

Introduction

Psychobabble has been put together by <u>Our Consumer Place</u> in response to a demand from people diagnosed with 'mental illness' for a collection of psychiatric jargon, acronyms and what we think are some of the silly expressions used in psychiatry – it's **our take** on the words used **by them** (and sometimes us) **about us**.

While some of the explanations are provided simply to define terms and acronyms that people are very confused about, *Psychobabble* is also an attempt to provide a consumer perspective on concepts that many people (including some dinicians and consumers) haven't thought through or may be happy to leave as they are.

Of course, some parts of *Psychobabble* are also about having a light-hearted spray at the pontification and judgements made about us – consumers – by some clinicians and medical researchers.

We don't believe that such a publication, written from a consumer perspective, has been produced in Australia before. Although *Psychobabble* is based on Victorian bureaucratic language, experience tells us that many of the words and explanations are transferable interstate and internationally.

This is the fourth in a series of publications written by and for mental health consumers by Our Consumer Place, a groundbreaking mental health resource centre run by people with a diagnosis of 'mental illness' (consumers). Our Consumer Place (www.ourconsumerplace.com.au) is funded by the Department of Health (Government of Victoria) and auspiced by Our Community (www.ourcommunity.com.au).

Our other publications

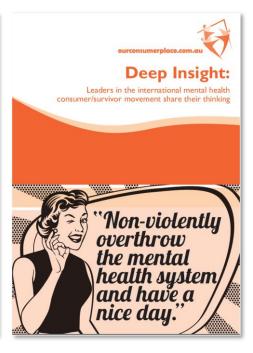
Click the images below to download PDFs of other Our Consumer Place publications:



So you have a 'Mental Illness' ... What Now? (PDF 4MB)



Speaking Our Minds: A guide to how we use our stories (PDF 4MB)



Deep Insight: Leaders in the international mental health consumer/survivor movement share their thinking (PDF 2MB)





Draft Permanent

We have marked this publication:

DRAFT PERMANENT¹

This first edition of *Psychobabble* has been put together by <u>Our Consumer Place</u> staffer and renowned consumer leader Merinda Epstein.

Although Merinda speaks with a strong consumer perspective, it is important to remember that 'The Consumer Movement' is a broad church.

In Our Consumer Place's first booklet, <u>So You've Got a 'Mental Illness'...What Now?</u>, we write about the difference between 'perspective' and 'views'. Perspective is the prism through which we choose to look at things, and our prism is our 'lived experience', but our views are **what** we experience, see and feel. Consumer views can be infinite and very individual.

In this context, our views are a reflection of our early lives, class, gender, experience of services (or not), experience of research, academic background, our interests, politics, belief systems and more.

It is probable that people will disagree with some of Merinda's interpretations and explanations — some may even want to question the very definitions used here. This is the purpose of the exercise. Please join in. We really want you to. All of us have our own language bugbears, definitions we want to share, differing interpretations that can be added to this publication. There is a real purpose to the 'draft permanent' status of this document.

Our decision never to see this booklet as the final word illustrates our belief that we could never hope to collect all the terms that need explaining, all the acronyms that keep being invented, or all the silly phrases we come across. Nor can we hope to encapsulate or represent all the possible meanings and interpretations of every word we include.

Psychobabble is just a start. With changes in government and policy and personnel, new bureaucracy-speak is always creeping into our vocabulary, being assimilated and spoken – often with complete disregard for the fact that consumers might have no idea what people are talking about.

Hopefully this publication will go some way to bridging the divide between those on the inside (including some consumers) and those on the outside of the knowledge/power divide.

We want you!

We want others to contribute to this work. Please send your ideas, disagreements, reinterpretations, silly stuff, acronyms, and new bureaucratic-speak to Merinda at Our Consumer Place (merindae@ourcommunity.com.au).

We are also happy for you to circulate the link to this document and to quote from it. Please cite Our Consumer Place (www.ourconsumerplace.com.au) as the source.

¹ This is a mechanism borrowed from a book by Dr Yoland Wadsworth and Ms Maggie McGuiness, *Understanding, Anytime*, which was published by the Victorian Mental illness Awareness Council (VMIAC) in 1993.



A note on style and language

We use inverted commas quite a lot in this publication. This is usually because we are wanting to distance ourselves from some of the language that is routinely used in psychiatry and we think is contested by at least some consumers.

For example, most of the time we use inverted commas around the term 'mental illness'. This is because we know that a large number of consumers no longer find this term a useful way of describing their experiences. On the other hand, we know some people have no issues with the concept – the inverted commas are simply meant to show that the use of the term is disputed by some; they are meant to flag the debate, not define it.

The same applies to some diagnoses such as 'borderline personality disorder' and some of the terms used in the science of psychiatry, as well as some important consumer language such as 'lived experience' and 'consumer perspective'.

Our use of inverted commas (indeed, our use of terms) may sometimes appear inconsistent. Our decisions have been driven by context, convention (or our flouting of it), as well as our own personal judgements and experiences. Language is messy, concepts are messy, lives are messy – we are unable to escape some inevitable messiness in this publication! Although we are convinced that individual treatment of language, like individual treatment of consumers, is the way to go, it does occasionally come at the expense of consistency.

The word 'consumer' is an important one in this publication, as it is our chosen language to describe people with lived experience of being diagnosed with 'mental illness' (see <u>So You Have a 'Mental Illness'</u>, <u>What Now?</u> for more on this). Having said that, we again have to acknowledge some apparent inconsistency – we might use 'patient' when we are describing inpatient experiences, or sometimes 'dient' when the situation seems to demand it.

We wrote *Psychobabble* from a first-person perspective. We struggled with pronouns: *Should we use 'you' to draw the reader in, or should we use the more inclusive 'we'?* The most important consideration, we decided, was the reflection of 'lived experience'. In order to reflect our fraternity we wanted to use the personal pronouns 'us' and 'we' as frequently as we could. This is deliberate. However it does create some challenges where we are talking about potentially thousands of different 'views' out there and a tiny proportion of them reflected by author number one (we hope for more to come).

We are aware that our choices in language can potentially annoy (even infuriate!) others. This is a risk we are willing to take – and it comes with an offer for many others to participate in constructing the next edition of this 'draft permanent' publication.

We hope you will take up the invitation.



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- 28. Care packages
- 29. CASA Centre Against Sexual Assault
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- 31. Case management
- 32. Case manager
- 33. Catatonic
- 34. CAT Team Crisis, Assessment and Treatment Team

5



- 35. 'Caught committing deliberate self-harm'
- 36. CBT cognitive behavioural therapy
- 37. CC&CC continuing care, clinical and consultancy
- 38. CCU Community Care Unit
- 39. Charge nurse
- 40. CHCs Community Health Centres
- 41. Cigarettes
- 42. Clinical depression
- 43. Clinical review
- 44. Clinicians
- 45. Closed ward/locked ward
- 46. Closing ranks
- 47. Clothes locker
- 48. Code grey
- 49. Co-dependent
- 50. Coffee
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- 52. Command voices
- 53. Community Mental Health Services
- 54. Community ward meetings
- 55. Co-morbidity
- 56. Complex needs
- 57. Complex post traumatic stress disorder (CPDSD)
- 58. Compliant
- 59. Confidentiality
- 60. Consumer
- 61. Contact nurse
- 62. Contract
- 63. Control group
- 64. Convention on the Rights of Persons with Disabilities
- 65. COSHG Collective of Self Help Groups
- 66. Counter-transference
- 67. Critical mass

D

- 68. Day release
- 69. DBT dialectical behaviour therapy
- 70. Delusions
- 71. Dependent
- 72. Depot
- 73. Depressive
- 74. Defensive medicine
- 75. DGPs Divisions of General Practice
- 76. Diagnosis language
- 77. Diagnostic traits
- 78. Difficulty engaging properly with the therapist





- 79. Dignity of risk
- 80. Discharge planning
- 81. Discharge from hospital
- 82. Disease
- 83. Dishevelled
- 84. Disinhibited
- 85. Disorder/disease
- 86. Disorganised speech
- 87. Dissociation
- 88. Dissociative disorders
- 89. Double-blind trials
- 90. DPI Disabled Persons International
- 91. Drug trials
- 92. DSA Disability Services Act 2006
- 93. DSM IV Diagnostic and Statistical Manual of Mental Disorders, Volume IV
- 94. DSP Disability Support Pension
- 95. Dual diagnosis
- 96. Dual disability
- 97. Duty of care
- 98. **Dysfunctional**
- 99. Dysfunctional family
- 100. Dysthymic pattern of behaviour

E

- 101. Early intervention
- 102. Eating disorders
- 103. Effective treatment
- 104. Elevated
- 105. Endogenous depression
- 106. Enmeshed
- 107. Evidence-based
- 108. Exit plan from public acute hospitals
- 109. Exit plan from private hospitals
- 110. Exit plan from working with psychotherapists
- 111. Exogenous depression

F

- 112. Factitious disorders
- 113. Feedback
- 114. Feedback form/sheet
- 115. Flannel flower
- 116. <u>Flat</u>
- 117. Flight of ideas
- 118. FOI Freedom of Information



G

- 119. Gen.med.
- 120. Glass-knocking techniques
- 121. Grand rounds
- 122. Grandiose delusions
- 123. Ground rounds
- 124. Guarantee your safety

Н

- 125. HACC Home and Community Care
- 126. Hallucinations
- 127. Handover
- 128. HDU high dependency unit
- 129. Headspace
- 130. Health Records Regulations 2002
- 131. High/low functioning
- 132. High/low prevalence
- 133. Histrionic
- 134. HoNOS
- 135. HOPS Homeless Outreach Psychiatric Services
- 136. Housing and support packages
- 137. HREOC Australian Human Rights & Equal Opportunity Commission
- 138. Hypochondria
- 139. Hypomania

- 140. Ideas of reference
- 141. Illusions
- 142. Impulse control
- 143. Inappropriate
- 144. Incident
- 145. <u>Individuals</u>
- 146. Individual service plan
- 147. Informal patient
- 148. Informed consent
- 149. In the best interest
- 150. Insight
- 151. Intake
- 152. IPP Individual Program Plan
- 153. IPS: Intentional Peer Support

J/K

- 154. 'Just' anxiety
- 155. Key workers

L

- 156. Language
- 157. Leave
- 158. Losing clinical language
- 159. LOTE language/s other than English
- 160. Low/high functioning
- 161. Low prevalence/high prevalence
- 162. LSE low stimulus environment

M

- 163. Mainstream services
- 164. Malodorous
- 165. Management plans
- 166. Managing clients
- 167. Mania
- 168. Manic
- 169. Matter
- 170. MDD major depressive disorder
- 171. Medical model
- 172. Medication queue
- 173. Medication rounds
- 174. Mental health triage scale
- 175. Mental Health Day/Week
- 176. Mini suicidal gesture
- 177. Mixed state
- 178. Mobile phone
- 179. MRC migrant resource centre
- 180. MSA mental state assessment
- 181. MSTS Mobile Support and Treatment Team
- 182. Multiple and Complex Needs Initiative

N

- 183. Narcissistic personality
- 184. Neurotic
- 185. NGO non-government organisation
- 186. Non socially-sanctioned self-harm
- 187. Non-compliant



