



Inaugural SANE Australia
Hocking Fellowship Report 2014

by Sonia Neale



Acknowledgements

I would like to heartily thank SANE Australia and the selection committee, Kylie Griffin, Dr Kathryn Strasser, Melinda Snowden, and Jack Heath for their unanimous decision to award myself the inaugural SANE Australia Barbara Hocking Fellowship 2014. As well I'd like to thank Barbara Hocking herself for her encouragement and support. This has been a unique, timely and magnificent opportunity to enable me to study and research organisations, services and programmes overseas to find out what works for people suffering from borderline personality disorder (BPD).

I would also like to thank my gorgeous husband and my children who have loved, supported and healed me throughout my most unwell years. I am most grateful we were all able to stand together as a family united.

There is also one other person who was integral in my recovery. Since 1996 I have had only one therapist, Jennifer Wright of Chelsea Psychology, Nedlands, Western Australia, a nurturing, supportive lady who has been able to tolerate my highs and lows during some very trying times always maintaining her grace and dignity. She never once gave up on me and thanks to her loving/kindness I am now able to accept all the challenges life presents me. It is the therapeutic relationship that heals.

I hope this report and the subsequent work I do for SANE Australia goes a long way to alleviating the stigma, discrimination, lack of support services, lack of inexpensive and accessible therapy that people with BPD currently suffer from. My over-arching vision is to see that Borderline personality disorder will be seen by the entire mental health industry as a treatable and recoverable mental illness and therefore will no longer hold the distinction of being a diagnosis of exclusion.

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NAMI Conference, DC Washington, USA
NAMI Connections Recovery Support Group
Sarah O'Brien, Programme Manager

Relevance for Australia: I would like to use parts of NAMI Connections Recovery Support Group as a general template for a BPD friendship/self help/support group.

Description and structure: NAMI Connections is a weekly recovery support group for people living with mental illness in which people learn from each others' experiences, share coping strategies, and offer each other encouragement and understanding. The idea is that people in the Recovery Support Group feed in from the Peer to Peer Education programme. At present, there can be anywhere from 2-15 people attending for 1.5 hours per week. There are several affiliate groups in each state of USA. There are group guidelines and principles of support and when issues, contentions, personality clashes or problems arise the group is quickly brought back to these. People can also create and add personal guidelines relevant to their situation. The group is run by two facilitators. The people in the group work hard on recovery, not just caring and sharing. **The group must be structured and manualised as this keeps the group cohesive.**

Evidence base: Pre and post surveys to find out what people with BPD want in a support group. This is always flexible and ongoing.

What works: People are connected and united and have a safe place to discuss their situations and bounce ideas off each other. Group guidelines keep the group cohesive and safe. Facilitators are there to direct the group and do not share as this takes time away from the participants.

What doesn't work: Contact outside the group is discouraged for the reason that if a crisis occurs, hotline numbers are to be used instead of ringing vulnerable group members.

Risk Management: At date of attending the NAMI Conference, September 2014, there have been no dangerous situations. However, as emotional issues can and do arise, two or more facilitators are needed so one facilitator can stay with the group and the other can attend to the individual. In a case of dispute or disharmony all parties are listened to and validated, everyone's viewpoint is relevant. The focus of these groups is a culture of positivity, staying in the present moment, not delving into childhood

or dwelling on past events. Diagnosis is not relevant (this is covered in Peer to Peer Education). There is a brief check in and time limited sharing around the group. Themes and trends that arise from this sharing are drawn out and addressed by facilitator in a generalised and safe context. The idea is for people to feel better upon leaving than when they arrived.

Challenges: Getting people to attend. Ensuring vulnerable people in the group are safe and contained and that their contributions and stories will be honoured and validated without judgement or criticism. People without transport can find public transport sporadic or difficult to use. Arranging private transportation between participants overcomes this. Sometimes facilitators can become mentally unwell, have their own issues or need a temporary or permanent break. This is where the co-facilitator takes over. Sourcing buildings and funding for promoting and advertising the group can be difficult. Social media and networking could be used.

Training for facilitators: NAMI provides a two day facilitator training focused on de-escalation of situations, group dynamics and role-playing.

Relevance and Action for Australia: These groups provide a framework of safety, context, connection, validation, sharing of stories, resonance. Sharing of contact details and contact outside the group is not encouraged within Peer Connections Recovery Support Group but is within Peer to Peer Education Programme. However, this could be negotiated as past experience suggests this has worked with no adverse consequences.

Contact Connect groups, Uniting Care West, Merriwa, Louise Howe (Mental Health Commission Peer Advocate) for funding, headspace and Recovery Network Centre with the intention for partnerships and to hold group meetings there.

Logistics: Hiring a building/library/community hall, administration, record keeping, advertising and promotion, providing tea and coffee, setting up resource library, stipendiary payment to facilitators.

NAMI Peer Funding: (National Institute for Mental Health) NIMH Funding does provide limited funds, as well is also supported by pharmaceutical company, AstraZeneca. The service is however mainly run mainly by volunteers and there is no charge to participants.

Lessons and Learnings: The main objectives are getting people to attend and keep coming back, making the groups attractive to people who are isolated, disconnected and vulnerable. Facilitators, consumers and peers do not always agree on what content is beneficial, ie technical language -v- accessible language, outside contact -v- no outside contact. Ongoing discussion and negotiation is needed in these areas.

Outcomes for the future: Surveys, articles and evidence based research to show proven outcomes to government, funders, patrons and sponsors that these programmes work and that people benefit from them, in order to create further and consistent, reliable funding for more groups.

NAMI Conference, DC Washington, USA
NAMI Peer to Peer Education Programme
Sarah O'Brien, Programme Manager



Relevance for Australia: To have a psychoeducation programme part based on Peer to Peer Education run by BPD peers for BPD consumers with the possibility of eventually targeting non-government organisations, substance abuse services, emergency departments, psychiatric facilities, prisons, courts, women's groups, men's groups and disability services.

Description and structure: This is a recovery-focused educational program for adults who wish to establish and maintain wellness in response to mental health challenges. The service provides information on the brain, mind, mental health and wellness, recovery tools, coping strategies and focuses on activities, personal stories and discussion. The ten week course provides critical information and strategies related to living with mental illness. Each week builds upon itself so attending all classes is crucial. They do have a flexible nature and are provided either on a weekend, weekly or twice a week.

What works: Getting people out of their homes to meet new people. It can be a two way learning process as the mentoring role is a giving and a receiving one. Getting the satisfaction watching consumers become facilitators and gaining the confidence to talk to other participants. As social media can be isolating and addictive this service ***gets people in real relationships rather than online ones.*** A goody bag full of resources is given out containing lists of books, articles, DVDs, schedules of other groups, hotline numbers, a relapse prevention chart and a contact list so people can get together for post programme lunches, friendship etc.

What doesn't work: Some people feel the data forms are too technical and need to be kept simple and relevant. Others prefer formal medical language taught so people can understand what their doctors are saying. **It was felt there needed to be less reading out from handouts and more research on finding out why people do not return.**

Survey for Improvement-Learning Outcomes Workshop at Conference

- Discussion was around hugs versus no hugs (this is a boundary issue - touch can be traumatising for people who have experienced sexual/physical abuse).
- There needs to be greater awareness of how body language is received by others such as unbroken eye contact, body odour and smells which can trigger flashbacks.
- Facilitators need to rehearse material before presentations so it does not sound stilted.
- There was discussion around advanced medical directives /crisis plans, the teaching of the science of illness and science –v- emotions connection.
- People were divided on whether hard copies of information –vs- electronically should be available or via the website.
- People felt physical attendance was better rather than webinars and programme as this is relationship based, however travel and distance issues for rural and remote places were noted. Conference calls/ skype could be available for this (visual cues are then available for better communication and connection).
- Termination is an ongoing issue because people find it hard to deal with ending the programme. After ten weeks it can be traumatising for some and therefore post programme contact was talked about.
- **More fun was needed with a greater sense of humour.**

Risk Management: Two facilitators, house rules, policies and procedures must be in place.

Challenges: Retention rates for consumers and facilitators. When people leave or are missing, perhaps phone calls for clarification on what happened or why they are not coming back. A larger initial intake of participants is needed for retention rates because a certain number of people are needed for group dynamics to occur. Peer to Peer Recovery Support and Peer Education needs to overlap so some people can attend both services.

Logistics: Hiring a building/library/community hall, administration, record keeping, advertising and promotion, providing tea and coffee, setting up resource library, stipendiary payment to facilitators

Funding: This is the same as Peer to Peer Recovery Support Groups.

Objectives: One of the objectives is for consumers who attend the group to become facilitators and expand the number of programmes throughout targeted areas. Ongoing discussions and negotiations about what works best is crucial to success. People differ on their expectations of the educational content of the group. This must always be flexible and everyone needs to have a voice on this. People who attend the group need a sense of connection, trust, community and belonging. The goal is for people to leave at the end with a sense of hope for recovery and self-worth and that personal goals are achievable. For people to know where they are going and where to from here. Follow up support is required and must be ongoing.

