes, Professor of Epidemiological Psychiatry, Oxford. *BMJ*, vol 332, 7 Jan 2006).

9. It is *sustained*. As those who have argued in the wilderness for many years (eg advocates of the psychosocial approach), know, sustained work with individuals is critical to the aetiology of mental illness and well being. Because the case load is not so big, the team members have time to properly assess the patient's state of mind, which, in conditions like manic depression, may be quite labile and protean and, thus, subject to change over the course of 30 minutes or an hour. They are not forced into 'snap' judgements, sometimes as a result of a 'crisis' call from a carer, which may tend to result in hospitalisation because there had been no alternative. It is 'time-rich'. The team stayed with us for about 8 weeks. (See Smyth, Sainsbury)

10. It is *multidisciplinary in practice*, not just in theory, employing a *team based approach*
11. It is *recovery oriented*, presenting a far more positive solution focused paradigm for all concerned (Smyth, p.3, NIMHE West Midlands guidelines, p. 102,; S Ramon, B Healy, N Renouf, 2007, 'Recovery from Mental Illness as an Emergent Concept and Practice in

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Australia and the United Kingdom', *International Journal of Social Psychiatry*, 53, 2, 108-122)

12. It is *a crucial and liberating opportunity for learning* – for the individual experiencing crisis, carers, professionals and others. Given mutual support, all parties can *learn*, collectively, how to negotiate the crisis, with its attendant emotional personal and family tensions. The ideal of Essential Shared Capabilities [ref] is thus enhanced but also broadened to include the capability of the individual experiencing the crisis and their loved ones.
13. It accomplished successfully and effectively one of its own key goals; the *avoidance of hospital admission*. This was a huge 'prize' for us all, not just Brian and myself (. (McGlynn, p.11).

Recommendations

1. *To the Southern Trust*: The clear and present danger is that the service may well become a victim of its own success. I recommend that the Trust continue the service and try to ensure that it does not lose its most precious quality, 'time' by recruiting sufficient staff of the high calibre that characterises the current team to cover an increasing caseload.
2. *To the Southern Trust*. While some research would indicate that there is no demand for a 24 hour service (McGlynn p.7), the evidence of carers would indicate the importance of the 24 hour model (*And Never Dared Ask*, 2007, p.54). I would recommend that the Trust commissions a scoping exercise which would incorporate the views of users and carers and also document practice in other areas
3. *To the Department of Health and Social Services*. While it is apparent that the current members of the HPCR team have received training from key 'experts' such as Kevin Heffernan, that training has (a) not been available in Northern Ireland (b) has not actively involved service users and carers as acknowledged 'experts'. Therefore, I would recommend that (a) HPCR teams within Northern Ireland, such as the Southern Trust team, become trainers and (b) users and carers and voluntary agencies can contribute much more actively to that training so that a genuinely person-centered, co-ordinated, 'capable practitioners' model of crisis management can be evolved which can be disseminated convincingly both among professionals and between users, carers and voluntary agencies
4. *To the Department of Health and Social Services and the new Trusts*. While the individual teams, like the Southern trust team, have been the crack troops, at the frontline of crisis response, there is a need for 'stepping back' to learn about the latest, cutting edge research and for the team members to contribute to that research. In terms of evidence

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based practice, but also in terms of considering some of the broader theoretical and policy issues as they emerge, ideally in partnership with carers and users with whom they have been working.

I would, therefore, recommend that resources be made available to enable teams to work with carers and users, either through the current for a, or independently, to engender co-training programmes and to foster emancipatory research projects, including, for example, the preparation of a guide to the new service, which would include a critical evaluation of it from all the parties concerned.

5. *To the Southern Trust, the Department and other Assembly Departments.* I would recommend that they recognise the interdepartmental nature of this service and make information available properly about the new service. This would include public advertisements, but also outreach work at grass-roots community level in a range of geographical and socio-economic communities. Use the many networks available, from local community development groups to Women's Institutes to sports clubs to carry the information. Ensure that it is accessible in terms of language and format. Consider how users and carers can assist in being advocates and ambassadors for this approach, on their own terms.

The value of such work would be enormous and would represent good value for money, since 'buy in' to the service would inevitably reduce hospital admissions and, therefore, save more money than it is reckoned is being spent on initiatives like the Home Treatment Service..