- 188. Obs
- 189. OCD obsessive compulsive disorder
- 190. Open ward
- 191. OT occupational therapist
- 192. Other clinical populations
- 193. Othering
- 194. Outcome measures
- 195. Outpatient
- 196. Outreach
- 197. Over familiar

P

- 198. PANDA Post and Antenatal Depression Association Inc
- 199. Paranoia
- 200. PARC Prevention and Recovery Care Services
- 201. Passive-aggressive
- 202. PDRS Sector Psychiatric Disability Rehabilitation and Support Sector
- 203. PDs 'Personality Disorders'
- 204. Peer reviewed
- 205. Peer support
- 206. Perceive
- 207. Perceptions of abandonment
- 208. Permission
- 209. Personal Helpers and Mentors Programs PHAMS
- 210. PHACS Primary Health and Community Support
- 211. Placebo
- 212. Planning for the future
- 213. Positivism
- 214. Power
- 215. Powerlessness
- 216. Precious belongings
- 217. Presentation
- 218. p.r.n. pro re nata
- 219. Prodromal
- 220. Prognosis
- 221. Promiscuous
- 222. <u>Psychobabble</u>
- 223. Psychomotor agitation
- 224. Psychomotor retardation
- 225. Psycho-social disability
- 226. Psycho-social rehabilitation
- 227. Psychotherapy
- 228. Psychotic
- 229. PTSD post-traumatic stress disorder



- 232. QA quality assurance
- 233. Qualitative research
- 234. Quantitative research

R

- 235. Raft of services
- 236. Randomised control trial
- 237. Reactive depression
- 238. Recommended/scheduled/sectioned
- 239. Recovery plan
- 240. Rehabilitation
- 241. Resilience
- 242. Respite
- 243. Rigid thought patterns
- 244. Rigour
- 245. Risk

- 246. Safe times
- 247. Sample
- 248. Scale or tool
- 249. Scheduled
- 250. <u>Seamless services</u>
- 251. (A) Search
- 252. Seclusion
- 253. Secondary consultations
- 254. Secondary diagnosis
- 255. Second opinion
- 256. Sectioned/scheduled/recommended
- 257. Section 8
- 258. Section 10
- 259. <u>Section 12</u>
- 260. SECU Secure Extended Care Units
- 261. Secure wards
- 262. Self-control
- 263. Self-harm
- 264. Self-management
- 265. Self-medicating
- 266. Service delivery
- 267. Shallow or exaggerated emotions

11



- 268. SHIFT Service for the Homeless, Intellectually Disabled, Frail and Transient
- 269. Short-acting and long-acting
- 270. Silos
- 271. SMI serious mental illness
- 272. Somatoform disorders
- 273. Splitting
- 274. SRV social role valorisation
- 275. Staff turnover
- 276. Step up, step down services
- 277. (a) Study
- 278. Subjects, objects, cohorts, individuals and people
- 279. Suffers from absent insight
- 280. Suicidal ideation
- 281. Support worker
- 282. Supportive psychotherapy
- 283. Surg
- 284. Symptoms
- 285. Syndromes

T

- 286. Take down
- 287. Taking instructions
- 288. Team leader
- 289. Termination of the rapy
- 290. 'The mentally ill'
- 291. The narcissistic personality
- 292. The program
- 293. The suicidal patient
- 294. The very large NGOs
- 295. Therapised
- 296. Therapy-interfering behaviours
- 297. This cohort of difficult females
- 298. Thought blocking
- 299. Thought disordered
- 300. Time out
- 301. Traits
- 302. Transfer
- 303. Transference
- 304. Treatment plan
- 305. Treatment resistant

U

- 306. UDS urine drug screen
- 307. Unipolar
- 308. Unit manager





- 309. VACCHO Victorian Aboriginal Community Controlled Health Organisation
- 310. VEOHRC Victorian Equal Opportunity and Human Rights Commission
- 311. VICSERV
- 312. Voluntary hospital admission

W

- 313. Wilfully immature
- 314. Word salad



315. YEP - Youth Early Psychosis program





- 1. **ABI acquired brain injury:** In Victoria, the advocacy organisation for people who have a brain injury is <u>Headway Victoria</u>. Having both an acquired brain injury and 'mental illness' is usually known as having a dual disability. The other common form of dual disability is people with intellectual disabilities and 'mental illness'. Regardless of whether the person with an ABI has a dual disability, it is important for us to start developing allegiances with other oppressed groups within the disability sector. In this sector the way we generally name ourselves is, 'people with psycho-social disabilities'. See <u>psycho-social disability</u>.
- 2. **Abscond:** This word refers to how we are described when we seek freedom from a locked unit or ward by going somewhere else when we're not supposed to. See also <u>AWOL</u>.
- 3. **Abulia:** Sometimes defined as a 'poverty of motivation', abulia is a restriction in will or motivation, often characterised by an inability to set goals or make decisions. Those of us who have been described in this way may get sick of always being forced to be goal striving. Everyone has the right to not have a goal at least one day a week!
- 4. **Acute Units:** These are inpatient services designed for intensive intervention (usually with strong doses of medication). The vast majority of 'patients' in public acute units are people who are there against their will —it is incredibly difficult to get into an acute unit voluntarily.
- 5. **Affect:** Refers to the experience of feeling or emotion.
- 6. **Agitated**: This term may be used when we wring our hands or pace around the psychiatric ward, when we might have a lot of trouble calming down. See also *psychomotor agitation*.
- 7. **AMHS Area Mental Health Services:** These services are supposed to provide public services on a regional basis across Victoria. In reality, they can't. They don't have the resources. That means that the plight of people with a 'mental illness' is worse in regional and rural areas of Victoria and the poorer suburbs of Melbourne, where there are far fewer private psychiatrists and clinical psychologists. The non-government sector is picking up some of the slack so it's worth a call to <u>VICSERV</u>, the peak body in mental health non-government services (phone 03 9519 7000). See here for information about Victoria's publicly funded mental health services and how they are organised by age and region/area.
- 8. **An incident**: This term is often used as a euphemism to describe an emergency in a psychiatric unit. Sometimes security guards are brought into the unit. Some of us think it's pretty dumb if the hospital thinks that calling a violent assault 'an incident' will make any difference at all to the reaction and knowledge of other patients/users/residents. See also <u>incident</u>.
- 9. **Anxiety disorders:** Shorthand for a group of sometimes quite debilitating experiences ranging from fear that seems to others to be an over-reaction to the circumstance, to the debilitating anxiety of what is called 'obsessive compulsive disorder'. Those of us who have these experiences really struggle with facing what for others would be normal life activities. See also *just anxiety*.
- 10. **ARAFEMI:** Association of Relatives & Friends of the Emotionally & Mentally III ARAFEMI has been around for a long time supporting those who care about us including our dogs! Over past years their charter has changed a bit and they are now playing a role in providing services. Phone 03 9810 9300 or 1300 550 265 (helpline) or email to admin@arafemi.org.au.
- 11. **ASD Autism Spectrum Disorders:** A few decades ago autism was rarely diagnosed and it was generally known as a single entity. It is now more commonly diagnosed and many more children are able to access services earlier. It is also considered a spectrum of different but related disorders. At one end of this spectrum are children who really struggle academically as well as with their communication, their imagination and their social interaction. At the other end are children diagnosed with Asperger's syndrome who can be exceptionally gifted academically, or have some other specific skill or ability, but still



struggle with those aspects of everyday life that involve social and non-concrete ways of being in the world. No matter whether it's us going through these challenges that can continue into adulthood, those who care about us, or our children, this stuff is hard work. It is not helped by the judgment of others in the community.

- 12. **Assessment:** A term that is used when we first present to a service as clinicians try and work out what they think we need and how they might 'treat' us ('treat' in this sense is used to describe medical treatment rather than interpersonal treatment!). Assessment is also the place where we are denied service. "Sorry, you failed the 'really sick' test, go home. Have you got enough left from your pension for a taxi?" Many of us are furious about the ways that all sorts of assessments are carried out (or not carried out). It is not good enough to assess someone at an Area Mental Health Service and send them away with just a phone number (or without anything!). This can lead to suicide but it is suicide that does not 'count' (literally not morally) because the person who is refused services is not recorded as a 'patient' of the clinic. At the very least there has to be someone whose job it is to link up those of us seeking help with someone who can provide that help, and to keep in touch until that link is made. We recognise this is hard but often the blockage is attitudinal, both systemically and individually, rather than just a question of resources.
- 13. **Avolition:** Describes an experience that is often associated with 'schizophrenia' and sometimes 'major depression', where a person is said to be struggling to find drive where our motivation disappears and our goals seem pointless. Unfortunately, one of the by-products of this is that many people think that it is their responsibility to prod us into gear. Maybe that is useful sometimes, but other times we just want some time to blob, and constant prodding just makes us feel even more dependent.
- 14. **AWOL absent without leave:** Used to describe the situation when we escape from a locked mental health ward or unit. Police can be called in this situation. See also <u>abscond</u>.

B

- 15. **BASIS-32:** This is a scale that is commonly used to collect data across mental health services. It is a brief self-reporting measure for use by consumers of mental health services. The 32 items that form the basis of the scale are grouped into five domains (relation to self and others; daily living and role functioning; depression and anxiety; impulsive and addictive behaviour; and 'psychosis'). BASIS-32 was developed by McLean Hospital in Massachusetts, USA. It's been around for a while and it wouldn't surprise us if some people have filled it in several times. The measure is not in the public domain. Copyright rests with McLean Hospital. The Victorian Department of Health has an arrangement in place with McLean Hospital governing the use of the scale in Victoria PDRS services using the BASIS-32 need to sign an end-user 'deed of licence' in order to be covered by this agreement.
- 16. **Beds:** This is peculiar jargon (not restricted to psychiatry) that medical systems and hospitals use to describe the number of people in hospitals. It is particularly strange in psychiatric hospitals when many of us are actively discouraged from lying on our beds even though we are supposedly 'sick'.
- 17. **Behaviour therapies:** Unlike the <u>psychotherapy</u> range of therapeutic interventions, the behavioural ones concentrate on 'us learning how to' change our behaviour. They tend to be repetitive, either singular or group-based, sometimes like classes, and often really appealing to concrete type thinkers who want something tangible to work with. They have a good evidence base but many consumers question some of this in that we know just how easy it is to pretend different behaviours if we're



tempted to do so — and tempted some of us are, often. Behavioural-type therapies tend to be time limited, which appeals to many consumers and also to funders. Many consumers say such therapies give them something back for their dollar — something tangible and potentially life changing. Others find them to be patronising, infantilising, and too easy to cheat.