Outcomes: Surveys, articles and evidence based research to show proven outcomes to government, funders and sponsors that these programmes work and that people benefit from them, in order to get further funding for more groups.

BPD Presentation on New Research into Adolescent BPD
Blaise Aguirre MD, Assistant Professor of Psychiatry, McLean Hospital
and Harvard Medical School, Boston, and
Alec Miller PsyD, Professor of Clinical Psychiatry and Behavioural
Sciences, Albert Einstein College of Medicine, Bronx, New York



**National Education Alliance for Borderline Personality Disorder (NEA-
BPD)**
NAMI Conference DC Washington
Special Interest Session
Dr Perry Hoffman, Joy Sprague NEA-BPD Liaison, and
Amanda Smith LMSW



As part of the NAMI Conference in September, Dr. Blaise Aguirre, Assistant Professor of Psychiatry and Dr. Alec Miller, both Directors on the Scientific Advisory Board of NEA-BPD, gave a presentation on new research for adolescents with BPD recommending that diagnosis and early intervention is essential for recovery.

At a special interest session, delegates from NEA-BPD gave an information session on their services and DBT principles and how to improve communication between clinicians, family members and consumers. I was asked to be part of that delegation and share my story with the audience, who said they loved hearing my Australian accent. NEA-BPD were instrumental in getting the US Congress to

recognise May as BPD Awareness month as a means of educating the general public about BPD. The Australian BPD Foundation has also worked hard towards having similar legislation passed. This occurred earlier this year and from now on, the first week in October is BPD week.

<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansards%2F4630d1fc-e7c9-4b04-8c13-d1aa918c703f%2F0083%22>

The presentations I also attended at the NAMI conference were: Using DBT's core mindfulness skills to resolve conflict by Dr Shari Manning. I was also invited to the Family Connections Leader Gathering.

Kevin Dawkins
Film-maker of five part series
'If only we had known: A family guide to BPD'



I met Kevin Dawkins at the NEA-BPD stand at the NAMI conference. He is a film-maker who has made a five video series of DVDs, Understanding BPD, Causes of BPD, Diagnosing BPD, Treating BPD and Coping with BPD. The first DVD is free and the second DVD I won as a result of putting my business card in a jar and having it drawn out first. I found a connection with Kevin in bird photography and documentary making. Kevin has also very kindly said he will donate the other three videos, as he is aware I work for an NGO with limited funding. These can also be purchased at www.bpdvideo.com.

Kevin is also making a documentary about Marsha Linehan called, *A Life worth Living* which unfortunately is on hold at the moment.

Dr. Jacqueline Simon Gunn – author and psychotherapist New York



Through my blog at Psych Central I was asked to review a book titled, 'In the Therapist's Chair' written by a psychotherapist about her clients on how psychotherapy works in relation to the therapist. Her book includes several case studies and gives a compelling insight into the psychotherapeutic relationship. <http://psychcentral.com/lib/in-the-therapists-chair/0004074> Having been in a long term relationship with a therapist I found this insight fascinating with many parallels to my own situation.

Dr. Simon Gunn has written another book, co-written with Carlo DeCarlo, and has asked me to review this one as well. Called 'Bare: Psychotherapy Stripped,' again it draws on case studies from her own practice. Here is my review. <http://blogs.psychcentral.com/being-borderline/2015/02/bare-psychotherapy-stripped/>

She has also written in conjunction with Brett Potter a third book called 'Borderline Personality Disorder, New Perspectives on a Stigmatising and Overused Diagnosis.' Dr. Simon Gunn provides the clinical perspective on BPD. She is also currently writing a novel.

As an author of two books and numerous articles myself, I met with Dr. Simon Gunn for lunch in New York and we spent a fascinating afternoon discussing literature, psychology and personality disorders.

Treatment and Research Advancement Association for Personality Disorder (TARA-APD), New York
Valerie Porr, MA, Founder and Director



Relevance for Australia: To create an international partnership and bring the TARA Method to Perth by inviting Valerie and business partner to Perth to train the trainer for select people who wish to help disseminate this proven, workable programme for families, spouses and carers.

History: Valerie Porr, creator of TARA-APD (Treatment and Research Advancements Association for Personality Disorders) and writer of the book, 'Overcoming Borderline Personality, A Family Guide for Healing and Change', said she initially attended a lecture by Marsha Linehan (creator of DBT - Dialectical Behaviour Therapy) DBT in the Nineties. She was so impressed she set up a conference to introduce Marsha to New York medical and psychiatric professionals. TARA-APD was the first organisation to focus exclusively on BPD. Valerie teaches a combination of TFT (Transference Focused Therapy), DBT and MBT (Mentalisation Based Therapy), Fonagy and Bateman. The TARA Method focuses on all members of the family and does not blame the victim, especially the mother. Her book aligns with her workshops and uses specific tools and strategies focussing on validating the family member with BPD. She also focuses on neglected siblings. The aim of her programme is to create new learning experiences and teach clear nuanced communication aimed at validation, acceptance and change. Valerie has a family member with BPD.

Evidence Base: TARA works on the theory that BPD is a neurobiological, genetic and temperament based illness. TARA does not believe BPD is caused by attachment issues.

Description and structure: Part of The TARA Method involves teaching a Family Survival Skills workshop that normally runs for eight weeks or, as I attended and observed, an abridged one weekend

course (Sat and Sun 8.30am – 5pm) based on psychoeducation and support for parents, spouses and other family members of people with BPD. People with BPD do not attend this workshop. The room is reasonably informal, with an instruction manual for the parents. A projector and power point slides are used as a learning resource. This is not a warm and fuzzy, touchy feeling caring and sharing session. This is a communications workshop designed to impart skills, tools and strategies in the art of subtle and nuanced communications skills needed to engage their loved ones effectively. There are exercises and homework. Anecdotes are not encouraged during the learning process as this can detract and diverge.

The Family Survival Skills Psycho-education Workshop consists of eight parts

- 1 Introduction to TARA – neurobiological aspect of BPD
- 2 CBT changing behaviour and emotions
- 3 DBT mindfulness
- 4 Validation
- 5 Practice validation – family letters (The Secret Life of Pro-Nouns) Writing ‘I’ stories
- 6 Radical acceptance – grief to hope
- 7 DBT skills
- 8 Putting it all together.

What works: Valerie is up to date with latest research on BPD. The first part of her workshop gives detailed explanations of neurobiological underpinnings (amygdala –v- pre-frontal cortex, fight, flight and freeze). She emphasises that the parents or spouse is not to blame, that there is a genetic and biological sensitivity which added to environmental factors, such as emotional invalidation, creates the conditions for BPD. There are also explanations of deficits in memory and information processing which affects social skills, learning experiences and consequences. She teaches participants a new emotional language as she believes alexithymia (with both parties) is part of the language/communication deficiency. She stresses parents need reliable, straight information without ambiguity or a psychodynamic component. She does not teach attachment theory and stays mainly in the present moment.

What doesn't work: Blaming the person with BPD and/or the parents.

Rationale: Designed to bridge the communication gap between parents and children in order to stop challenging behaviours, such as self-harming, suicidal behaviour and substance abuse. Valerie helps

the parents to experientially feel both internally and viscerally the shame and self-loathing that Borderlines feel. It is designed to help parents understand the intense pain and distress people with BPD feel. The method was designed to help relieve the stress and pain of people with BPD, rather than feed and nurture the parent's frustration, rage and helplessness. The focus is not on the parents but on the Borderline

Risk Management: There is the possibility of some emotional dysregulation of participants. However none of her participants have a BPD diagnosis. People with BPD are not encouraged to be part of this workshop. There is a separate workshop she conducts that addresses the person with BPD's needs.

Challenges: Educating the professional community, the general public that this is a biological illness and not bad, bratty behaviour, funding for training in the TARA Method in Australia and stigma within the mental health industry. Finding people willing to be trained as this is a large commitment. This can be overcome by advertising, promoting and networking. Instilling the non-blame solution focused approach and getting the communication process through at a visceral, body-felt level (participants need to feel in a safe way the shame and self-loathing)

Outcomes: Families will feel less guilty about their loved ones. They will have more hope that this is a treatable and recoverable illness. Better understanding of and greater validating communication leading to less self-harming, reduced or eliminated suicidal gestures/ideation/completed suicide. Essentially this leads to families functioning more effectively and having a better quality of life.