To DHSSPSI, DENI, DSL, Office of the First Minister and Deputy First Minister, DRD. The Department and the Southern Trust must be warmly congratulated for the courage and vision and insight (a word used so frequently about 'patients'), but, it must be acknowledged that, while those directly involved in pioneering the service are very familiar with it, users and carers may not be au fait, and the wider community may be completely unaware of it. Proper accredited training based on a learning paradigm needs to be developed. An interagency approach also needs to be taken to ensure that a 'whole systems' approach to the delivery of mental health services is developed

To carers and users

- In my own case, I have slowly learned to fashion something of an imaginative space, or a persona, that enables me to be a bit more thick-skinned when my loved one lashes out. I have also slowly learned

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to be more patient, to recognise that I have to give time to the situation, that I cannot continue as normal. But at the same time, I have begun to learn also that I need to have 'safety valves'; some activity or place that I can escape into, which also lets my loved one be alone and free of the feeling of being policed and supervised continually. This time around, I was lucky in that the crisis took place in Spring and I was able to get a whole vegetable garden created and planted. Probably, if my loved one had not been unwell, I would not have managed this or would have done so at the cost of being pretty pressurised and stressed with work. So it is important to develop a 'head space' to deal with the long haul, practical strategies to combat tiredness, irritation and a sense of entrapment, and to get reinforcements; family or friends who can relieve you from time to time and regularly.

I also wrote when I could get peace to do so; one of the team members is a great believer in writing things down, and I think that this had meaning for me, but would not necessarily have meaning for every carer or every person experiencing a crisis. I wrote fragmentary diary entries, bits of poetry and prose, and started upon the document that you are now reading, some of which, in a much rawer form, I have saved, but have judged it to be too personal and angry headed for public consumption. But it was a great outlet at the time, and may be useful for the future, as a 'real' unedited record of how things seemed to me in the middle of a crisis.

I was also very lucky to have three people in my family who were, in different ways, very supportive; my mother, who is now 88 years old and who gave me space and held back on her own needs, my mother-in law, whose non-judgemental, sensitive and tactful attitude was as crucial as her making time to come and stay with my loved one while I went reclaimed some of my work and other identity, and my sister, who, despite many other competing demands on her time, made time for my loved one and myself.

And sometimes I said a rushed, urgent prayer; of thanks, of entreaty. And this is not for everybody either. I am not a pious person or 'saved', but a person, full of failings. My neighbour, going to a different church, says, 'there's what brambles will burn us all.' But for both my loved one and myself (from different churches), the bits of prayers were a great help.

Big rec here about HT as [aradigm for brader delivery of culture shift

14.

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15. The *calibre of staff* in the service is, almost without exception, enormously impressive. (see Appendix A).

Potential limitations

The HTCRT may not be for everybody:

- Many people do not really understand the purpose of the service or how it works. HT is a crisis intervention response so it may well be that many people encountering it for the first time may not have the luxury of learning fully about it. This applies both to carers and users and indeed to other professionals (Cohen, op cit, p.168). So a learning paradigm is crucial. I will return to this in Section 3)

One of the reasons why my own response was so positive may well be that I knew about the service in advance, had actively supported its introduction and had been involved in a structured learning paradigm about mental illness with the Out and About Group for a number of years. At a recent meeting with carers and users, most of whom had not been involved in this project, it became evident that even before I spoke about my own experience, there was considerable scepticism and even hostility to the new service. Some of the specific explanation for this is given below, but I believe that if carers and users are afforded opportunities to learn about and critique new services like this at times when they are *not* in crisis, a number of the negative anxieties about it could be reduced if not ameliorated. The alternative is to risk alienating users and carers by seeming to impose the service on them]

- Some people experiencing a crisis, or/and their family, may feel that they *need* to be in hospital, completely removed from a set of home situations that that are overwhelming, damaging, or inimical
- Some individuals experiencing crisis may not be able to negotiate between the fine lines; the extremely difficult and demanding existential discipline of retaining responsibility and ownership and holding on to insight when the overwhelming call is to abandon so banal and boring a prospect for the liberation of gaining rarer and more dramatic insights.
- Some carers may find the burden of managing the crisis at home, even with expert and sustained support, too much and may feel pressurised into accepting the service whether they want it or not (Brimblecome? They may not be able to get time off work, or they may have other caring responsibilities, or they may be too distressed, upset, exhausted, angry or alienated to be able to tolerate the prospect of continuing care with their loved ones. . In our case, the duration of the Home Treatment intervention was about 8 weeks. There is no doubt, that it was a major challenge and very tiring. There is also a sense that

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there is precious little opportunity for 'escape' during the long hours between visits from the team.