- 18. **BigPharma:** The nickname given to the pharmaceutical industry. The name comes from the acronym used by the industry's lobbying arm the Pharmaceutical Research and Manufacturers of America (PhRMA). Critics of the industry often use this nickname when discussing abuses by the industry. Accusations against BigPharma include: that drug companies rename old problems so that people will 'need' more seriously expensive medications for conditions that have simply been redefined, often after drug company funded research; that drug companies are huge monoliths squeezing money out of people who are sick and dying; and that drug companies are actively involved in medical imperialism expanding the number of illnesses so there is an ever increasing pool of people to treat.
- 19. **Bipolar:** This term is shorthand for bipolar affective disorder or manic depression and is considered a 'real' and 'serious' mental illness which is both good or bad depending on how we need to be treated. There are thought to be several forms of Bipolar. Bipolar 1 is where our high moods can be described as 'psychotic' or manic, and Bipolar 2 is where our highs can be described as 'high but not psychotic'. This is sometimes described as 'hypo manic'.
- 20. **Black and white thinking:** This is a term clinicians use to describe us when they think we are seeing everything in extremes. For example, we might see a hospital situation we are in as either all good or all bad. It's often perceived by clinicians to be a 'symptom' of 'borderline personality disorder'.
- 21. **Blind trials:** This term describes scientific experiments we might be asked to take part in which trial medical drugs. In these experiments the word 'blind' has a meaning like 'blindfolded' that is, we are not given information about whether we are taking the real new drug or a substitute that looks like it but has no medical value (a <u>placebo</u>). This is designed so that those of us who might desperately want the new drug to work don't accidently report improvements that might be exaggerated. See also <u>double-blind trials</u> and <u>placebo</u>.
- 22. **Bloods:** This is shorthand for taking a blood specimen, which is often tested for levels of the medications (medical drugs) we are taking to make sure we have the 'right' levels in our system.
- 23. **Blunted affect:** Affect is psychological jargon which describes the way we experience very normal things like feelings and emotions. We usually 'affect' with our mood. 'Blunted affect' describes the horrible place we are in when we just can't feel anything anymore. It happens to many of us. We can't feel up and we can't feel down. Of course, if we feel nothing we show nothing much to the world either. We tend to stop talking and stop demonstrating emotional indicators like expressions and animated body language. It's a bit like we're wearing a mask when facing the world. Losing access to our emotions is awful.
- 24. **BPD 'borderline personality disorder':** a diagnosis which has been controversial and is associated with chronic self-harm and childhood trauma. Those of us who have been labelled in this way have frequently been refused services and have often been treated with derision within services. It is not seen as a serious 'mental illness' and those given this diagnosis usually have very restricted access to public services if that's what they want. There is a state-wide Victorian service, SPECTRUM, but it does a lot of its work as secondary consultation. Private hospitals also offer programs for people with this diagnosis, both in inpatient settings and as outpatient clinics.

C





- 25. **C&LP consultation and liaison psychiatry:** The interface of psychiatry and general medicine. Specialists in this area often work in major public hospitals.
- 26. **CALD culturally and linguistically diverse:** Some CALD people accessing mental health services will need to use an interpreter. As such, anyone getting involved in the consumer movement must learn how to work with interpreters (it's quite an art to do it well). Also, it's worth noting that any of us can act as watchdogs of a service. If we see anyone using a child as an interpreter or speaking to someone who obviously doesn't understand, it's not our place to intervene but it is our place to get the receptionist to order pamphlets from the <u>Mental Health Branch</u> and write a short note to the manager of the service to politely complain.
- 27. **Capacity:** The language of 'capacity' is confusing in psychiatry because there are two different ways in which it is commonly used. The first is 'legal capacity', which relates to whether or not a person is considered to have the 'insight' to make legally binding decisions. Under extreme circumstances, it may include others (usually the Office of the Public Advocate) being given the right to manage your money against your will. For most of us this feels like the ultimate demeaning act. For more information see the Mental Health Legal Centre website. The second context in which the term 'capacity' is often used is in relation to 'medical capacity'. People deemed to lack 'insight', and therefore the capacity to make informed and insightful decisions about their health needs, may be held against their will either in a psychiatric hospital or in the community (on a Community Treatment Order).
- 28. **Care packages:** Specially designed care packages are available for people with complex needs. We might not want this intervention (probably not, in fact) but those who are providing resources are usually confident that we 'need' a whole bunch of different services, relationships and interventions. Care packages are usually co-ordinated through either the <u>Area Mental Health Service</u> or the <u>Multiple and Complex Needs Initiative</u>.
- 29. CASA Centre Against Sexual Assault: People diagnosed with 'mental illness' are more likely to be sexually assaulted than average. Women diagnosed with 'mental illness' are more likely than other women to have flashbacks to past experiences of child abuse, as well as sexual and physical abuse, and neglect. Find out more about CASA at here or phone (03) 9635 3610.
- 30. **Case load:** Describes the number of people a clinician is responsible for. Sometimes a clinician's caseload will blow out and in those cases, unfortunately, consumers can copit. This is especially the case in overstretched public <u>Area Mental Health</u> <u>Services</u>. It can lead to some of us feeling we're not important anymore and even to an escalation of symptoms in order to try and shore up the time we get with a worker we may have come to rely on.
- 31. Case management: "We are not cases and we do not want to be managed!" This has become a consumer slogan. The ideas of 'case' and 'management' are both problematic. For an explanation of why 'managed' is a difficult word, see <u>Managing clients</u>. 'Case' is yet another term that 'others' us. 'Othering' can be seen as any action that renders a person or a group of people different and less than the norm. While the term 'case management' has come across from mainstream health, it must be understood that things are a bit different in psychiatry because psychiatry is about our whole being, the essence of who we are as people. Care with language is therefore a whole lot more important in this context.
- 32. Case manager: This is the person in an Area Mental Health Service or private hospital who is responsible for co-ordinating our experiences of the service. He/she is the person with whom we are supposed to develop a working relationship. In practice, however, it is extraordinarily rare for there to be sufficient staff to match us to someone who will be able to work with us best, or for us to be given the opportunity to change case manager if we are paired with one with whom we cannot communicate (unfortunately, in such settings, personality clashes are usually perceived as products of our emotional disabilities). The turnover rate of case managers in public services is very high and it would be unusual to see the same case manager for more than eight months in the public sector. This is not conducive to building trust.
- 33. **Catatonic:** This is when we are characterised by clinicians as being unresponsive to external stimuli, and seen as moving and walking 'like a robot'.



- 34. **CAT Team Crisis, Assessment and Treatment Team:** These are teams of clinicians (usually two people) who come to us in times of crisis, either to enable us to access an acute unit, or to support us as needed... Well, that's the theory unfortunately the reality doesn't always quite match!
- 35. 'Caught committing deliberate self-harm': Your guess is as good as ours! We came across this term in a letter to the editor written by an emergency department specialist in Britain. We think it's reflective of the very negative attitudes of many emergency department clinicians to those of us who 'self-harm'.
- 36. **CBT cognitive behavioural therapy:** This is a combination of looking at the way our thinking patterns affect us (the cognitive part of this therapy), and self-examination of how our thinking patterns influence our behaviour (the behavioural aspect). CBT is perhaps the best known of a set of behavioural therapies that now claim a substantial evidence base and concentrate on the here and now rather than therapies like supported <u>psychotherapy</u>, which guide us into a place of retrospection. Like so many medical interventions, some of us simply hate CBT, feeling our intelligence is being insulted, where we simply get bored, where there is no place for reflection, and where interactive groups are the norm. Others have found this therapy really useful and often talk about the importance of the group process. CBT is in favour at the moment. It is a form of therapy that concentrates on the here and now and uses techniques like 'teaching us' different ways to think and behave. It is often short term and can be seen to show changes in behaviour quite quickly so it's relatively easy to find research methods which pronounce it evidence-based. It suits some of us, while others find it useless, regardless of what the 'evidence' says.
- 37. **CC&CC continuing care, clinical and consultancy:** This is the key work of <u>Area Mental Health Service</u>. Clinicians see people by appointment and therapeutic programs are offered.
- 38. **CCU Community Care Unit:** Along with <u>SECUs</u> (Secure Extended Care Units), CCUs are places where some of us stay full time. Different clinicians run both CCUs and SECUs and there are staff (forming part of a 'multidisciplinary team') rostered on full time, providing 24-hour clinical care and residential rehabilitation to people with severe 'mental illness' and associated disability who are unable to be supported in less intensive community options.
- 39. **Charge nurse:** The charge nurse is the nurse in charge of a psychiatric unit. S/he is responsible for everything that happens on the unit. His/her position is mainly a managerial one but good charge nurses will govern the unit in a way that sets an outstanding example of a nurse as well as a manager. See also *unit managers*.
- 40. **CHCs Community He alth Centres:** CHCs provide a wide range of services and many are funded to provide psychiatric services. It is in these services that we are most likely to find public mental health attention and, hopefully, help. This is because they are not mental health services; they have much broader intake criteria. Unfortunately, the non-specialist CHCs are only available for people in their municipality. During the early 1990s many of those were closed down.
- 41. Cigarettes²: These form a currency within an acute unit. In the public system, in particular, cigarettes are often the last thing we have left of our own. So metimes everything else has been taken off us, including any money we might have. The amount of staff time consumed with dealing with cigarette-related issues is staggering some hospitals have experimented with allocating special staff the task of dealing specifically with cigarettes as they were taking up so much clinical time. New laws which ban cigarettes from acute units have been roundly critiqued by consumers, many of whom believe it is vital that people get access to what they need (including cigarettes) in times of crisis when we are all at our most vulnerable. Some hospitals have ignored the protests against the bans (and then wonder why the level of violence has escalated); others give acutely distressed people nicotine patches when they are admitted. The cigarette debate has not run its race yet. Keep tuned to the Our Consumer Place newsletters.
- 42. **Clinical depression:** This is a depression of our mood that is seen by clinicians to come from a chemical imbalance in our brains. Treatments are usually medical drugs. See also <u>endogenous depression</u>, <u>exogenous depression</u> and <u>reactive</u> depression.

² See article by Indigo Daya in the September 2011 issue of the Our Consumer Place newsletter – a vailable at www.ourconsumerplace.com.au



- 43. **Clinical review:** This term describes the time when the consultant psychiatrist and 'the team' (i.e. all the clinicians who are involved with our 'treatment') review our 'treatment', our leave entitlements (for those of us in hospital), discharge planning, etc. These reviews happen regularly when we are in hospital and less regularly if we are clients of a public <u>Area Mental Health Service</u>. Some of us would like to be part of this planning but are only very rarely included, for two main reasons:
 - Clinicians actually do know that the 'clinical shorthand' that is used in these meetings can be viewed as dismissive, rude, 'hopeless' and 'judgemental' with the result that what is said in these meetings can be quite different from what we are told outside of them; and
 - Clinicians may, if we were there, <u>lose their language</u> (acronyms, words that could be perceived as judgemental) for fear of our reaction (including, at its extreme, litigation).
- 44. **Clinicians:** This used to be a word used to describe doctors. In mental health these days the word 'clinicians' is used to describe doctors, social workers, psychiatric nurses, occupational therapists and clinical psychologists.
- 45. **Closed ward/locked ward:** This is a psychiatric unit which is locked and where you have to seek specific permission to leave. Leaving, where it is allowed at all, usually requires either a staff member or a friend or family member to go with you. See also <u>AWOL</u>.
- 46. **Closing ranks:** Describes the protective/reactive action of a group of individuals who have more social power than those they surround in forming a figurative protective shield around the group. Such actions might be expressed as a reluctance or refusal to publicly question or criticise their colleagues. In health, it is usually doctors who are described as 'closing ranks'. This is the reason why it is sometimes difficult to get a 'second opinion'.
- 47. **Clothes locker:** Each public psychiatric unit has a clothes locker, which contains a stock of clothing of different sizes and styles. This is both a good and very sad thing. Many people who are admitted to a psychiatric unit have no change of clothes. We may be homeless. If we need anything in the way of clothes, we should be able to ask for it (it's probably not the right time to call on our pride). Despite our circumstances, we are all deserving of decent clothes to wear. It is repugnant to see worn clothes thrown back into the clothes locker without being washed.
- 48. **Code grey:** Hospital emergency codes are used worldwide to alert staff to various emergency situations. The use of codes is intended to convey essential information quickly. Code grey means 'combative person with no weapon'.
- 49. **Co-dependent**: In psychiatry and psychology this term means someone who goes beyond a 'reasonable' level of self sacrifice and personal denial in order to be liked by or to control others. It also describes someone who needs to be needed and will go to some lengths to keep the helping relationship intact by encouraging the other person's 'dependency'. This is usually far too simplistic a characterisation of a relationship; often things are so much more complex than a psychiatrist or psychologist can see and hear in their rooms. Families, for example, are complex networks of interactions and clinicians very often only hear from only one point of view.
- 50. **Coffee:** Many acute units only have decaffeinated coffee. This is because people seem to drink so much and, we suspect, also to bring the level of aggro down. We have the right to better coffee even if we have to bring it in ourselves. Needless to say, if there were more things to do people wouldn't drink so much yuk coffee. Wouldn't it be nice to have a cappuccinomaking machine [grin]!
- 51. **Cognitive therapies:** Often these types of therapies are combined with <u>behavioural therapies</u> and are called <u>cognitive-behavioural therapies</u>. Sometimes they are in groups and sometimes they are individual. Cognitive therapies are about the way we think. The logic is that if we can change the way we think we'll be able to change the way we act, react and feel. Like behaviour-based therapies, they have a good evidence base (thanks to us: sometimes we have to spend half our therapy time filling in questionnaires). Some consumers find these sorts of therapies useful and get wonderful "A-ha!" experiences that surprise and thrill them. Others, though, find fiddling around with our brains annoying, and the refusal to countenance