**The Haven Project
Colchester, UK
'A Brick Mother with a Brick Family'
Dr Heather Castillo, ex-CEO, now retired
Pernille Petersen MBE, Chief Executive
Ines Hunns, Service Manager for Day**



History and Background: In 2003, the National Mental Health in England wrote a report titled 'Personality disorder: No longer a diagnosis of exclusion,' a policy implementation guidance for the development of services for people with a personality disorder. As a result of this document, funding for eleven different borderline personality disorder-oriented service pilots was initiated. The Haven Project, Colchester was one of them. The Haven is a brick building with both crisis and day services. The house is an 18 room old rectory with several crisis beds, a 24/7 crisis telephone line, taxi vouchers for quick crisis response. There is also several respite beds which need to be planned in advance and people can stay for up to two weeks. There are weekly therapy and group programmes. The Haven is a Community Interest Company rather than a charity, so they are restricted in whom they can apply for funding from but this has made the service and paperwork easier to manage.

Description and Structure of Day Services: These include DBT skills group, counselling service, client computers skills group, creative writing group, addiction workshop, healthy living group, friendship group, welfare rights advisory service, arts and crafts, gardening group, outdoor well-being, family and carers group, advisory group, massage and trauma reduction therapy, reflexology, walks, outreach visits, yoga, life skills group, and a transitional recovery group. There is also ongoing staff training (Knowledge and Understanding Framework) which is a three day DBT skills course held on non-consecutive days. <http://www.suffolkmind.org.uk/personality-disorder-training.asp>

The Haven is an alternative to emergency department presentation. It is a wrap around service which means everything needed for people with BPD is at the Haven; it is a unique and complete service. One to one counselling goes on till 11pm for working people. The Haven meets the client needs rather than the client fitting in with the Haven. There are community discussions, new people have all boundaries, sanctions and transgressions explained to them. There are 24/7 staff and a 24/7 crisis line, one line, one text phone. This is for registered clients. There are approximately 10 contacts each night

Relevance for Australia: To use The Haven Project model to set up a similar house with wrap around services in WA. The only service similar to The Haven Project in WA is the Open Borders programme at Hampton Road Services in Fremantle.

Evidence and theory base: John Bowlby and the secure base and attachment theory. The Haven is a secure base that clients, who have never had one before are able to engage with.

How to register for the Haven: Service users need to be registered before they use the service. There are approximately 180 registered users at The Haven. When people register, information is given and a support plan is made. People then go home and the Haven calls back later to see if they are ok, this creates a connection. However, when they come back they see another person (creates connection with many people rather than an attachment to one). Rarely do people not come back, but some register and stay registered as a safety net but do not engage. People stay in crisis beds one to two weeks, rarely more as the Haven tries not to create a dependency. Some have just one or two nights as this meets their immediate needs. Crisis beds are met during anniversaries, birthdays, Christmas, loss, grief, bereavement, separation, family issues, financial strains, mood changes and/or medication changes. There is a 98% engagement of service users in day therapy and ongoing engagement is very high. There is an open notes policy and people are able to access their files at all times. There is an acceptable behaviour policy leaflet available.

What works: Dr. Heather Castillo wrote a book in 2003 called 'Personality Disorder – Temperament or Trauma?' <http://www.amazon.co.uk/Personality-Disorder-Temperament-Emancipatory-Diagnosed/dp/1843100533> which is an emancipatory research study carried out by service users diagnosed with BPD. It looks at the classification and treatment of BPD from the perspective of the users themselves. The template for The Haven was based on this client survey which was conducted by four people with a diagnosis of BPD who asked 100 people what they wanted from service

organisations. This book contains the survey and my plan is to conduct the same or a similar style survey and use this as a guideline for direction in the creation of a one stop service similar to the Haven Project.

Service users are part of the fabric of The Haven. It is a service user driven service. All decisions are made by the community including acceptable behaviour policies. Clients also have full access to their records. Staff are allowed to talk about themselves (self-disclosure) within reason. There is a positive culture focus and negative talk is highly discouraged by the service users themselves.

Art work is displayed throughout the house giving a sense of homeliness, community and belonging. Anyone can paint something and hang it on the wall. There is also great benefit having a community pet. The Haven has a live-in cat. The community takes care of the cats needs. The Haven has a very homely, comfortable, lived-in, non-clinical, non-medical, non-sterile feel to it.

What doesn't work: Some clients have displayed active suicidal behaviour and self-harm on the premises. There are stepped consequences from the therapeutic community for this and meetings are held where other service users make the decisions on what punishment will occur.

Paperwork: The Haven has a Client Registration Form, Activity Disclaimer, Care Pathway Record, Acceptable Behaviour Agreement and a short term support plan.

Risk Management and OHS issues: Based around Acceptable Behaviour Agreement. Heather Castillo, previous CEO of The Haven Project (now retired) said that risk management is always at the forefront of her mind. The Haven operates under the umbrella of risk management and OHS ***at all times***.

Ines Hunns, Service Manager for the Day said that there are annual health check-ups for staff – especially night staff. There is also monthly line manager supervision and clinical (psychologist/counselling based) external supervision. The Haven is based on a culture of trust. There are incidents very occasionally where the Haven is not able to contain emotionally dysregulated clients, perhaps 3-4 times per year and then outside help is sought. The Haven provides, according to Ines Hunns, Service Manager, a service 'so solid, clients can pull on it in times of crisis.'

Acceptable Behaviour Agreement: If a client transgresses group therapeutic community (TC) boundaries, they can be excluded either for a period of time or permanently. If permanently they still have the right to approach for an appeal to the TC, and prove to the community why this won't happen again, what steps they have taken and how these changes have been made.

Challenges: There is a two year waiting list with approximately 100 people currently waiting. Only two to three clients per month are added. Clients are self referred or by MH Services, housing services or families.

Some of the most challenging situations faced involve attachment issues. These are addressed by modelling healthy attachments by the staff. There were some escalation issues and one minor potential stalking issue. The Haven emphasises it is crucial to have a supportive, tight-knit team, which includes ongoing supervision, team meetings with a team inclusion approach, not an individual one.

Staff: The average length of employment at Haven is seven years. Ines Hunns, Service Manager for the Day has worked there for ten years. The Haven workforce has a 10-20% peer workforce. The Haven staff do not make any medication decisions.

Family Focus: There is a monthly afternoon support group (which is under used) where concerned family members can speak to staff on a one to one basis.

Funding: The Haven lost their funding two weeks before I visited. The Haven was initially part of eleven BPD focused pilot projects funded by the NHS. This pilot funding was initiated because of the release of a document by the National Institute for Mental Health in England, titled 'Personality disorder: No longer a diagnosis of exclusion.'

http://www.candi.nhs.uk/_uploads/documents/miscellaneous/pd_no_longer_a_diagnosis_of_exclusion.pdf

There was a campaign (Change.org) to have the funding decision overturned. Local MHS want to close The Haven as they feel it does not reach enough diagnosed people and want a service that is wider reaching and covers the whole county rather than just a part of it. Local MHS want a new model in a new area. An option is to have it part commissioned by Social Services and it will be a package that clients can 'buy.' Or it can be commissioned from other funding sources such as Lotteries. Clients are being made ready for total withdrawal of services. There is parallel planning with this as full service

however funding runs out in February, 2015. There is a directed service (Social Inclusion Transitional Recovery) run by the Haven, to address client's attachment issues with the Haven to alleviate concerns and fears about the withdrawal of funding. This is focused on resilience and recovery.

The Local MHS Funding body commissioned an independent company to compare services. **Enable East** document was presented which was a review of services. The Haven compared very favourably in the report. I have a hard copy of this document.

Update: I received an email from Dr. Heather Castillo on 16/12/2014 confirming the Haven will close its doors on 13th February 2015.

Lessons and Learnings: I was advised it would be best practice to buy a house rather than rent. It was also advised to plan for endings in case of funds withdrawal. For media presence and destigmatisation of BPD, if at all possible enlist a celebrity willing to disclose a BDP diagnosis. The Haven did mention that they only pursue media contact when something positive happens.

Outcomes: Less emergency department time as registered clients will phone the Haven rather than go to hospitals. Greater employment opportunities, which means less taxpayers dollars for disability support pensions. People who are recovered will have more opportunities for further education and more fulfilling community involvement. Families of people with BPD will be able to engage more with their diagnosed loved ones.

Making it happen: Monique Williamson, CEO of The Mental Illness Fellowship of WA, in Midland has expressed an interest in involvement in creating a Haven Project. I have organised a group called the WA Haven Interest Group with several people interested. In May this year, 2015, we will have a meeting to design what the Haven will look like. In the future I hope to have meetings with the Mental Health Commissioner, Tim Marney and Minister for Mental Health, Helen Morton to discuss the future of the WA Haven. I will be pursuing funding opportunities with Lotteries West as funder for the brick building and the Mental Health Commission for funding for staff and programme requirements. There is also the issue of finding the right house in the right location that is zoned to suit our purposes. There could be formal complaints from neighbours who have objections to being in the vicinity of a crisis/safe house.