- Some service users and carers may no longer have the patience or resilience to learn 'on the hoof', this whole new model, having battled for years against the system, against the illness.
- Some individuals experiencing crisis and/or their carers may feel that this service is just another cynical government ploy to force them to take even more responsibility for care in the community
- Others may not accept that they are unwell or their carers do not accept that they are unwell, so no negotiation can take place. The role of the assertive outreach team may be more appropriate here (telephone interview with Adrian Corrigan, co-ordinator Southern Trust CRHT, 6 September, 2007)
- Carers and family may not wish to accept that a loved one is ill, and not just being a person whose behaviour is insulting, abusive, ridiculous, outrageous, selfish. The 'diagnosis' changes the goal posts and forces family and friends to alter their perceptions and judgements, in ways that are deeply uncomfortable. We can no longer be pure in our anger. We have to decide whether we can handle the explanation, since we must still deal with it and be subject to the symptoms. This raises the issue of targeting and referral, to which I will return. But there is evidence that HT can be used successfully with first episode mental illness (see first episode psychosis stuff]
- Some medical professionals, equally, may feel very uncomfortable with the current culture shift which obliges them to look beyond symptom reduction and primarily bio./pharmacological forms of treatment. This new mantra of person centered treatments may jar with the traditional training which emphasised a 'positivist' value system (though not declaring itself as such), which rendered an individual, human or personal response from the professional, let alone engagement with the patient through dialogue, extremely difficult. So, as with many professions, people tend not to question the value base of their training and this must, therefore, make it very difficult for established professionals to meet the challenge of changing their entire orientation as impartial, objective, uninvolved, experts, treating classified symptoms rather than causes and social systems, cases rather than individuals, trained to ignore the personal situation and context of an individual and trained to regard the user as ill and, therefore, by definition incapable of insight or choice and the carer as unqualified, lacking in proper knowledge and awkwardly impinging upon patient confidentiality. I will take this issue up in Section 2.
- The team may be so intensely focused on the individual and their family that they miss the support and advice and expertise

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available from other parts of the Department of Health and Social Services (eg the Community Development teams, Benefits advisors, from other departments and agencies, eg, The Housing Executive, Councils, educational and training providers and from the voluntary sector, which is a huge and often extremely expert sector, ranging from Rural Isolation services to CABs, mental health charities, user and carer support groups and regional, national and international networks, agencies and foundations. The Cavan Monaghan model demonstrates how an effective 'whole systems' approach involving the voluntary sector moiré fully can actually be done.

- The team may be so focused on the individual and their family that they may simply not have the time to consider the broader research and policy picture, some of which comes from Government sources, some from academic sources, some from voluntary sector sources

Team working and a multidisciplinary approach is still very new and not well articulated. Professional silos are still very much norm. **Recommendations**

6. *To the Southern Trust:* The clear and present danger is that the service may well become a victim of its own success. I recommend that the Trust continue the service and try to ensure that it does not lose its most precious quality, 'time' by recruiting sufficient staff of the high calibre that characterises the current team to cover an increasing caseload.
7. *To the Southern Trust.* While some research would indicate that there is no demand for a 24 hour service (McGlynn p.7), the evidence of carers would indicate the importance of the 24 hour model (*And Never Dared Ask*, 2007, p.54). I would recommend that the Trust commissions a scoping exercise which would incorporate the views of users and carers and also document practice in other areas
8. *To the Department of Health and Social Services.* While it is apparent that the current members of the HTCR team have received training from key 'experts' such as Kevin Heffernan, that training has (a) not been available in Northern Ireland (b) has not actively involved service users and carers as acknowledged 'experts. Therefore, I would recommend that (a) HTCR teams within Northern Ireland, such as the Southern Trust team, become trainers and (b) users and carers and voluntary agencies can contribute much more actively to that training so that a genuinely person-centered, co-ordinated, 'capable practitioners' model of crisis management can be evolved which can be disseminated convincingly both among professionals and between users, carers and voluntary agencies

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9. *To the Department of Health and Social Services and the new Trusts.* While the individual teams, like the Southern trust team, have been the crack troops, at the frontline of crisis response, there is a need for 'stepping back' to learn about the latest, cutting edge research and for the team members to contribute to that research. In terms of evidence based practice, but also in terms of considering some of the broader theoretical and policy issues as they emerge, ideally in partnership with carers and users with whom they have been working.

I would, therefore, recommend that resources be made available to enable teams to work with carers and users, either through the current for a, or independently, to engender co-training programmes and to foster emancipatory research projects, including, for example, the preparation of a guide to the new service, which would include a critical evaluation of it from all the parties concerned.