respect for our damaged pasts unhelpful. (And sometimes we just experience some of the more poncy psychologists as painful.) We all need different things, but we should all aim for the confidence to not blame ourselves when this or that therapy turns out to be the wrong one for us.

- 52. **Command voices**: These are voices that we hear that other people don't hear. What is unique about them is that they can, and often do, dictate (or command) us to behave in certain ways. Those of us hearing these voices tend to believe them because they are real to us at the time. They can be dangerous because they can tell us, indeed demand us, to hurt ourselves or, sometimes, hurt others. They're one of nastier experiences people with 'mental illness' can endure. They generally fall under the 'psychotic' range of experiences.
- 53. **Community ward meetings:** These meetings happen daily in most acute psychiatric units and are supposed to be a time for all the patients to get together with staff to talk about how the ward or unit is functioning. They are generally compulsory and we get rounded up to attend. Mostly it is about amusing us for an hour and checking out how we are interacting with other patients. Some of us are a bit cynical about whether our suggestions for improvements on the ward are taken very seriously.
- 54. **Co-morbidity**: Co-morbidity is the presence of one or more disorders (or diseases) in addition to a primary disease or disorder; or the effect of such additional disorders or diseases. In mental health we tend to use the language of 'traits' and 'secondary diagnoses'. One of the reasons some of us with the lived experience of 'mental illness' are not avid users of or admirers of the term 'co-morbid' or 'co-morbidity' is precisely because it sounds so morbid.
- 55. **Complex needs**: This term came out of a desire to find an acceptable way of describing 'experienced seriousness' without resorting to the lazy language of <u>SMI</u> (Serious Mental Illness) defined by diagnosis. It's useful because it trusts our experiences to some degree at least.
- 56. Complex post traumatic stress disorder (CPTSD): This is another and, many of us believe, much more respectful way to describe those of us who have been diagnosed with 'borderline personality disorder'. It is a term that honours (at last) our early experiences. It was coined by feminist psychiatrist Professor Judith Herrman in the USA. There has been some politics around CPTSD because post traumatic stress disorder (PTSD) is so often used to diagnose war veterans and people getting over major traumatic events. Because 'borderline personality disorder' is so devalued, some people diagnosed with PTSD and their representative bodies have felt people diagnosed with CPTSD are muddying the water of apparent innocence which accompanies PTSD. The reality is that the 'complex' prefix connotes that the trauma happened in early childhood and the complexity is that this is when 'personalities' are still growing and developing so many of us have ways of coping with the world (including self-harmin various forms) that might now be called maladaptive, but which helped us a lot when we were growing up.
- 57. **Compliant:** This is a term which is used when we make decisions that doctors agree with. Some consumers think of it as being 'good', "doing what we are told" or "doing what is good for us".
- 58. **Confidentiality:** When you are an inpatient in a psychiatric hospital, it's wise to be aware that 'confidentiality' never means the same to you as it does to the staff person/clinician you spoke to. That person is ethically obliged to pass on what you said to 'the team', and they are also obliged to pass on what was said at handover if it's deemed relevant. The working definition of confidentiality is, "confidential to the medical staff responsible for your treatment", which can expand to mean any number of medical people who are deemed to need to know. You can try and stop this by putting some limits on where the information you convey goes but this may not work in practice. The acute unit is where the problems with confidentiality manifest most starkly, but the same process can happen in other settings. Some consumers comment that everything about them spreads like wildfire through the establishment, leaving themselves as the only person not "in the know". Confidentiality can also be used against us for example, where clinicians in a community setting or private practice refuse to talk to the people we want them to talk to because of 'confidentiality'!
- 59. **Consumer:** the term used in Australia to describe people who:

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- Self identify as users of mental health services; and/or
- Have been diagnosed with a 'mental illness'; and/or
- Have been active within a mental health consumer/survivor/service user movement that is aiming to bring change, both radical and incremental, to the way people labelled with 'mental illness' are treated by services and society; and/or
- Describe ourselves as a 'patient', 'client', 'service user', 'psych. survivor', 'sufferer', 'person with a psychiatric disability' or use reclaimed language (language that is used against us) such as 'mad', 'crazy', 'loony', 'nutcase' or 'batty'.

Simply put, you are a consumer if that is how you identify. See So You have a 'Mental Illness'... What Now? p. 9.

- 60. **Contact nurse:** Every patient in a psychiatric acute unit is allocated a 'contact nurse'. This is the person who is responsible for keeping an eye on us during the shift or for being available for us when we need a nurse. The idea was introduced to try and improve continuity of relationships, with hospitals trying to limit the number of people each patient has to have contact with. Unfortunately it can be used to fob us off leaving us to be forever waiting for 'our' contact nurse who never seems to materialise.
- 61. **Contract:** A contract, in this context, is a document that is supposedly drawn up between the case manager and the client. The intention is to write it together to formally agree on the relationship between the mental health services and the client. It is meant to set out the terms with which the client is accepted into the service or the behaviour that is and is not accepted. It can be revised. This is a device frequently used with people who are diagnosed with 'borderline personality disorder'. In reality, many people play little part in drafting the document because they believe it is a waste of time; they sign documents they don't like, don't want and don't agree with because they are scared: scared of losing their children, scared of losing clinical support. The dream of joint decision making rarely happens because of the extreme power differential.
- 62. **Control group:** Most research in mainstream health is based around the principles of what we generally call '<u>positivism</u>'. This term was coined by philosopher Auguste Comte and basically means that the only knowledge worth knowing is that which comes from logic, science and mathematics. Most 'studies'/'experiments'/'trials'/'medical or psychological' research compete to prove their rigour (good science) through a positivist philosophy about good (usually called 'rigorous' science). The 'control group' is essential to this claim of exemplary rigour. The research method which is most often preferred is called a 'double-blind trial', whereby a group of 'subjects' is given a <u>placebo</u> and another group is given the real drug. Although the placebo looks, smells and tastes exactly like the drug being trialled it actually has no active ingredients in it. This gives the research greater credibility because the 'subjects' don't know whether they have taken the real drug or the placebo. In a <u>double-blind trial</u> the researchers also don't know which group of patients is given placebos and which is not.
- 63. **Convention on the Rights of Persons with Disabilities:** This Convention marks a 'paradigm shift' in attitudes and approaches to people with disabilities, from viewing people with disabilities as 'objects' of charity, medical treatment and social protection towards viewing them as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society. The Convention has been ratified in Australia. It breaks through some significant barriers for the human rights of people with psycho-social disabilities firstly, we were included, and secondly, it has named forced 'treatment' as a form of torture. Consumers are totally divided on these outcomes. Some of us are really excited and are already using the document as a lobbying tool, while others believe that defining forced 'treatment' as torture is over the top.
- 64. **COSHG Collective of Self Help Groups:** A network of self-help and social action groups. These groups are made up of and controlled by people who are directly affected by a particular issue. You can have your group listed on the <u>COSHG database</u> by phoning 03 93492301 or email to <u>info@coshg.org.au</u>.



- 65. **Counter-transference:** relates to some of the feelings a therapist might have towards us that do not come from the therapeutic relationship but might, instead, come from other central and informative relationships in the therapist's 'other' life. Psychodynamic therapists may use these phenomena as part of therapy. However every psychotherapist must recognise they have an overwhelmingly more powerful position in every clinical relationship they are part of. With this power comes the responsibility to manage transference and counter-transference and protect us from harm. See also *transference*.
- 66. **Critical mass:** A sociological term which can be understood in the context of a metaphor of the scales we used to use for weighing produce, or a see-saw. On one side there are people who come from the powerful groups in mental health: psychiatrists, drug companies, ministers of mental health and their bureaucracies, and so on. All of these are 'heavyweights'—they tip the scale down decisively on their side. On the other side of the scale are consumers. We have little power, most of us have minimal influence, and mostly we don't have economic or political authority. We weigh very little. In order to balance the scales, more and more and more consumers have to hop on board. Even though we individually weigh very little, we start to weigh a lot more collectively. 'Critical mass' describes that point at which our numbers provide enough weight on our side to balance the power of the heavyweights on the other side. We should always argue for a critical mass of consumers in anything we are involved in, from the 'collaborative' endeavour of the <u>National Mental Health Strategy</u> down to local level decision-making. In reality, we will rarely achieve this because those with the power and the capacity and determination to organise will often quite genuinely believe that having one consumer in the room is a pretty good offer.

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- 67. **Day release:** Used to describe the situation where we are able to leave hospital for the day but have to get back and ticked off each evening. Often our belongings are searched when we return to check we haven't brought in any substances or objects that are banned. This can be done nicely or horribly, depending on the clinician's attitudes towards us. See also <u>AWOL</u>.
- 68. **DBT dialectical behaviour therapy:** A type of therapy developed by Marsha M. Linehan, a psychologist in the USA. It is at this stage one of the favoured treatments for 'borderline personality disorder'. Like cognitive behavioural therapy, DBT concentrates on the here and now. It also puts a lot of emphasis on the importance of relationships, and tends to happen in groups. Like cognitive behavioural therapy, some of us get a lot out of DBT while others find it a terrible experience.
- 69. Delusions: Used to describe the 'state' some of us can get into where we believe things that others say are not 'true'.
- 70. **Dependent:** A term commonly used to describe some of us who are seen by clinicians as unable to make decisions on our own. Mostly clinicians don't factor in the reality that acute psychiatric units are places where some of us HAVE to behave dependently in order to survive in the healthiest fashion. See also <u>co-dependent</u>.
- 71. **Depot:** Sometimes 'the system', in striving to provide a duty of care, ascertains that a person will not 'responsibly' have the 'insight' to take the medication that system doctors indicate are 'essential' for their health. Most often these people are put on a Community Treatment Order (CTO), which means they are virtually held in the community against their will. A whole heap of rights are taken off them and they are nearly always required to come to the <u>Area Mental Health Service</u> clinic or be seen by the Mobile Treatment and Support Team (MTST) every two weeks to have a long-acting injection in the buttocks.