Suffolk Waves, Ipswich and Bury St. Edmunds UK
Claire Sims, Community Worker
Becky Attwater, Peer Worker
Kobe Borich, Community Worker



Relevance for Australia: To have a day service drop in centre similar to this at the Haven WA, where people can meet and talk, participate in lifeskills groups and other activities and one on one counselling.

History: Ipswich Waves and Bury St. Edmund Waves – both going since August 2013. Previously Ipswich was a monthly evening group.

Evidence base: The programme has its roots in attachment theory.

What works: Having a Three Tiered Tool Box (similar to fishing tackle box).

Top Layer – text/email someone, chocolate, food, DVD, memory stick with pictures, uplifting songs, photos, pets, friends, family (if safe), cards, positive quotes (grounding), perfume soap, sensory items, massage oil, self-soothing, list of distractions, books, dog lead, bubble wrap, stress balls.

Middle Layer – Alternative ways of self-harm, red pen, elastic band, red ice cubes, Tabasco sauce for dipping finger in, duct tape wound tight around arms.

Bottom Layer – Anti-septic wipes, clean blades, steri-strips, band aids, needle and thread, cotton wool.

See website: www.recoveryourlife.co.uk

Family and friends are very important, families are glad loved ones are getting help, they are trying hard to understand and staff are great at explaining what is happening to them. Monthly meetings are held with family and loved ones.

Valued aspects of Suffolk Waves include having freedom of speech. ED and MHS staff are not as understanding as Waves staff. **MHS have focused, time limited and goal oriented services.**

Waves is open-ended and people work at their own pace.

Marie: *'I don't get judged on being a carer of a person with BPD.'*

'Tell honestly (what is happening) without people freaking out or jumping to conclusions.' *'You wouldn't know who is staff and who are clients. No lanyards, no 'Psych Nurse' lanyard when taken out to shop at Tesco's.'*

Teresa: *'I've lost every service support due to cutback changes during a difficult time. I have two daughters, one with BPD and another with MH issues. Life is stressful. I did not feel like I was alive, I did not socialise, I was too scared to come here (Suffolk Waves). I came to look around, I panicked, didn't want to know but came and tried. I feel safe, I trust the staff, but I don't trust hospital staff.'*
'Life skills and DBT gives me different things to think about, as does tapping, creative writing and drama. I try everything and have persuaded others to give it a go.'

Andrew: *'People listen, there is a good balance here with life skills, can learn to be objective, can interact with other people, have social time in the afternoon, all important stuff happens in the morning and can wind down in the afternoon. Human beings are social animals and if isolated can feel frustrated and angry.'*

'People listen and respect you here and you don't want to burden others (people in your life).'

'Life skills lead to experiences in the room, you can have a mini epiphany, it gets you in touch with yourself, the positive part, it makes sense of your illness, looking at it slightly detached in an observing way.'

Julie: *'No support quite like it. Nobody judges you, talking to others you are not on your own.'*

Gemma (Community Representative): *'You learn from each other, not just the staff, this is more powerful. Mission Possible 2009 increased my confidence, turned my life around, allowed me to do things outside Waves, the drama sessions and acting helped work scenarios out, similar to role playing.'*

'I made friends, Wednesday is a lifesaver, a structure to my week. It is the one place to be yourself.'

What doesn't work: ED, NHS mental health services and psychiatric nurse visits. Service Users who do not comply with the acceptance behaviour policies. Clients who do not use positive language or embrace the positive culture or have boundary and limits issues can present major problems.

Description, Structure and Content: *Creative Writing (5 weeks – special funding)* – free writing, ten minutes given on a topic. This is for enjoyment, relaxation and fun. People can read out what they wrote for the comments of facilitator and participants. The facilitator describes how the person has written, what stands out, is it written in 1st or 3rd person and why. There is much colour and detail in writing. Strong descriptive characters are important. Details are also very important; it is what makes you want to read on. People have choice to read out or not. Questions are asked, what do you want from creative writing? Books are used to facilitate the creative learning process. One creative writing exercise is: Song titles, write a piece on first song title or on 'fur, feathers or fin.' Cards are handed out with a picture on and write what you think this is all about or what it means to you. There is a collection of cards to draw from. People are taught to observe and comment, the more you observe the more you can see and decipher (great for mindfulness skills.)

Life Skills Programme 2012 – This is a living programme. Surviving Christmas was added in by the participants.

Introduction

- 1 Physical relaxation
- 2 Anxious thoughts
- 3 About self-harm
- 4 Understanding eating distress
- 5 Understanding addictions (see notes)
- 6 Assertiveness
- 7 Confidence building
- 8 Understanding anxiety
- 9 Dealing with anger
- 10 Understanding relationships
- 11 Managing your time and routines
- 12 Managing finances
- 13 Understanding sleep difficulties

- 14 Positive solutions
- 15 Haven Recovery Programme Part 1
- 16 Haven Recovery Programme Part 2
- 17 How to survive Christmas
- 18 Life skills feedback form

Other activities and Events: One on one counselling is provided. Also included (funding dependent) yoga, dance, drama ('Mission Possible 2009' – script available), music (5 weeks, special funding). People wrote songs and someone sang, played guitar. CD was recorded in a recording studio. Card making, jewellery making (petty cash and community members funded), cake making, Wii, movie afternoon, loom bands, museum, walks, henna tattoos, healthy eating/fitness (5 weeks, special funding) and paper mache. Ideas for the future – photography, community art (funding needed), visit to Mersea Island. Visiting charity shops for art and craft. These all come from small pots of funding – art grants. Funding - 'scrounge, beg and borrow.' These activities are seen as clients coming together to do something to connect.

Risk Management: Paperwork is important and includes a referral form, client and staff harassment policy and acceptable behaviour policy, weekly emotional needs audit. There were two small safety incidents at Waves. ***While risk management is foremost, so is dignity of risk.*** The community makes the rules, enforces the rules and instils the consequence based resolution. ***It is not about punishment but more about creating a safe place for the transgressor, the clients and staff.*** These rules are well respected and people have the right to appeal. Rules of acceptable behaviour and client and staff harassment policy guide these meetings. People state this works for them, they use the space wisely, feel safe and not judged, and use the service to better their lives.

Challenges: Personality conflicts, conflict management, people who do not abide by the rules set down by the Suffolk Waves community. There are rules and boundaries. Meetings are held to change what does not work, or for upholding rules and boundaries and instilling that there are consequences to impulsive actions. This is with client community involvement as well as staff. For people who break the rules there are consequences. Others speak about feelings when these rules are broken. People need and want to be in a safe place, but problems and feelings are not silenced.

Training for facilitators: Volunteers are a crucial part of Waves. Qualifications ranged from Community Support Workers to psychology degrees.

Catherine: *Qualified as an Occupational Therapist in 2009. Suffers from depression and was working in mental health, feels the Mental Health Service was not the right place for her, suffered from workplace bullying, retired from paid employment, became a volunteer because she wanted to use her OT skills. She says she is here for the clients, has one to one chats and helps with art.*

Marie says Catherine is always around, is good company, empathic, enquiring, has a good conversation that is not closed and not one-sided, it's nice to think she is being helpful and enjoys the social side of being with the clients.

She enjoys being with people, has a sense of purpose, it's her focus for the week.

Catherine says that the MHS wants counsellors to be a blank screen and that this is drummed into you.

Lessons and Learnings: The Suffolk Waves client community make the rules and hold meetings to decide outcomes for transgressors. This is empowerment at its best. There is no hierarchy in this situation and as a rule, this works well. Everyone is equal and everyone has a voice. Being heard in a safe environment and not judged or criticised is crucial in a BPD Community.

Outcomes: It was an honour to be accepted into this BPD Community for the day. The outcome is that people can share freely, and by sharing a connection is made. BPD is a disorder where there is disconnection with self and self and community. Some of the stories were painful to listen to, including one where a lady put a notice on the internet wanting people to come to her house and hurt her and she would pay them. This was very difficult to listen to but people in the room welcomed her sharing and empathised. Suffolk Waves is a place where people with BPD feel among like minded. General mental health services are not enough as people with BPD do have very special needs and requirements. Trust is crucial to recovery. Trust can only happen in a non-judgemental, safe, non-critical space and I felt that WAVES provided that space with their programmes and services.

**Mindfulness Based Stress Reduction
Massachusetts University – held at Wicklow, Ireland
Facilitators: Lynn Koerbel, Beth Mulligan and Anne Twohig**



I participated in a five day Mindfulness Based Stress Reduction course based on Jon Kabat-Zinn's teachings. This was held at the Glenview Hotel. Attending were 92 people from 27 countries.

Included were psychologists, psychiatrists, GP's, therapists, and financial advisors and business men. Everyone attending had a yoga mat which was their personal space for the five days. This is where we meditated, including standing, sitting, lying and walking meditation, as well as conducting self body scans, self massage and yoga.