10. *To the Southern Trust, the Department and other Assembly Departments.* I would recommend that they recognise the interdepartmental nature of this service and make information available properly about the new service. This would include public advertisements, but also outreach work at grass-roots community level in a range of geographical and socio-economic communities. Use the many networks available, from local community development groups to Women's Institutes to sports clubs to carry the information. Ensure that it is accessible in terms of language and format. Consider how users and carers can assist in being advocates and ambassadors for this approach, on their own terms.

The value of such work would be enormous and would represent good value for money, since 'buy in' to the service would inevitably reduce hospital admissions and, therefore, save more money than it is reckoned is being spent on initiatives like the Home Treatment Service.

11. *To the Assembly's Health committee and the Assembly departments.* That the potential of the Home Treatment Service as a working model of the multidisciplinary, partnership, user focused approach advocated by Bamford, Professor Roy McClelland and others be examined and acted upon as a matter of urgency

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Appendix B: Research on hospital admission rates

Smyth (, op cit, pp.20-22) offers an annotated bibliography of the history of research on hospital admission rates, dating back to the 1930s.. An emergency domicillary service was established in Amsterdam. About 50% of the acute presenting cases could continue to live in the community. Carse, 1958 reduced admissions by 40% in Worthing. Scott, 1980 London, avoided 270 admissions per year., Hoult and Reynolds, Sydney, Australia reported that 60% of the cases were managed at home. Burns, 1993, focusing on suburban London, reported significantly less admission.

Early research in America – as far back as 1980 - suggested that home treatment greatly reduced the need for hospital admission and 'enhanced community tenure. (L I Stein and M A Test, 1980, 'Alternative to mental hospital treatment, 1. conceptual model, treatment program, and clinical evaluation,' Archives of General Psychiatry, vol 37, no 4, unpaginated.) When the special programme was discontinued, many of the gains seteroirated and the use of hospital rose sharply

A later British study, conducted in 2002, comparing reduction in hospital days in America and Europe concluded that American patients in' experimental services' seem to spend no fewer days in hospital,' implying a disparity in control services' (T. Burns, H Watt, C Wright, M Knapp, J Henderson, 2002 , ' International differences in home treatment for mental hjealthj problems: results of a systematic review.' *British Journal of Psychiatry*, 181: 375-382

Orme and Cohen rightly interrogated the available research in 2001 by drawing attention to a number of problems including the difficulty of comparing a wide range of services which could come under the rubric of home treatment, the issue of sustainability in admission reduction, referral criteria, and other factors such as the impact of HT 'gatekeeping' at the discharge end as well as the admission end (S Orme and B Cohen, op cit, p.56).

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No significant difference was reported by T Burns, M Knapp, J Henderson, 2002, 'International Differences in Home Treatment for Mental Health Problems' *The British Journal of Psychiatry*, 181: 375-382

The REACT study was conducted in 2006 by H Killaspy, P Bebbington, R Blizard, S Johnson, F Nolan, S Pilling and M King, 2006 ('The REACT Study: randomised evaluation of assertive community treatment in north London.' *BMJ*, 332:815-820 (8 April). This concluded that there was no significant differences in inpatient bed use or in clinical or social outcomes between patients treated through community mental health teams and those who availed of the services of assertive community treatment teams

A Daly, 2007, 'Re-admissions to Irish Psychiatric Units and Hospitals, 2001-2005, DCU, Health for Life conference paper reports the insignificant impact of community services. But the scale and delivery models of Home Treatment in Ireland would have to be factored in.

Self help programmes are reported on by L Burti, F Amaddeo, M Ambrosi, C Bonetto, D Cristofalo, M Ruggers, M Tansala, 2005, ' Does Additional Care Provided by a Consumer Self-Help Group Improve Psychiatric Outcome? A Study in an Italian Community Based Psychiatric Service. *Community Mental Health Journal*, 41 (6), 705-720. No significant difference in hospital admission rates is the finding..

A reduction of 37.5% was reported by K Jethwa, N Galappathie, P Hewson, 2007, 'Effects of a Crisis Resolution and Home Treatment Team on In-Patient Admissions', *Psychiatric Bulletin*, 31: 170-172)

Home management of 54% of people with first episode psychosis was reported on by R Tomar, N Brimblecombe, G O'Sullivan, 2003, ' Service Innovations: Home Treatment for First Episode Psychosis, *Psychiatric Bulletin*, 27: 148-151) .