This is shorthanded to the jargon 'depot'. People know that if they don't front up they can 'rounded up' and sent back to hospital straight away. A big ethical dilemma surrounds CTOs and depot injections. The large number of people on depot injections in Victoria is frightening. Their constant risk of rehospitalisation is alarming, as is the fact that one of the medical drugs of choice is the injection of Risperdal Consta, which is very, very painful and obviously leads to people not wanting it and therefore ending up back in hospital.

- 72. **Depressive**: This is a judgemental and sometimes dismissive term used to describe people who have a tendency to experience life in ways where they often feel hopeless, or people with a diagnosis of clinical depression.
- 73. **Defensive medicine:** Describes medical practices designed to avert the future possibility of malpractice suits. In defensive medicine, responses are undertaken primarily to avoid liability rather than to benefit the patient. In psychiatry, this often mutates into a total preoccupation with risk control. In many cases this does harm to the person with the 'mental illness' and their 'recovery'. It can translate not only into over-medicating but also residential services beginning to look, behave and feel like custodial institutions rather than people's homes.
- 74. **DGPs Divisions of General Practice:** Obviously people diagnosed with 'mental illness' have had very varied experiences with GPs. Sometimes it takes more than a year of visits to even broach the subject of 'mental illness'. Other times GPs are very switched on to 'mental illness' but not always in the way we'd like. And at times they are our best advocates. Some people diagnosed with 'mental illness' have talked at education days and sessions for Divisions of GPs. Our experiences have been mixed. Some of the more cynically minded consumers still believe that the GPs only attend to get their points for continuing registration and to eat and drink courtesy of drug companies.
- 75. **Diagnosis language:** There are several terms that are used in relation to diagnosis. A 'diagnosis' or 'primary diagnosis' describes the term that is given to us by clinical psychologists and/or medical doctors (psychiatrists or general practitioners) to describe an illness/disease that they believe we 'have'. In order to make this decision they use the <u>DSMiv</u> (Diagnostic and Statistical Manual) or the ICD -10 (International Classification of Disease). Sometimes the diagnosis does not have the characteristics of a classical 'mental illness'. For example, it might be seen as a problem of 'self' rather than a disease of the mind and is thus described as a 'mental disorder' rather than a 'mental illness'. Or, it might be seen as a number of characteristics of dysfunction that seem to fit together but have not yet been formally classified and then it is seen as a 'syndrome'. Once a diagnosis has been made, it is possible for clinicians to go further and decide we have a 'secondary diagnosis'. This is when we are seen to experience a number of 'symptoms' that the classification system used by our doctor (medical or psychological) associate with an 'illness' or 'disorder' but less than those symptoms that seem to fit us for the primary diagnosis. This is then called a 'secondary diagnosis'. Further to this, a doctor might see aspects of the way we are when we see them (they use the jargon words "the way he/she presented" to describe this) that show a few signs of a different condition but not enough for a diagnosis to be made. These are called 'diagnostic traits'. So, potentially we could have a primary diagnosis of 'bipolar affective disorder', and a secondary diagnosis of 'obsessive compulsive disorder' with 'borderline personality disorder' traits. See also diagnostic traits; syndrome.
- 76. **Diagnostic traits:** A term used to describe a doctor's ruling on the third rung of the diagnostic ladder; after 'primary diagnosis' and 'secondary diagnosis'. It is when we seem to show a few characteristics of a particular diagnosis but not enough to make a full diagnosis. It all sounds very innocent but we all have to be aware of the damage that can be done when traits of a very prejudicial diagnosis such as 'borderline personality disorder' are given as a throwaway line that makes its way into our records. It has the potential to do irreparable harm to our reputation even when the traits that are described may be tentative, non-convincing and few. Those who diagnose must be fully aware of the consequences of their actions this is one of the reasons some people regularly peruse their records through <u>Freedom of Information</u> (FOI) legislation.
- 77. **Difficulty engaging properly with the therapist**: It is interesting how often difficulties in communication in mental health are attributed to the 'patient'/'client'. Some of us never know this language is being used to describe us and maybe don't want to know. Others feel we need to know we access our files through <u>Freedom of Information</u> (FOI) legislation (available to users of public services) or <u>Access to Health Records</u> and the Health Records Regulations 2002 (for private



services). When a consumer sees sentences like "difficulty engaging properly with the therapist" they may make no sense to us whatsoever – we had no problems engaging with the therapist! Maybe s/he had engagement problems with us but if that was the case, why didn't s/he tell us s/he wasn't getting it? Maybe s/he was a bit threatened by our knowledge or instinct to explore for our own explanations? A relationship is two ways – always. In a therapeutic relationship it is beholden on the therapist to take first responsibility for a communication breakdown because they are the ones with the power.

- 78. **Dignity of risk:** This is our jargon! Many consumers believe that we have to be allowed to take risks in order to transform our lives into lives that we want to live. It is much more important than rehabilitation and stronger than 'recovery'. It's hard to talk about this because we are heading full steam ahead into the world of <u>defensive medicine</u> that is now part of everyday life for people diagnosed with 'mental illness' in America.
- 79. **Discharge planning**: Some of us find it difficult to leave a service or supports we have become used to. This does NOT mean we have a deficiency, that we are 'dependent' or 'institutionalised'. It is yet another example of the way society works by engulfing us with subtle pressure to fit in. But it's not us; it never was. Our feelings of inadequacy and genuine fear of an unsupported or less supported life are the product of the institutions which have supported us and protected us in ways that are both good and bad. Inevitable uneven power relationships occur where one person is, by definition, relatively powerless (not the owner of power), while the support worker/key worker/psychologist/psychiatrist is the person with knowledge (and where knowledge equals power). It's important to acknowledge that some workers/clinicians are not very good at easing this process and some organisations have insufficient guidelines about how to proceed amidst this very sensitive and potentially harming part of the therapeutic process. This is the time when it may well be beneficial to join a group of people who have been through the same sorts of experiences as we have.
- 80. **Discharge from hospital**: Describes the process that happens when we leave hospital. It includes getting back everything from the safe, signing out, and being visited by the <u>CAT team</u> if we have been in a psychiatric ward at a public hospital. Sometimes this process can seem to go forever before you actually get out of the building.
- 81. Disease: see disorder.
- 82. **Dishevelled**: Clinicians often use this judgemental term when we appear to not be looking after ourselves. We think it also has a lot to do with judgements about poverty, gender and/or homelessness.
- 83. **Disinhibited**: Describes what clinicians experience as our inability to understand the social expectations of our community; for example, when we say and do things sexually that we might otherwise never do (sometimes leaving us with a lot of talking to do to regain friendships).
- 84. **Disorder/disease:** Interestingly it is sometimes consumers who feel the most passionately about the over-simplification of the <u>Diagnostic & Statistical Manual</u> (DSMiv). Superficially, the DSMiv locates a large group of illnesses, syndromes and 'diseases' in the category of 'disorders', with a smaller group of conditions defined as 'mental illness'. Thus 'mental illness' is seen as a sub-group of mental disorders.
- 85. **Disorganised speech**: The word 'disorganised' is used a lot in psychiatry. In this sense it is used to describe a situation where it is difficult to have a conversation, where you feel like you almost need to have a special code to unlock your friend's meaning, where it's hard to process information, and discussions seem to go off on wonderfully exciting but weird adventures as you talk together.
- 86. **Dissociation:** Describes a situation commonly associated with early childhood abuse, neglect and/or chaos, where past trauma can cause our mind to distance itself from present experiences that are too much for our psyche to process. It's like we sort of zone out for a while. Due to their unexpected and largely inexplicable nature, periods of dissociation tend to be unsettling.



- 87. **Dissociative disorders:** These 'disorders' include experiences called 'derealisation', which is a subjective experience of unreality of the outside world, while 'depersonalisation' is unreality in one's sense of self. It is a feeling of watching oneself act, while having no control over a situation. These are very real, very scary and very neglected experiences.
- 88. Double-blind trials: This is a way of testing new medical drugs by not giving out certain information (like blindfolding hence the use of the term 'blind') so as to minimise the amount of bias on the part of the patient who wants the drug to work, and the academic researcher or clinician who may expect a certain outcome and subtly influence the interpretation. Such a study is called 'double blind'. Both the patient and the researcher are 'blind'. Participants literally have no idea whether we have received the 'look-alike' (placebo) drug or the real thing. The 'double' part means that the researchers have no idea who has received the placebo and who has received the real drug either. Double-blind trials do not just have to be drug trials. There are other forms of experimental research which use these methods. They are often heralded as the state of the art in research techniques with 'failsafe' protocols. Yet consumers have reason to critique the reputation of double blind trials. First there is the funding of big pharmaceutical companies of so much of this research. The ethics of this is questionable. Because the conventional medical and psychological research industry has created its own privileged place for 'its' knowledge which is tied to an industry-promoted ideology of rigour it captures nearly all the funding that is available from government and has created a self-rejuvenating cycle of research privilege. Double-blind trials are the centrepiece of this. There are questions to be asked about the practical ethics of double-blind trials. When we end up in the control group and not receiving a drug that is proving life saving or, alternatively, when a drug is given (randomly) to us that proves harmful, do we really believe our consent was as informed as it should have been? Despite the necessity of 'informed consent' many of us forget just how experimental an experiment really is. It can even feel like an adventure for those of us who are bored. There are many other reasons some of us choose to take part in this potentially dangerous work that have to do with the disadvantage we experience because of system-inflicted wounds, impoverished lives, or mental distress. Obviously this is not always true but it can be. See also <u>drug trials</u> and <u>blind trials</u>.
- 89. **DPI Disabled Persons International:** DPI Australia is the Australian branch of the broader disability community.

 Traditionally people diagnosed with 'mental illness' have been awkwardly placed somewhere between disability and health.

 This has meant that we don't have a lot of credibility yet in the disability movement.
- 90. **Drug trials:** Often when we are patients in acute units we may be asked to take part in drug trials. We're usually told that this will lead to a new generation of better medicines for other people diagnosed with 'mental illness'. In order for us to participate we need to give formal written consent to confirm that we understand the implications of taking part in the trial. The most common and recognised of these trials are randomized control trials or double-blind trials. These are seen as scientifically rigorous. See also <u>double blind-trials</u> and <u>blind trials</u>.
- 91. **DSA Disability Services Act 2006:** This is a piece of Victorian legislation which infuriates some of us. This legislation was specifically drafted to provide protection from prejudice and oppression for people with disabilities. It's relatively new (introduced in 2006) and we are still experiencing oppression at an official level. The very disappointing aspect of this piece of legislation was that people with psycho-social disabilities were deliberately excluded apparently we don't need protection from discrimination. See hereal/need/.
- 92. **DSM IV Diagnostic and Statistical Manual of Mental Disorders, Volume IV:** This is the doctor's 'bible'. It is the book most doctors in Australia use to diagnose us. In actual factitis a pretty simple classification system. It is designed to give clinicians a way to talk to each other using an experience (what they call a 'symptom') counting method. For example, a doctor might look at and talk to the patient, mentally tick off each 'symptom'; if they get more than five, they can make such-and-such diagnosis, but if they only get three they have to look for another diagnosis, be prepared to wait and see, or just use the DSM as an expensive door stopper. A new version of this publication, DSM V, is due out in 2013. There are rumours that we might find a new set of brand new diagnoses. See here.
- 93. **DSP Disability Support Pension:** This rises and falls at the whim of the Federal Government so it's really important to keep up to date with the Centrelink information, which can be found on its website (www.centrelink.gov.au). There is a very good piece about the DSP in Our Consumer Place's first booklet, Mental illness'... What Next?