For the first two days most people fell asleep during meditation until their bodies were relaxed enough to be alert. This was taken into account by the facilitators and by the third day we were encouraged to stay upright. That was when the real, more difficult work began. We were also told we may receive a gold nugget during this course.

On day three I felt quite miserable and felt heavy and drained. I was fed up with being on a yoga mat for eight hours a day surrounded by annoying people. We did sitting meditation and yoga all morning and I decided to approach my yoga practice in a different way. Instead of ignoring the pain and visualising sitting on a beach or in the mountains, I pushed myself into the pain and paid attention to it and what it might be telling me. I felt quite uplifted after that, as though I had made a breakthrough in emotional pain processing.

Each day we were asked to fill out a Pleasant Events Calendar on experience, awareness, body sensation, moods, feelings and thoughts, post event thoughts to gain insight into our level and ability for non-judgement, awareness and mindfulness. After each event, the facilitators checked in to see how we were doing as sometimes intrusive thoughts and flashbacks can occur. There were several silent sessions during communal mealtimes and one 24 hour silent period we were to remain silent and without TV or internet contact. This felt confronting and comforting at the same time. I had been interacting with others for four weeks in previous countries, and it was a relief to stay silent. Several times I wanted to leave the course. I was not alone, that is quite a common feeling, known as the tipping point. I experienced a lot of dialectical thoughts during that time.

Most people had physical and emotional pain releases, and many people cried. We were told we would have 'visitors', people knocking in our heads that we had unresolved issues with, and I was very grateful for my long-term therapy as this was not so much of an issue for me. I had shared my story during debriefing and found that people wanted to talk to me about my recovery and tell me about their journey. I was starting to like these people.

While I recall only five minutes of perfect meditation out of five days which is considered the average, it was enough to give me confidence that with practice it will increase.

We also conducted, in pairs, a mini therapy session where we role-played an event in our life (a non-traumatic one) and the other had to listen for content as well as body language and give feedback. That created much awareness of my coping skills and repeat patterns of behaviour. I was told that I gave away a lot of my personal power and that my demeanour did not reflect my experience. In other words, I smile and laugh when I tell a story that I should have made me angry. It occurred to me then that this was the nugget of gold I was told I may receive.

On the last evening, we were invited to an impromptu concert, where we could sing a song, read poetry or act out something from our country. I nearly did not attend because it was too confronting but I did and even got warmed up enough to get on stage (with two other Australians) and belt out Waltzing Matilda. I even got in an 'Aussie, Aussie, Aussie, Oi, Oi, Oi.' That evening cemented the warmth, companionship, sharing and connection of the entire course. I was now very sad to leave these amazing people I had become rather attached to.

Since that time I have been able to become more mindful more easily under difficult situations. I just picture myself sitting cross-legged on my yoga mat and my body anxieties seem to melt away leaving my mind fresh and alert.

**8th Annual National Peer Support Conference
International Association of Peer Supporters (INAPS)
Changing Times, Changing Profession
Atlanta, Georgia**



This conference ran over two days and was attended by peer support specialists who are advocates for peer support and peer supporters. INAPS reaches 4,000 peer supporters and numbers are continuing to grow. INAPS have developed national peer support practice guidelines and have plans for the development of the profession with the identification and description of core competencies and a model code of ethics. They are also part of the Recovery to Practice project resulting in the development of a recovery based curriculum. INAPS offers free webinars covering a variety of topics and has a monthly newsletter as well as providing information to governments, agencies and other peer organisations. Assistance is provided free and operates with a volunteer workforce.

This conference was fantastic for networking and gaining knowledge, ideas and experience especially learning how others work within the peer and recovery paradigm. As well, there were some very knowledgeable and informative speakers, including Larry Davidson, PhD, Yale University on the history of peer support and challenges for the future, and Larry Fricks, Peer Support Pioneer, 'Where we are, where we can go with whole health.' Anthony Stratford from Mind Australia gave an account on peer advocates in Australia and Anne Beales, Together from the UK, gave an account of Peer Support all around the world. Anne also put me in contact with Emergence Plus UK which is a personality disorder service user organisation <http://www.emergenceplus.org.uk> and has many valuable resources I will be utilising in the future including this manual (already passed on to people I work with) which is a comprehensive guide to challenges in services for people with BPD.

<http://www.emergenceplus.org.uk/images/Documents/meeting-the-challenge-making-a-difference-practitioner-guide.pdf>

I enjoyed the many keynote speakers, plenary sessions, presentations, talks, workshops and focus groups and in particular, had much empathy for Steve Ford, son of Gerald and Betty Ford, ex-president of the United States, who asked for confidentiality when telling his personal story of alcohol and drug addictions in his family. Money, fame and power do not the perfect family make.

Part of the wonder of conferences is speaking to people outside the schedule and listening to their stories of recovery. I was particularly interested in pet services. I saw many (very well behaved) service dogs and emotional support animals for people with mental illness and disability. Service pets are allowed in hotels and on planes as part of the anti-discrimination laws in the United States.

<http://www.nsarco.com/> In the future would like to see service pets in Australia.

I attended a presentation on 'Measuring Peer Group Efficacy' presented by Patricia McDermott, PsyD where she gave a power point presentation on evaluating the effectiveness of peer programmes. This will be most valuable for consumer and carer support groups to find out how they are running and ways to improve them.

**NEA-BPD informal gathering,
Atlanta, Georgia
Host: Susan Davidson**



One of the NEA-BPD Family Connections leaders and trainer, Susan Davidson, invited me to her house to experience some 'Southern hospitality.' There were several other leaders and trainers there, Bill and Jean Millkey, Dot Keith and Cheryl Davis, and they all very politely answered my curious questions as to their relationships to their loved ones with BPD. I found this quite refreshing and very enlightening as before speaking to these wonderful people, I had only my own experience to go by. Hearing other people's perspectives has opened my eyes and widened my knowledge of intimate relationships within BPD which will greatly enhance my communication skills with families of people with BPD within Australia.

Hope for BPD, Waco, Texas

Amanda Smith LMSW (Licenced Master Social Work)

Borderline Personality Disorder Support Groups



I met up with Amanda Smith, who runs Hope for BPD, Treatment Navigation and Support for Borderline Personality Disorder. Hope for BPD was created to meet the needs of individuals diagnosed with BPD who are often confused and overwhelmed by navigating therapeutic schools, short-term and long-term residential care, and outpatient treatment options.

Amanda also has a lived experience of BPD. In 2006, she served as the executive director of her local NAMI (National Alliance on Mental Illness) affiliate. In 2007, she founded Florida Borderline Personality Disorder Association dedicated to BPD education and awareness. Working on her own without help or support, Amanda found herself quickly overwhelmed and was unable to continue with the group.

She helped me understand what was *not* useful when running a BPD support group.

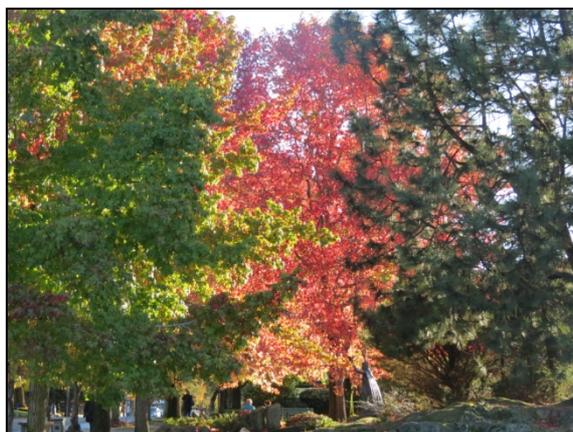
BPD Consumer Support Group	Pros	Cons
Venue	Use Local library/Community room	Cost, location and public transport availability. Not people's homes ever.
Tangible resources	Whiteboard, laptop for power point etc, butchers paper for brain-storming ideas	Cost. People may feel this is too formal
Attendance	Advertising and promotion. Meetup.com/gumtree/networking/social media	Cost.
Policies, Procedures and Insurance	Information page/house rules/crisis numbers. Policies and procedures Risk management. Mental Health First Aid/de-escalation skills training. Debriefing	No matter how much you plan for something, sometimes things can go wrong. Risk versus dignity.

	and safety at end of meeting. Self-care page with things that calm/soothe. People to help make house rules and policies etc which gives a sense of responsibility and ownership.	
Resources A short manual/booklet for information, group rules, what to expect from the group, weekly agenda and topics, psycho-education and simple homework sheets.	Specific information on what to expect from the group can be safe and containing. People have reference material for during the week they can refer to if overwhelmed.	Some may want a more informal atmosphere. The information may be too overwhelming, technical or scientific. Not everyone wants homework.
Facilitators	Must have at least two or three people facilitating for support and debriefing.	Make sure facilitators are well recovered, know their triggers and are emotionally regulated. A facilitator may be ill or may wish to not participate anymore.
Structure and topics	Must have structured agenda and weekly topics. Some people may feel this is too formal.	This is not a gripe session. People can become dysregulated, bored or frustrated if people wander off on tangents. It should never become a free-for-all conversation. Staying on topic/bringing people back on track when they go off on tangential issues.
Recovery Based Group	Must always focus on moving forward, self-care and recovery	Some people can get bogged down in their story and pull the atmosphere of the group into despair
BPD Education	Psycho-education with neurobiological component. Use DMS criteria for descriptive purposes. Discuss alexithymia – naming, understanding and talking about emotions. Information processing and memory deficits. Emotional and social intelligence. Attachment theory/invalidating environment discussion	This may be too formal and difficult for some people and may be off-putting for them enough so they leave.
Flexibility	Knowing what people want and responding to their needs	Not everyone will be happy all the time and compromising will have to occur.
Hope for Recovery	Use peer recovered lived experience for hope.	Some people can be triggered by good stories, it makes them feel bad that they are not that recovered as well.