Appendix C: Training/ learning programmes

Heath, op cit p.126 refers to an implementation tool kit

Illness self-management strategies are reported on by. K. Mueser, P Meyer, D Penn, R Clancy, D Clancy M Salyers, 2006, 'The Illness Management and Recovery Program: Rationale, Development, and Preliminary Findings'. Schizophrenia Bulletin 32 (Supplement). Positive results

Schools based programmes are evaluated by G Noam and C Hermann, 2002, 'Where Education and Mental Health Meet: Developmental Prevention and Early Intervention in Schools.' *Development and Psychopathology*, 14, 861-875) RALLY programme

CAUSE and Carers UK and their counterparts in the Republic of Ireland do excellent and valuable work, but short, unaccredited one-day courses are simply far too limited in scope to be able to confer upon users and carers the range and depth of knowledge and skills needed to become real co-negotiators, partners in care. (Carers UK Training Calendar, www.carersuk.org/Policyandpractice/Training/TrainingCalendar. Accessed 28 August 2007).

Rethink's CESP. Is recommended by carers (See Smyth, op cit p.93,.

FRED Programme – enskillment as a tool for a power shift, Health 4 Life conference,

Recovery in Health module, FETAL level 5 (co-presence of users and providers)

IAN peer advocacy training – Paddy McGowan

Scottish Recovery Training Framework – mental health nurses and promotion of formalised peer support- Taryn Carlton, 2007, 'Promoting and supporting recovery: the Scottish model. DCU Health for Life conference paper), Collective learning – Shari McDaid, 'Redefining empowerment in mental health: the connection to 'power to' ' DCU Health4Life conference paper).

A Matthews, 2007, 'Foucauldian interpretations of risk, gender and power and gender in mental health nurses' descriptions of managing aggression and violence in their practice' DCU, *Health4life* Conference paper;

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L MacGabhainn, 2007, 'Discovering intercultural meanings and mutual understandings in a hostile place' DCU, *Health 4 Life* Conference paper

E Shanley, 2007, 'Recovery Alliance Theory: A Fresh Look at our common humanity' DCU, *Health4Life* conference paper

Western Massachusetts Training Consortium (Oryx Cohen) oral history work with 'psychiatric survivors – recovery model

Former patients who have been trained as Consumer in Australia. Seminar to Armagh and Dungannon Trust, reported in *Armagh Observer* 28 March , 2007

Appendix D: User research

British Council of Disabled People, 2002-2003, 'The Social Model of Disability and Emancipatory Disability Research.' Briefing document.
<http://www.bcocdp.org.uk/about/research.shtmj.l> Accessed 23/03/2006.

N Kotecha, 2007, *A Guide to User-Focused Monitoring: Setting Up and Running a Project*. London: The Sainsbury Centre for Mental Health.

O Cohen, 2005 'How Do We Recover? An Analysis of Psychiatric Survivor Oral Histories, *Journal of Humanistic Psychology*, 45, 3, 333-354

K Lynch, 1999, 'Equality Studies, the Academy and the Role of Research in Emancipatory Social Change'. *The Economic and Social Review*, vol 30, no 1 (January), pp. 41-69.

T Maginess, 2006, 'Are you mad? A Meta-analysis of an Emancipatory Research Project Undertaken by Service Users and 'Voluntary' Carers'. In *Inter-Cultural Perspectives on Research into Adult Learning: A Global Dialogue' SCRUTEA 2006 Annual conference proceedings*. Leeds: University of Leeds, pp.263-270.

T Maginess, ed.and the Out and About Project, 2006, *And Never Dared Ask: A Manual for Individuals, Families and Friends Affected by mental Illness*. Armagh: Out and About Project

C Barnes, 2001, 'Emancipatory' Disability Research: Project or Process?.' Glasgow: Public lecture

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http://edf3.gallaudet.edu/indev/www/Images/Emancipatory_Research_Barnes.pdf;

M Oliver, 1997, 'Emancipatory Research: Realistic Goal or Impossible Dream?' in C. Barnes and G. Mercer eds. *Doing Disability Research*. Leeds: The Disability Press.

J Tew, 2003 'Emancipatory Research in Mental Health'. SPN Paper 4, http://www.spn.org.uk/fileadmin/SPN_uploads/Documents/Pspers/SPN_Paper/SPN_Paper_4.pdf , 23-27.

J Walcraft, 2003, 'User focused research' *SPN Paper 4*, op cit, 3-4,31-38. Accessed 28/03/2006.

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