- 94. **Dual diagnosis:** Describes people who are seen to have both a 'mental illness' and a drug and alcohol or other substance abuse problem.
- 95. **Dual disability:** Describes people who are seen to have both an intellectual disability and a 'mental illness', and people seen to have an acquired braininjury and 'mental illness'.
- 96. **Duty of care:** A broad ranging legal principle, meaning that one must act with due diligence and take all reasonable steps to ensure their actions do not knowingly cause harm to another individual. People diagnosed with 'mental illness' are often aware that the claim of 'duty of care' is sometimes used as an excuse for tightening the control of the state over people's choices and sovereignty. We don't want to dilute the concept of 'duty of care' but some of us want it to be interpreted more liberally. Consumers have coined the term 'dignity of risk', which describes where we can realign our lives and attempt things we might not be very good at yet, transforming our lives into healthier risk-taking people.
- 97. **Dysfunctional:** This is another one of those words which clinicians pop out almost unconsciously from their mouths and yet they would hate to be described like this. We're not even sure what it means! If having an untidy house is dysfunctional then this applies to about 50% of the population; if forgetting an appointment because you've got so much on your plate is dysfunctional then about 80% of the population is dysfunctional. Once we have the label 'mentally ill', the word 'dysfunctional' can be attached to us extraordinarily easily. It is often associated with relationships and, unfortunately, it is often stereotypical. So, for example, relationships where there is turmoil on again, off again; love/hate are often described as 'dysfunctional' when perhaps it may be perfectly normal in this context.
- 98. **Dysfunctional family:** This term refers to families of origin the 'family' we grew up in. Many of us come from families that didn't do much good for our mental health and for many of us the term 'dysfunctional family' makes sense as it is quite difficult to describe stuff that did harm but wasn't 'abuse' or overtly obvious trauma. However, others of us have been on the receiving end of clinical (and other systemic) judgement which comes frequently with this label and we steer clear of it. All our experiences are unique, extraordinarily complex, and hold very mixed emotions and powerful memories. To sum all this up in one piece of jargon is insulting and unfair for some.
- 99. **Dysthymic pattern of behaviour:** Dysthymia is a type of low-grade depression that is often dismissed as ill humour or a chronically bad mood!

E

100. Early intervention: Early intervention is on the airways at the moment! The term means a couple of different things. On one level it is being used to describe the stage in a person's lifecycle at which, it is believed, intervention should start in order to minimise future suffering, cost to the community and productivity. Secondly, it describes what time in an 'episode of illness' an intervention should be made. As people diagnosed with 'mental illness' we are possibly the most cynical group in relation to this term (and its practice). Many of us feel we haven't been respectfully included in the discussions around early intervention. Many of us don't trust that services will be sufficiently different to make them safe places for young people (some of us have been so badly harmed by 'the system' that we desperately want to protect young people from the same). Many of us believe that young people don't need labels; that they don't need to have their distress medicalised; and they don't need dependence, powerlessness, institutionalisation, patronisation. We don't trust the rhetoric of those who say they are here for the young people. Equally worrying is the thought that the way these early intervention services are set up

can be damaging. The strict age limitations offer no understanding of the way young people mature (normally) in very different ways ("No, I'm sorry, you can't come in, you're 25 and three months. Back out on the street you go!"). Secondly, and of great importance to us as consumers, the early intervention model once again sets up a system in which young people can 'fail' – "Sorry, you've reached 25 and you are still having these experiences; out on the street you go!" This is horrible. Setting young people up in this way is seriously problematic in ways that we understand because we understand the service provision culture. The concept of 'early intervention' in relation to the cycle of 'episode' is not quite so problematic.

- 101. Eating disorders: Eating disorders effect lots of people particularly young people. The two most commonly known eating disorders are anorexia nervosa and bulimia. See the website of Eating Disorders Victoria or call them on 1300 550 236. The traditional group of people who develop these eating disorders have been women, particularly young women and girls, though (unfortunately) the last decade has seen a rapidly growing number of boys and young men developing traditional eating disorders. At the same time the 'mean' (average) age for people 'presenting' (coming to a service or a clinician) with eating disorders is getting younger; services report children as young as eight with quite significant experiences of eating disturbance. We do know that evaluation of the Government's 'war against obesity' has resulted in an unprecedented increase in the number of young people with anorexia and bulimia. This is a problem. 'Obesity' might also be seen as an eating disorder. However untargeted attacks on people who are large seem to have done not much good and quite a lot of harm. It is important that any consequent 'treatment' doesn't further shame those of us with eating disorders. Shame and lack of control over our lives are often two significant contributors to eating related ways of dealing with distress.
- 102. **Effective treatment:** This is a term that clinicians, especially psychologists and psychiatrists, use to describe therapeutical interventions that have an 'evidence base'. On one level this is really good because it helps guide us towards therapies that might be useful and we can have an evidential guide to help us. On the other hand, it renders our own very good work invisible our effectively run learning days, our small organisations, self-help, narrative research, participatory action research and so much more gets lost. It is really hard to find funding for our own work despite the fact that our initiatives cost a millionth of the big drug company trials. We have no (or little) evidence, not because our hard work hasn't produced real changes in people's lives but because we can't produce an evidence base that is visible to those who matter in the distribution of dollars.
- 103. **Elevated:** One of the words that is used to describe having a high mood. It doesn't necessarily imply mania or 'psychosis'. It is jargon for describing experiences that some of us have where our mood goes up over a bit of time perhaps three weeks or so. It is not always that we are 'happy' that's a misconception, although some of us might be for some of the time. We might be sleeping badly, or even not at all. We might be 'agitated' (this is another jargon word, used to describe not being able to sit still for very long and having some trouble keeping our body parts under control). Talking too much might be a signal for trying to achieve over-ambitiously. The term 'elevated' is often associated with the diagnosis of bipolar affective disorder. Sometimes it is hard to know when you're getting what other people might label as 'elevated' because you are too busy getting on with your life. For other people the difference is obvious. Neither response is right or wrong. They're just different.
- 104. **Endogenous depression**: This is a term that is out of fashion these days but still used occasionally. It is similar in meaning to clinical depression. It means a depression that is biological in nature. See also <u>clinical depression</u>, <u>exogenous depression</u> and <u>reactive depression</u>.
- 105. **Enmeshed:** Sometimes we are criticised for being too caught up with family and other relationships. The shorthand for this is to describe us as 'enmeshed', and the critical aim of <u>psychotherapy</u> is to help us to disengage sufficiently that we can live our own lives without experiencing overwhelming feelings of guilt when we are not 'doing for' those with whom our lives are 'enmeshed'. It's a complex situation in mental health where the consumer/carer dynamic makes things more difficult.
- 106. **Evidence-based:** This refers to treatments that seem to have 'good', 'reliable', statistical evidence to back them up. Some of us are sceptical of this term because certain therapies lend themselves to the types of research that are perceived by governments, academics and policymakers to be sound, the most traditionally convincing methods being <u>randomised</u>



<u>control trials</u>. Apart from a total lack of resources to get the 'acceptable' evidence to support an evidence base for consumer-run services and <u>Intentional Peer Support</u> programs, when we know empirically how successful they are, some of us are also sceptical of the role of drug companies in the traditional <u>positivist</u> research which so often 'creates' an acceptable evidence base.

- 107. Exit plan from public acute hospitals: The first sort of exit plan is one that is designed to provide a bridge between an admission to a public hospital and 'returning to the community' (a term that amuses many consumers who wonder what sort of 'community' they are actually returning to, but nonetheless this is the term that is generally used). In public services a lot of the antics concerned with pre-discharge (before release) have disappeared as stays have become shorter and shorter, and the need is, very rudimentarily, picked up by the <u>CAT team</u>. We have to bear in mind, however, that the posthospital role of the CAT team is simply a visit or two mainly to check medications. Their role is not to debrief, no matter how traumatic our hospital stay may have been. From public hospitals a letter will eventually be sent to our case manager or private psychiatrist but this might take weeks and will be short and rudimentary. Before discharge those of us who have been held under the Mental Health Act 1986 (soon to be replaced by a new Act) will be approached re a 'family meeting'. This meeting is stipulated under the Act to be held to help 'carers' and enhance a smoother exit transition. However, the Mental Health Act clearly states that this meeting can only take place if we specifically agree to it. We have the legal right to say no when approached about it. The problem is that few of us who have been held against our will feel like standing up for our rights at the very point of time when such action might jeopardise our release. For many of us this is the extent of the 'exit plan'. Some of us will get more support in transition as we will be discharged to a PARC (Prevention and Recovery Care Centres) service. Some of these services are run by the mental health system and others are run by Psychiatric Disability Rehabilitation Services. They are described as 'step up, step down' services and this means they are 'sub-acute' (this is jargon used to describe those of us who are showing signs of worrying experiences but are not 'sick' enough to be admitted into a hospital). The function that the PARC services provide is a stepping stone for some people between an acute unit and 'backinto the community'. Those of us destined for PARCs will have an articulated exit strategy in place and we will know about some of it. Whilst in hospital, we might meet staff from the PARC or might even visit the PARC on 'day leave'. The staff at the hospital, PARC staff and our 'case manager' will be in quite a lot of contact just before the transition.
- 108. Exit plan from private hospitals (and some public hospitals still): Exit plans are different in private hospitals and some public hospitals still provide some of these measures. On the whole, we stay longer when we are admitted to private hospital. This has some advantages but it also has some disadvantages and one of these is we can get institutionalised. Some of us can lose confidence in ourselves as coping individuals in as little as two weeks, so four, five, six week stays in hospitals can have a dire effect on our confidence. Private hospitals also run far more 'programs', so-called 'therapeutic' exercises that generally we are required to attend as part of our 'treatment'. Most private hospitals will, amongst other things, incorporate an exit plan into 'the program'. Groups (which are sometimes excruciating) are likely to be held on things like 'preparing for going home'. In one hospital, consumers took over the group and renamed it 'the escape committee' and a lot more productive learning seemed to take place. Private hospitals also have the capacity to build into our exit plan progressive leave and they do this routinely. We might start with day leave, followed perhaps by weekend leave. This builds up to final discharge. Up until a few years ago private psychiatric hospitals only provided 'programs' for inpatients. This has changed so it is possible now that an exit plan will include discharge from an inpatient situation to what these hospitals generally call 'outreach' programs, where we are required to come in daily to continue programs which are deemed to be helpful. Sometimes private hospitals will have developed an exit plan that discharges us to a 'case manager' operating from that hospital.
- 109. Exit plan from working with psychotherapists: Practitioners of many different forms of talking therapies often learn a staged way to 'help' people, at the end of their needed time of therapy, to move on from a developed dependence on this important relationship. We've all got to remember a few things. Firstly, there is absolutely no shame in becoming dependent. There are so many reasons why we would become dependent and so few reasons why we would not. Firstly, if we're going through horrible head experiences, dealing with past trauma, having trouble coping on a daily basis, for example, we will be justifiably needy and need brings dependence with it. Secondly, the relationship is so uneven in terms of power and this breeds dependence. Thirdly, many therapeutic practises have the relationship as central to the

therapeutic model, and this too breeds dependence. There are other reasons too. Some therapists are experienced, talented, personable, clever and know us very well —in such cases, the exit plan that they will have clearly thought about can almost pass us by. Such a therapist prepares us for substantial loss in a mature way that does not shame. Such a therapist gradually helps us start to see advantages in 'going it alone'. Such a therapist doesn't string us along for their own financial gain. Such a therapist ends up helping us to really believe that we have made the sound decision to put our energies somewhere else. This is part of their/our exit plan. Not all therapists implement their exit plan with this degree of sophistication. Sometimes we can see right through what appear to be games being played by the therapist and it becomes a farce. Sometimes we end up feeling humiliated and shamed because it feels like we're clinging on to a relationship where we're no longer wanted. Sometimes it feels like we're being kicked out and we start to rethink the positives that have come out of the relationship previously. There will always be an exit plan to be implemented at some stage. The most important thing is how it is implemented and by whom. The public system presents all sorts of challenges to therapists (such as they are) and consumers. Therapists suddenly leave, consumers move house and find themselves in a different 'area' (precinct covered by a different <u>Area Mental Health Services</u> with different staff) and have to change therapists despite a relationship being established. Exit strategies under these circumstances are rudimentary in the extreme and some consumers feel very badly let down.