DBT and social skills	Address anything DBT does not address. How you come across to others and perceiving neutral faces as hostile. Use empathy/perspective/role playing. Discuss compartmentalising. Perhaps separate DBT skills group.	Some people may find this insulting and patronising. Some people dislike DBT. For some DBT simply does not work.
Other people	Have a friend and family session for education and enlightenment purposes	Some family members may not want to attend, may feel it is not their problem. Arguments may occur about private matters.
Outside Support	Ideally individual therapy, professional consultation for medications, DBT programmes. This group cannot supply all needs to all people.	Cost. Time. Motivation. May be too much to do all this.
Transgressions	The chance for a learning experience	Can lead to feelings of disunity within the group. Or it could be triggering. Being able to reinforce any group decisions effectively.
Outside contact	Highly encourage out of group contact as this is real life. A shared phone list with guidelines about crisis contact not being allowed, have to phone emergency list instead, but friendships is one of the reasons for having a support group in the first place.	Emphasis on no crisis contact. Other mental health groups meet up very successfully.
Ideas	Self care/self harm/self-cutting tool box.	Can be triggering for some. Very controversial.
Boundaries	What does healthy boundaries/good friendship look like – explore with group	Boundaries are difficult to learn and put in place. People have differing ideas on what boundaries should look like.
Crisis Care	Crisis calls not appropriate	People to have safety/crisis plan – text/phone support.
Group Triggers	If contained can be an experiential learning experience in the context of safety.	May lead to self harm, hospitalisation, crisis situation, suicide ideation or suicide completion
Sharing Stories	Resonance, connection and validation	People can get triggered by stories no matter how it is told. No ugly, intimate sharing details as this is triggering) unless separate cohesive, long term safety group is established
Transport	Transport to and from group with safe people at the end of the meeting to debrief with.	Without transport people cannot attend. Some may have public transport. Some may be house-bound, have

		disability issues, agoraphobia. Not live near adequate public transport. Group members offering rides can overcome this. Safety issues for group rides. Insurance.
Outcomes	Meet up with others for connection and validation.	People may feel this group is not for them as connection and validation can be frightening for some.

BPD Society, BC Canada
Weekly BPD Support Group
Deb McKnight and Baylie McKnight, facilitators



Financial and Funding: This is a peer driven support group which combines family members, consumers and friends. The room is in a Community Mental Health Centre. It is not affiliated with any other organisation; therefore they are autonomous, flexible, independent and creative. People donate money to them and they have a donation bin. Post meeting there is a small supper and coffee. This is for socialisation purposes. BPD Society has a resource library (in a box) and does presentations for many different organisations including businesses, colleges and universities. They sell memberships at \$2 each, and have Patron donors, Gold, Silver and Bronze. BPD Society works with and has social functions with other mental health groups. They have adopted a blue orchid as their symbol and sell symbol badges. They also conduct fund-raising ventures. The group is a non-profit looking to become a charity.

Community Standing: They have great standing in the community and are a credible organisation within health services. They have created their own email, blog and website and have brochures. They are referred to by psychiatrists, courts, emergency departments, psychiatric facilities, release plans and other mental health staff. **They are considered a service provider who promotes research and advocacy.**

They have anecdotal evidence that their service works for people who state they would not be here if not for the group. Someone (Baylie's friend who was a co-facilitator) completed suicide a year ago.

Crisis lines in Victoria BC were alerted in case people phoned for help because of this. **Deb guides the group and makes sure people stay on topic and do not digress. This is very important to keep the group focused on recovery.**

Support Group Agenda: The group sits in a circle. People share how their week has been for 2-3 minutes each. Out of that various topics can arise. People are mainly comfortable with their diagnosis. Topics include: asking people what topics they want, how to ask for help, looking after one's own needs, separating from family members, how self-harm and suicide were avoided. This is an open discussion where people are encouraged to share. There are rules and guidelines. Other topics might be opposite action, bipolar -v- BPD, the meaning of the symptoms. **The emphasis is on validation not advice.** The group talked about secondary emotions (shame is about anger, guilt etc.) Resources include: Joyce Meyers – The Approval Fix. Tera Brach, self compassion on YouTube and TED talks.

Other Services: The support group is a society and the support group is only part of what they do. Education of others is a large part, educating psychiatric nurses, psychiatrists, and other MH staff. The Society wants BPD embedded in the curriculum at university level. Many staff work with outdated BPD information which is not relevant today, however this old information is still being taught. I would like to find out what is being taught about BPD at university level in Perth to see if what is being learned currently is correct information.

DBT Skills Group: There is also an informal DBT skills group attached to the support group that meet once a week and go through a DBT manual, 'The Dialectical Behaviour Therapy Skills Workbook: Practical DBT Exercises for Learning Mindfulness, Interpersonal Effectiveness, Emotion Regulation and Distress Tolerance', at a cost of \$30 from the Society.

Making it Happen: I have started up a weekly BPD consumer Support Group at Uniting Care West where I work as a Peer Support Worker in the Personal Helpers and Mentors programme. My co-facilitator is Melanie Holland who is studying for a TAFE Cert IV in Mental Health Peer Work. We have had five meetings so far. The structure is 30 minutes introductions and socialising, one hour education topic and care and share and 30 minutes discussion and debriefing. Attendance is 3-6 consumers so far. We are conducting a survey both now and in six months time to evaluate the effectiveness of the group.

Borderline Personality Disorder Consumer Support Group Template

Based on visits with:

Debbie (mother) and Baylie (daughter) McKnight - BPD Society BC, Canada
Amanda Smith - Hope for BPD, Waco, Texas, USA
Claire Sims, Becky Attwater and Kobe Borich - Suffolk Mind, Suffolk Waves, Ipswich/Bury St. Edmunds, Suffolk, UK
Pernille Petersen MBE, Chief Executive, Ines Hunns Service Manager for the Day, and Dr Heather Castillo (ex-CEO now retired) - The Haven Project, Colchester, UK

Background and History: There is no single model that works for people with BPD. My investigations have found that different people suit different approaches and therefore an eclectic approach where people are asked what they want and then try to incorporate that into the structure of the group may be validating and helpful. The basis of the group is a mixture of diagnosis acceptance and the Recovery Model.

BPD is a shame-driven illness exacerbated by the fact that historically the diagnosis has been a reason to exclude people with BPD from mainstream services. There are limited non-DBT clinical psychologist services available that are inexpensive (only ten Medicare sessions per year). A BPD crisis is mainly in the context of a relationship breakdown which causes much shame, guilt, embarrassment and feelings of alienation, isolation and feeling misunderstood which can lead to self-harm, suicide ideation and suicide completion. An inexpensive semi-formal non-judgemental, confidential self-help group for information, education, support, connection and friendship may prove invaluable for helping people live a life worth living.

Relevance for Australia

- To run a weekly BPD consumer support group, run by at least two BPD peer facilitators in a central location. Once a group has been established the idea is to take the model into other suburbs promoting this through contacts, networks, mental health organisations, Australian BPD Foundation, SANE Australia, Connect Groups, Mental Health Commission, COMHWA and others.
- Preference is for this to be independent and autonomous in order to be flexible and creative - for the present - till we can present evidence to seek to incorporate this into established mental health organisations as a branded and funded programme.

- To be part of a linked-in treatment, support and recovery approach with mental health professionals.
- To make connections with and thus gain credibility so as to be referred to by mental health professionals, mental health units, emergency departments, psychiatric units, NGOs, GPs, psychiatrists, psychologists, DBT programmes and others.
- To invite mental health professionals along to listen and increase their knowledge base of non-medical intervention and give up to date information on treatment and recovery (if group allows this).
- Promotion of latest research and advocacy.
- To establish a database of public speakers to disseminate information and correct misinformation about treatment options and hope for recovery in the medical/psychiatric/psychological arena.
- To create a data base of personal stories of recovery (to turn into a book).