110. **Exogenous depression:** This is a term that is out of favour these days but means depression that has causes associated with real life, external trauma or stressful event. See also <u>reactive depression</u>, <u>clinical depression</u>, and <u>endogenous depression</u>.

F

111. Factitious disorders: This term describes conditions where we genuinely need to be seen as experiencing physical illness, where we deliberately feign symptoms of a physical disorder to lead people to believe we are physically sick rather than mentally distressed. Those of us who have had this diagnosis often have extremely difficult lives because we know that it is considered 'wrong' to want to be in hospital -it's the last thing 'ordinary' people would want. We can be very skilled at creating the 'correct' symptoms that imitate a physical illness. Hypochondria is very different because it leads people to really believe they are psychically sick. With 'factitious disorders' we really know we are not physically unwell but we want/need what we see as some of the positives that go with physical illness: being cared for, for once; having people fussing over us; not having to self-harmina more obvious way; getting away from terrible lives for just a short while; and so on. We are treated as a real problem to the medical system partly because we are often very well read and knowledgeable about disease - medical practitioners find this to be the ultimate denial of their authority and power so it does make them very cross. It's sad that we should need to resort to such lengths to find caring; it usually reflects a lack of basic caring in our childhoods. Unfortunately the result is the exact opposite of what we are so desperately looking for. The very name, 'factitious disorder', doesn't help! It means 'made up' or 'contrived' and reinforces that we must be unworthy and untrustworthy and should be punished by the system. Often we are called 'liars' and our medical records reflect the disdain with which we are treated. In reality, it is never about attention seeking or manipulation because it comes from somewhere deep inside us and probably a long way in our past. Munchhausen syndrome or Munchhausen's by proxy are the most famous of the factitious disorders. See also somatoform disorders.

- 112. **Feedback form/sheet**: This is an official form that consumers are often asked to fill in. Most of us can't be bothered doing so because we have little faith that it will make any difference. Also, most attempts at feedback sheets ask only questions about what the staff want to hear, with no questions designed and owned by people diagnosed with 'mental illness'. See <u>feedback</u>.
- 113. **Feedback**: Feedback can be given to a service in whatever way we want. We certainly don't have to wait to be given an official feedback form. Some people honour the professionalism and special treatment given to them by a staff member by giving a gift. Some write official letters of complaint or take our issues to one or more of the agencies set up to receive official complaints, e.g. the <u>Chief Psychiatrist</u> or the <u>Office of the Health Complaints Commission</u>. Some of us put in writing what we are hopeful will be useful suggestions for the service, including criticisms and really positive encouragement.
- 114. **Flannel flower:** The flannel flower is the national emblem for mental health in Australia. You can get a copy of a postcard which explains why the flannel flower was chosen, and a lapel pin of a flannel flower (\$2), from the Mental Health Council of Australia.
- 115. **Flat:** This is one of the descriptions of our mood that actually makes sense to lots of consumers. It's not too jargony. It kind of means that we can't feel anything even if we try very hard. People say our face is expressionless and that our voice changes and loses its tonal qualities.
- 116. **Flight of ideas**: This is when we seem to clinicians to be switching topic mid-sentence in a way that they find difficult to understand or 'inappropriate'.
- 117. **FOI Freedom of Information:** The Federal *Freedom of Information Act 1982* came into effect on December 1, 1982 and gives individuals a right to see all their public mental health records. As with all legislation of this type, there are exemptions which are very relevant to people diagnosed with 'mental illness'. There is a small cost to lodge an FOI request, though information is generally supplied free to people on the Disability Support Pension (DSP). For more information, see here or contact the Mental Health Legal Centre, phone 03 9629 4422. See also Health Records Regulations 2002.

G

- 118. **Gen.med.:** General medicine. General medicine is practiced by 'general physicians' (differentiated from general practitioners, or GPs) who have expertise in diagnosing really complex, often chronic problems in adults. These problems may cut across several speciality areas including psychiatry. They are trained to deal with ambiguous and contradictory symptoms as well as psycho-socially informed physical problems.
- 119. **Glass-knocking techniques:** Describes our ability to get the attention of staff by knocking on closed windows, in what often amounts to an internal inner shell of impenetrable glass (through which we are, however, still keenly watched!). These are essential skills for many of us during a period in an acute setting. One day someone will acknowledge a world record in fruitless knocking! On a more serious note, ignoring people who are politely (or desperately) seeking assistance or attention in an acute setting portrays a really bad image and can lead to violence. Staff sometimes say that the problem lies further up the chain of command and that what appears to us to be hibernation is in fact one way of dealing with emotional and



interactional burn out. If this is the case then structural, systemic change is urgently needed. Most commonly it's caused by shortages in staffing, rotten architecture, dreadful attitudes, divisions between different sorts of clinicians, and a failure to work as a team. However, architectural changes are being made in some acute units which enables people to speak directly to a clinician who does a shift 'out the front' at a curved desk outside the glass. Their job is to help connect people to their 'contact nurse' or whoever is dealing with cigarettes etc. People just do a limited shift on the desk, which possibly helps the burn-out problems. See also *contact nurse*.

- 120. **Grand rounds:** This is when the Consultant Psychiatrist (the boss, or one of the bosses) brings the troops (the students, the registrars, the medical officers and the Charge Nurse or head nurse) with her/him and calls us in one at a time. It's a bit like an inquisition and it sometimes has more to do with teaching the next generation of doctors than it has to do with our health. Some patients love it because it breaks the boredom. Others find it difficult because there are so many people in the room. See also *ground rounds*.
- 121. **Grandiose delusions:** This is the way clinicians describe the situation when we really believe we are famous or God, science-fictional or supernatural. It's most often associated with those of us who have a diagnosis of 'psychosis'.
- 122. **Ground rounds:** This can refer either to what we do (walk around the grounds) when we're not welcome to visit a friend on an acute units; or when we are allowed to take a friend out of the locked unit for a short walk. The authorities always describe the mainstreaming policies of the early 1990s (where the big institutions were closed down and psychiatric services were 'normalised' into units of general hospitals) as being driven by consumers. This is simply not true. We were demanding lots of things. We definitely wanted de-institutionalised behaviour of staff, but losing our lawns and lovely gardens and trees to sit under in the old places was **NOT** one of them. Many consumers believe that, in the main, deinstitutionalisation had a whole lot more to do with the expensive real estate than an ethic about practising psychiatry.
- 123. **Guarantee your safety:** This phrase is often used to stop people moving ahead and on with their lives. Now that risk management and a bureaucratic fear of being sued are driving services, these ideas will continue to be used to limit experimentation, keep staff in control, and disallow new ways of responding to things. The truth is, sometimes this short-term over-protection will lead to the loss of long-term goals or, at the very least, justified cynicism about the goal-planning games that seem to be so much a part of rehabilitation work. Sometimes we talk about 'dignity of risk'. Dignity is one of the most precious gifts we can have but for many of us diagnosed with 'mental illness', what we have left of this sacred commodity after our first episode is wrenched away by services' over vigilance.



- 124. **HACC Home and Community Care:** The Victorian HACC Program is Victoria's principal source of funding for services that support frail aged people, younger people with disabilities, and carers. See here.
- 125. **Hallucinations:** This may be simply defined as the perception of an external object in the absence of a corresponding stimulus. This is an over-simplistic definition but a hallucination is basically seeing, hearing and/or smelling things that others can't see or hear or smell. It is a total commitment to the reality of these external objects. It is often associated with a diagnosis of 'psychosis'.
- 126. **Handover:** Psychiatric nurses work in shifts a morning shift, which generally starts at about 7am; an afternoon shift, which generally starts around about 3pm; and a night shift generally starting at 11pm. 'Handover' is when those on the departing shift give a summary of every one of us on the ward to those starting the new shift. We have to remember this when we are