Theory and Evidence base

- DSM V diagnosis and symptoms
- Attachment Theory and a secure base (John Bowlby)
- DBT (social skills and strategies)
- Mentalisation Based Therapy (empathy and Theory of Mind)
- Schema Therapy (internal rigid, inflexible core belief system)

Pre-group action: Survey questions and interviews for potential BPD consumers (through workplace clients, contacts, networks and other organisations) to find out what people want from this group and how they want it run – such as input into house-rules, guidelines, policies and procedures. There will be an educational support booklet, resources list and contact list for between groups contact.

Description and structure: Best practice appears to be a two hour once weekly evening group 7-9pm, preferably at a central location (Joondalup).

- 7.00 -7.30pm - meet and greet and introductions, time to read the guidelines.
- 7.30 - 8.30pm - check in, structured topic discussion
- 8.30 - 9pm - tea/coffee and supper and half hour socialisation.

The Support Group set-up

- Check-in
- Caring and Sharing
- Topic focused (very important)
- Mindfulness skills/grounding exercise/guided meditation (5 mins)
- Friendship
- Support
- Social inclusion
- Connection
- Validation
- Advocacy
- Self-guided learning
- Education on BPD symptoms
- Psycho-education (based on a ten week turn-around) from the manual plus handouts)
- Social skills
- Links into existing services
- Crisis phone numbers and suicide help

There is also an option for a separate DBT skills peer-led weekly group. BPD Society BC Canada uses the book, 'The Dialectical Behaviour Therapy Skills Workbook: Practical DBT Exercises for Learning Mindfulness, Interpersonal Effectiveness, Emotion Regulation and Distress Tolerance' as a guideline. There are homework exercises.

As well a potential for informal facilitators meetings, links with other peer led support groups leading to social events such as family bbqs and fund-raising events.

Advertising: Promotion and Advertising for the support group would be through personal contacts and peer networks, such as Australian BPD Foundation, local WA emailing lists as well as Connect Groups, meet-up/gum tree/Quokka, workplace flyers and associated mental health organisations such as COMHWA, Consumer Advisory Group Joondalup, Joondalup and Clarkson Mental Health Units and major mental health organisations such as SANE Australia, Mental Illness Fellowship of WA, Richmond Fellowship and AFAFMI.

Media Promotion: There will be opportunities through community newspapers, community radio and hopefully mainstream radio and print outlets and SANE Australia.

Risk Management/OHS: The Australian BPD Foundation and BPD Society Canada have strongly advised that public liability insurance is crucial.

Requirements and Training for facilitators:

Must have a recovered lived experience

Must be committed to ongoing BPD education

DBT skills – Behavioural Tech 3 month online training \$400

Funding: Funding/donations/sponsors/patrons/fundraising events

Logistics:

- Insurance
- Finding a venue
- Expenses
- Logo and symbol
- Vision/Mission statement
- Disclaimers – ie offering no medical advice/pharmaceutical advice/prescribed treatment
- Advertising/promotion
- Advocacy and presentations
- Establishing relationships with clinical staff (to attend meetings)
- Finding suitable facilitators
- Conducting a survey
- Establishing email address/website/twitter/facebook
- Contact list signed permission
- Brochures
- Frequently asked questions
- List of resources ie books/websites/DVD's
- Education booklet and handouts
- Separate mobile phone

Lessons and Learnings: The best learning came from Amanda Smith, Hope for BPD, Waco Texas. Amanda started a support group in Florida by herself and lists problems encountered including:

- Only one facilitator for everyone, so when someone was dysregulated, there was no-one to support the rest of the group.
- No guidelines, house-rules, boundaries or topic structure which led to inappropriate sharing.
- The facilitator taking crisis calls on personal mobile.
- The facilitator having no support and feeling overwhelmed.
- Having to disband the group because it was not working effectively.

As a facilitator it is vital to have your own therapist and know your personal triggers. If unpleasant feelings arise debrief with other facilitators after each meeting. Keep the group zeitgeist well ordered, well regulated, structured and calm. Make sure everyone is ok after meetings. Do not post inappropriate comments on websites. Do not engage with social media trolls. Google your name regularly for adverse entries.

Outcomes: According to all investigated support groups and organisations, there are less emergency visits, less hospital admissions, more employment opportunities, less people on disability, greater public awareness and empathy, less stigmatisation (including self stigmatisation), less discrimination, more individual hope for recovery, better family, spouse and relationships, greater capacity for authentic friendships, more happiness and a life worth living.

Marsha Linehan
Creator of Dialectical Behaviour Therapy
Meditation classes at her house
Seattle, Washington



I met Joy Sprague at the NAMI Conference in Washington DC and she invited me to visit her in Seattle later on in my visit. Joy is a friend of Marsha's and phoned Marsha to see if I could attend her meditation class held on Tuesday mornings at her house. During this time we did sitting and walking meditation. After the class, I was able to have a brief chat with Marsha about her upcoming memoirs, 'A Life worth Living.'

Behavioral Tech LLC
Preston Thompson, CEO
Emily Hazelton, Sales and Information Manager
Seattle, Washington



Joy Sprague and I met with CEO of Behavioural Tech LLC, Preston Thompson. Preston met with Dr. Marsha Linehan via the University of Washington Centre for Commercialisation, which supports their researchers in commercializing their research. Preston served as a consultant to Behavioral Tech's sister company Behavioral Tech Research.

Sales & Information Manager, Emily Hazelton leads the implementation of Behavioral Tech's sales, marketing, and information systems initiatives. Emily joined Behavioral Tech in 2011 and supported the Customer Service and Marketing teams in her first year and a half of employment. In late 2012, she began working on Behavioral Tech's front-end web design and back-end programming and subsequently completed a Web Technology Solutions Certificate from the University of Washington in June 2014.

Behavioral Tech's latest achievement has been to develop a Suicide Safety Net application which will be available in December 2014. They are also hoping to set up training of DBT skills in schools and are meeting with the school systems board of directors. They also feel there is a gap in the market to teach DBT skills to businesses. As well they are hoping to teach DBT skills to war veterans. Developing products which requires a non face-to-face approach, such as on line training, books, apps, DVDs, webinars are their priority as they are not reaching out to enough people fast enough in order to cope with the growing demand for DBT-based products.

Paid webinars are being developed to introduce Marsha Linehan's new updated DBT Skills workbook in December 2014. Behavioral Tech also wants to do technology based training in different languages.

They are connected with Young and Well Cooperative research Centre (Jane Burns) with a proposal for matching grants to develop products and research together. They are also involved in Psychwire which is a shared research project, where web-based free academic research is available.

Emily recommended the online DBT skills training, which lasts for three months at a cost of \$400 per person for community and peer support workers. At the end there is a certificate of completion.

<http://behavioraltech.org/ol/details.cfm> Behavioural Tech are in the process of DBT therapist accreditation so that clients will be able to distinguish between DBT as Marsha created it in its entire capacity rather than just ad hoc DBT skills set some therapists are teaching.

**Hero House
North Creek Business Park
Bellevue, Seattle, Washington, USA
Erica Horn, Executive Director**



Joy Sprague, Liaison officer of NEA-BPD and her parents Fred and Betty Hume drove me to several places in Seattle. The first one was Hero House which is an international clubhouse dedicated to the social and vocational recovery for people with a mental illness. The Executive Director of Hero House is Erica Horn, who has a recovered lived experience. It is an evidence-based, non-clinical, psycho-social rehabilitation model of recovery.

Members are encouraged to develop their skills and talents, and perform all operations of the running of the clubhouse including reception work, writing the newsletter, working behind the snack bar, cooking, cleaning, serving meals, computer maintenance, fundraising and orientation of new members. People there can choose to pursue employment in the open market, under a programme called transitional employment, where one can work for up to nine months to build up skills and create a resume. If someone can't make it that day, someone else will take over their job so they don't lose it. There are also supported and independent employment opportunities. Much support is given for applying, acquiring and maintaining these jobs.

Regular events include Dine with a Hero where guest speakers with a vested interest in mental health speak on their experiences of providing education opportunities to people with disabilities or how to empower people to become more self-sufficient and productive. There is a programme for emerging artists called 'Artists on the Edge.' Daily wellness walks and healthy eating programmes are also provided. Social events are held on Saturdays, including a visit to the Tulip Festival.

Sponsorship options at different levels are available for businesses and organisations. There is no psychiatric, therapy or counselling services. The total operating budget for 2011 was US\$475,410.

NAMI Eastside Redmond, Washington Facilitator: Linda Sherry



NAMI Eastside is an affiliate of NAMI in Redmond, Washington. Fred and Betty Hume, (Pictured in the Japanese Gardens, Seattle) very kindly drove me to several locations including Hero House and NAMI Eastside where I met with several people who explained to me how the affiliate works.

There are several programmes, all free and open to the public, Educational programmes such as Family to Family (for relatives of people with mental illness), Peer to Peer Education (a ten week recovery education course), Connections Recovery Support Groups (for people with mental illness) and a Basic class (for parents of young children).

As well they have a speaker's bureau, In Our Own Voice, something I am eager to replicate, as personal storytelling and presenting is very powerful for both the speaker and the listener. Also upon request is an event called Educating the Next Generation. Monthly forums are held once a month. Other benefits offered include events, activities, newsletters, public awareness activities, an annual children's conference, an extensive library (something I noted, which seems to be a factor in quite a few mental health facilities is that libraries are quite under-utilised), annual NAMI WA State Conference, state and national training, discounts on brochures, videos and promotional items, local social events and fundraisers. NAMI Eastside is one of more than twenty Washington State affiliates.

Personality and its Implications for Psychotherapy
University of California
Berkeley, San Francisco
Nancy McWilliams, workshop speaker



Many years ago, my therapist gave me a photocopy of a few pages of Nancy McWilliams book, *Psychoanalytic Diagnosis, Understanding Personality Structure in the Clinical Process*. I fell in love with her accessible writing style, witty intellect and self-deprecating sense of humour. She maintains a great many therapists, including herself, have a depressive, schizoid nature with a masochistic bent. I have also enjoyed her other two books, *Psychoanalytic Psychotherapy, A practitioner's Guide*, and *Psychoanalytic Case Formulation*. I have read them each twice and often reference her work in my academic studies. This led me to study psychoanalytic psychotherapy at the Churchill Clinic in Nedlands, Perth. In San Francisco, I was very excited to not only hear her speak but I was able to have a short conversation with her as well.

During her workshop, she cleverly interwove clinical cases with anecdotes from her family based on Freudian concepts. There was a video presentation where she conducted psychodynamic therapy with a schizoid oriented client followed by an enthusiastic question and answer from the audience. She discusses all eleven personality disorders in the context of mentalisation, attachment theory, object relations, arrested development, developmental phases, CBT, DBT and of course psychodynamic psychotherapy. **She explains that clients diagnosed with BPD suffer from separation/individuation issues and can feel as though therapists are being sadistic when they set boundaries.** She explained personality developmental structure in the context of neurotic, borderline and psychotic states, something which many people feel is irrelevant, incorrect and outdated. She calls people with BPD stably unstable and that they have problems with identity integration and rely on primitive coping mechanisms. She utilises in her talk Otto Kernberg's work

(neurotic/borderline/psychotic), James Masterson (separation/individuation struggle – regression issues), Marsha Linehan (position of learning theory, affect regulation, Zen Buddhism and mindfulness and her own experience), John Gunderson (problems people with BPD create in institutions and with family and friends, dominated by acting out), Peter Fonagy (attachment theory, mentalisation, lack of reflective function, not fully understanding the subjective experience of others and their own experience), Giovanni Liotti (attachment and trauma with dissociation), Australian Russell Meares (self-psychology model, stimulus entrapment and deadness, dissociation), and Jeffrey Young (CBT, cognitive schemas, limited reparenting).

She asked herself the question. What do these people all agree on? She read all their recommendations and found commonalities – *all acknowledge the suffering of people with BPD, emphasise the absolute centrality of the relationship, the therapeutic alliance (rupture and repair takes precedence over all other therapeutic ambitions as well as respect for the borderline experience).*

If there is one thing I wish I could instil in all mental health professionals, psychiatrists, psychologists, mental health workers, psychiatric nurses and occupational therapists, it is the repair of the rupture, regardless of what happens and who thinks who is to blame. The non-BPD in the relationship needs to know how to validate and apologise. It was wonderful to hear Nancy echo my thoughts, theory and experience about how best to engage people with BPD and keep them in the relationship long enough to make a difference. That was the take-home message for me.

Summary of my Study Trip

Integrated Vision for the Future

The West Australian government is closing Graylands Psychiatric Hospital and using the money to fund new innovative and different ways to approach mental health through a Ten Year Services Plan which the public are able to lodge submissions through the Mental Health Commission website. Borderline Personality Disorder is a mental illness that is largely ignored, however the government is now seeking alternatives to treat people in BPD crisis rather than attending Emergency Departments.

Monique Williamson, CEO of the Mental Illness Fellowship of WA, myself and several other interested parties have formed a working group, The Haven Interest Group to make this happen. I have written a submission which will be lodged with the Mental Health Commission. Afterwards we will be designing what the WA Haven should look like followed by writing funding submissions to Lotteries West and the Mental Health Commission WA and seeking a meeting with the Minister for Mental Health and the Mental Health Commissioner to discuss further.

I was advised by Dr. Heather Castillo, it is best to purchase the property rather than rent. The integrated vision will include:

- A large brick crisis/safe house (the Haven WA), with a 24 hour crisis line for registered consumers, taxi vouchers for transporting people in crisis. Included in this house will be a wide variety of psychoeducation groups, support groups, self-help groups and friendship groups based on the models I visited. Included in these will be programmes, outreach clinical psychology and occupational therapy courses. Instead of turning up at an emergency department with many hours-long waits in uncomfortable plastic chairs, bright lights, noise and unpleasant stimuli from other people, the Haven WA would fast-track this process and use taxi vouchers to transport people into a safe and nurturing environment. ***When a person is in a BPD crisis and is in danger of self-harm or completing suicide, this is an emergency. Instant, empathic help is crucial at this point.*** In general terms, in this house there will be acceptable behaviour rules and a culture of positivity will be highly encouraged. ***This will be designed as an exclusive one stop shop for people with BPD and their loved ones.***
- My role as Consumer Representative for the Australian BPD Foundation will help spread a more positive culture through public awareness fund-raising events and targeted campaigns,

such as a Bike Ride for BPD and an enhancement of the arts (writing, dancing, painting, poetry etc) through courses at the WA Haven.

- Several BPD consumer support groups around the metropolitan area, both during the day and the evening. One of which is already established at Uniting Care West and the other one has funding and is in the planning process.
- A bureau of speakers, both consumers and carers who will be able to do stigma-reducing presentations and talks and advocate for greater public health funding for people with BPD. Spreading the message that BPD is a treatable and recoverable mental illness will help decrease associated stigma within mental health services and without treatment ten percent of people diagnosed will complete suicide.
- The creation of more BPD focused peer support worker positions to work specifically with people with a BPD diagnosis within the WA Haven house.
- The creation of social media opportunities and a networking database of people, services, resources and events through the Australian BPD Foundation so everyone can stay informed of current events, new research or any other relevant information.
- A BPD book. Several overseas BPD consumers expressed interest in allowing me to contact them via skype at a later date and take a detailed account of their recovery story for a book I plan to write. At some stage I would like to write a TV script, with a BPD scenario, for any popular series depicting young people.

Learnings: I learned a great deal of knowledge overseas that I would not have found within Australia. Travelling to the USA, UK, and Canada broadened and expanded my knowledge based on the experiences of parents and spouses of people with BPD. Instead of working from my own limited experiences based on my own situation (which was all I had before) I spoke to parents whose lives had been ravaged because of their child's mental illness as well as many recovered and recovering consumers.

Although there is much disagreement on the causation and balance of nature and nurture, the suffering is still the same and very real. I was astounded by the dedication of parents and spouses to the programmes they had enrolled in. I also found that their relationships had much improved due to the interventions.

One of the best learnings came from sitting in support groups of people diagnosed with BPD and hearing their unique experiences of the nuances of BPD symptoms. Hearing first-hand the subtleties and nuances of my own mental disorder resonated and I felt supported and validated.

Not everyone on my trip agreed with my views and visions. Some tried to actively discourage me from using the diagnosis as a starting and finishing point and instead felt I should work from a people-centred, recovery based perspective only and anything else was retraumatising and stigmatising.

Training and implementation

- I will be writing an psychoeducation programme for the BPD consumer groups utilising all my knowledge from the support groups of NAMI programmes, NEA-BPD programmes, Suffolk Waves, the Haven Project, Hope for BPD and the BPD Society of BC Victoria.
- Dialectical Behaviour Therapy skills and BPD psychoeducation training needs to be accessible to all BPD mental health workers at the proposed Haven WA. The easiest way to do this currently is online through Behavioural Tech for three months at a cost of approximately \$400.
- Dr. Heather Castillo has written a new book, called 'The Reality of Recovery in Personality Disorder' due to be published in 2015 about the creation, establishment and running of the Haven Project in Colchester. When funding for the WA Haven is established, I would like to enlist more people onto the working party to make this all happen. As well, I would like to extend an invitation to Dr. Castillo to come to Australia and help set it all up.

I am most passionate about setting up these services and programmes, and I have support and help from many people, but I know this will not be easy, there may be setbacks, but with sheer tenacity, willingness and ambition it is amazing what can be achieved. *The SANE Fellowship is a gift that keeps on giving.*

Let the Work begin!

Sonia Neale
April, 2015