- speaking to staff members it is their job to pass on this information at handover. This is understood to be 'good practice'. Be careful what you say and to whom. No staff member ever works as an individual everything goes back to 'the team' and everything from the team gets discussed at 'handover'. There is little point in knocking on the glass during handover; there is only a skeleton staff on, and they are usually unavailable.
- 127. **HDU high dependency unit:** A high dependency unit is similar to what mainstream hospitals call 'intensive care'. It's very telling that the two terms have such a different feel. Somehow the 'care' word disappears when it comes to psychiatric hospitals.
- 128. **Headspace:** This is a huge initiative funded by the Federal Government. The focus is squarely on the mental health needs of young people. At the time of writing, 30 services are already up and running around Australia, and more are planned. See here. See also early intervention.
- 129. **Health Re cords Regulations 2002:** This is the legislation that enables people receiving private psychiatric services to access their records. It's similar to <u>FOI</u> for public services but it is Victorian state legislation rather than federal legislation. See <u>here</u>.
- 130. **High/low functioning**: Some of us get labelled 'high functioning', which means that despite having a 'mental illness' we are perceived to be intellectually, socially and behaviourally competent. Others get labelled as 'low functioning', which means we are seen as intellectually, socially and behaviourally incompetent. This is classic <u>medical model</u> thinking, and some of us don't like it. We think that these concepts are in big part issues of social privilege, education and so on. Both groups lose by being labelled in this way. So-called 'high functioning' people can't get services and so-called 'low functioning' people are often told they are hopeless.
- 131. High/low prevalence: 'Low prevalence illnesses' describe 'illnesses' that occur relatively infrequently in the community and 'high prevalence illnesses' describe 'illnesses' that are more common. At least, that's the theory. People get very confused because in practice the usage of the terms often involves mixing up prevalence with seriousness. They are very different concepts but we suspect that the language of prevalence was brought in, in part, to calm the increasingly vocal demands that we stop using SMI (Serious Mental Illness) to describe the 'most needy' in a way that excludes everything except 'psychosis'. Research methods used to gain information about so called 'high prevalence' and so called 'low prevalence' consumers are flawed because for low prevalence data the researchers only used people already engaged in public mental health services when resources are so depleted that nearly all the people involved as research 'subjects' had a psychotic illness anyway. The flaw? There are many more people with low prevalence diagnoses than just those with psych otic traits. This research is worrying for some of us because it is used as a basis for future planning of services.
- 132. **Histrionic:** This is one of those derogatory terms that is used to describe women diagnosed with 'mental illness'. It means we are seen as having shallow and insincere emotions and chronic, attention-seeking behaviours.
- 133. HoNOS Health of the Nation Outcome Scale: HoNOS is a set of 12 scales, each one measuring a type of problem and experience we bring to services. A completed HoNOS score sheet provides a profile of 12 severity ratings and a total score. It is a numerical record of clinical assessment but is not supposed to replace clinical notes or any other records. It is intended that it becomes an integral part of a minimum data set. HoNOS is used by comparing the severity of each problem/experience we have, giving us (and the service) some indication of improved health over time. Many of us will have an encounter with HoNOS sometime during our 'career' through mental health services.
- 134. HOPS Homeless Outreach Psychiatric Services: HOPS provide a specialist clinical and treatment response for people who do not engage readily with mental health services. HOPS work in partnership with homelessness services and use assertive outreach to locate and engage with clients to create a pathway out of homelessness by providing early and appropriate treatment. HOPS also link clients into the mental health service system.
- 135. Housing and support packages: This is a new area of priority in the Psychiatric Disability and Rehabilitation Sector (PDRS). It has belatedly been recognised that if we don't have anywhere to live it is unlikely that that we will have a good quality of life, including good mental health. Recent research has shown that it is not just a matter of people with 'mental illness' and 'mental disorders' being debilitated to the point of losing their housing but that in factit also works just as damagingly the other way; that is, that people who lose their housing security are likely to develop 'mental illnesses' or 'disorders'. Some of us who have been homeless tell a salutary tale that sometimes we choose to be 'homeless' rather than live in conditions that destroy our spirit (perhaps with excessive rules and regulations, perhaps with being infantilised and patronised).



Housing and support packages are an attempt to individualise service responses to better suit the expressed needs of clients. See the excellent report by VICSERV <u>here</u> (PDF).

- 136. HREOC Australian Human Rights & Equal Opportunity Commission: A Federal Government commission based in Canberra. See https://example.com/hemostern/ Canberra. See hemostern/ in relation to the equal rights of all Australians both citizens and non-citizens. It has five divisions. They are departments that have a predominant interest in: age related issues; disability related issues; human rights of all in Australia; issues to do with race discrimination and issues to do with sex discrimination. The section of HREOC of most interest to many of us campaigning in mental health is the area responsible for disability. We have rights as people with psycho-social disabilities. Perhaps the finest hour for HREOC in relation to people diagnosed with 'mental illness' was the publication of the critical, hard hitting and bluntly honest National Inquiry into the Human Rights of People with Mental Illness in 1993. It was damning in its critique. The then Commissioner was Brian Burdekin and this report went on to be known (affectionately by some) as the *Burdekin Report*. The Federal Minister for Health at the time, Labor Minister Brian Howe, launched the Federal Government into the affairs of mental health systems around Australia for the very first time in Australian history in coordination with the publication of this report. The first Federal National Mental Health Strategy was launched alongside the Burdekin Report in 1993.
- 137. **Hypochondria:** Hypochondria is a <u>somatoform disorder</u>. This is different from a <u>factitious disorder</u>. The difference is that people with somatoform disorders don't make up symptom and present to services mimicking a physical condition (which is main characteristic of people diagnosed with factitious disorders); rather, people with hypochondria very sincerely believe they are ill and are scared (often time after time) that they are getting very unwell physically. Those of us who seem to have hypochondria are usually living with extremely high levels of anxiety. In order to deal with this debilitating anxiety the thing that seems to work for us is to have investigations into many, usually serious, physical health problems which we believe exist. Many of us suffer enormously from others' judgements of the way we have found to relieve our anxiety and often we, too, wish we could find a way that doesn't attract so much negative attention. Unfortunately, even a diagnosis of anxiety doesn't help much because we are often scared of being diagnosed with 'mental illness' which is one of the reasons why we are crying out for a physical explanation. Unfortunately, as far as 'mental illnesses' go, anxiety disorders are often neglec ted as non-serious even though full-blown hypochondria can be so consuming that we lose our jobs, stuff up our relationships and end up with depressive illnesses on top of everything else. Hypochondria is also sometimes called hypochondriasis.
- 138. **Hypomania:** Describes a state of mind where we have a persistently elevated mood and decreased need for sleep, where we can be chirpy and very friendly, and on the go much more than usual, but are not seen as <u>psychotic</u> or having a fully fledged 'manic state'. Sometimes we can be really productive during these periods. See also <u>bipolar</u>.

139. Ideas of reference: Also called 'delusions of reference', this describes the situation where sometimes those of us who experience what psychiatrists call 'psychotic' symptoms, or consumers might call psychotic experiences, we truly believe, experience and understand that inanimate objects are communicating especially with us. This might be a television, a griller in a stove or an air conditioner, for example. Sometimes the messages are called 'command voices' or 'command messages'. This means that these inanimate objects tell us to do things that make sense to us at the time but don't make much sense to anyone else. We might be told to do a terrible act, even to the extent of stabbing someone, but the reason might be beneficent – that it's the only way we can save the planet, for example. This message might be relayed to us through the TV



talking to us. Sometimes the messages coming from the air conditioner or the computer giving us special messages are not 'command messages' but rather just awful, insulting, nasty, accusative attacks on us as people. We are often very scared of these.

- 140. **Illusions**: The condition of being deceived by a false perception or belief. This can include a belief that services are going to be healthy, helpful places that do good, not harm! Many of us remain seduced by this illusion even though we know it is not true.
- 141. Impulse control: Issues of impulse control are present in most of us. Sometimes we 'lose it' (and if we don't lose it we get diagnosed with <u>passive-aggressive</u> personality disorder!). Anger, and what psychologists like to call 'acting out', doesn't matter for most people it only tends to turn into a major issue when you have a psychiatric diagnosis, when you are in a psychiatric unit, when you're in prison, when you're under scrutiny by child protection agencies, when you are known to bash your partner, when you're Indigenous, or when you come from overseas and look different from 'us'.
- 142. **Inap propriate:** This is a word sometimes used in a clinical setting to describe our behaviour. It is used when clinicians think we are trying to solve our problems in ways that they don't like or don't think the community will like. This word is possibly one of the five most commonly used terms in psychiatry. Obviously we don't like being described in this way but the real question is which group is making the decisions about what is, and what is not, 'appropriate'.
- 143. **Incident:** The word 'incident' is generally a euphemism for some very scary and sometimes violent happening on the ward or in the community service. Sometimes 'incidents' involve security guards or even the police. The term 'incident' is used in the mistaken belief that we, the patients, will be kept calm by being kept in the dark about what is happening.
- 144. **Individuals:** Most of us prefer the word 'people'. We are people just like any other people. Apart from making us feel different and 'other', the term 'individuals' makes service providers and services sound like the police.
- 145. **Individual service plan:** An individual service plan (ISP) is a working plan put together by us and our <u>case managers</u>. It is a written summary of our goals and strategies. The plans may vary in length, depending on the types of needs we have and the time it is going to take for these needs to be met.
- 146. **Informal patient:** A description of a patient who is not held under the *Mental Health Act*, meaning they can leave the hospital whenever they want (this is the case in theory, but in practice there can be huge informal pressure placed on people to remain under the 'care' of the service).
- 147. **Informed consent:** Every patient in any area of health must give their 'informed consent' to any procedure except in a psychiatric situation, where the *Mental Health Act* trumps concerns about informed consent. Once we are held against our will we can be treated against our will. The one exception to this is electro-convulsive therapy. For this to be introduced into a therapeutic regimen, extra legal procedures need to take place. Informed consent in psychiatry often ends up being 'uninformed consent'. As potential subjects, we can be intimidated into wanting to please people who seem to have a lot of power and standing. Often the information we are given is poorly articulated and does not give us enough information to allow us to make an informed decision. On other occasions we are given insufficient time to wade through everything, so we just say 'yes'.
- 148. In the best interest: This is a legal term which means that in certain circumstances, for example when a child is involved, the legal representative has a responsibility to make a decision, which their training and experience enables them to make, on behalf of the child. The same legal argument is sometimes made in relation to people diagnosed with 'mental illness' when they are deemed 'unwell'. There are two legal positions that can be taken either in an open court or in the Mental Health Review Board of Victoria. Lawyers acting for consumers can 'act in the best interest of their client' thus assuming a superior position to make a decision and working from the assumption that the consumer they are representing 'lacks capacity' to make decisions for themselves; or they can, unless it is absolutely impossible given the consumer's experiences at the time, 'take instructions from the client'. Mental Health Legal Centre lawyers argue that it is rare for them to be unable to 'take instructions' regardless of the severity of 'illness' at the time.



- 149. **Insight:** This term is used specifically within the context of the 'medical model' understanding of 'mental illness'. It assumes there is a right and a wrong way to understand what we are experiencing. Our own understandings, or insights, often don't qualify as insight.
- 150. Intake: Intake clinicians do the community services end of what the <u>CAT team</u> does at the acute end. 'Intake' describes the process which (public) <u>Area Mental Health Services</u> go through to come to a decision about whether to accept a new client. Many of us are despairing of intake procedures for several reasons: Firstly, intake clinicians become hardened. They are so used to turning people away that they fail to recognise and honour the individual desperation of many of our lives. Trying to get into services is a heartbreaking experience for many. Secondly, intake depends almost exclusively on diagnosis. If we don't have a <u>psychotic</u> diagnosis we probably won't get into a public service (we're hoping his might change). Thirdly, for some of us the route to being accepted into services is to take more overdoses or cut ourselves deeper and more dangerously. When we pick up a pamphlet in almost any public mental health service it tells us if we've got <u>anxiety</u> and/or depression that we have to escalate (or report an escalation of) our symptoms, while people with a diagnosis of 'borderline personality disorder' are told that we have to be a danger to ourselves and/or others in order to get through the door. Fourthly, even when people with the 'right' diagnoses do all these things, the likelihood of getting a service is still bleak; these days, many people with psychotic experiences don't even get past the Intake Guards. Finally, intake clinicians do not have a responsibility to help us find somewhere outside the public mental health system when we get knocked back. This is unhelpful and potentially dangerous.
- 151. **IPS:** Intentional Peer Support This is a very specific form of peer support that was developed by Shery Mead and Chris Hansen from the USA. It is based on four essential concepts: connection, world view, mutuality and moving towards. Both Merinda and Flick from <u>Our Consumer Place</u> are trained to teach Intentional Peer Support in Victoria.
- 152. **IPP Individual Program Plan:** This is a key document used in the <u>Psychiatric Disability Support Services</u> sector. It is a working document frequently updated but usually the 'participant' doesn't get to see it until after staff have completed it. This is very strange. Surely our commitment to a plan of action increases exponentially when we play a vital role in deciding what we want to do and where we want to go in our lives?

J/K

- 153. 'Just' anxiety: It is upsetting and annoying that anxiety is so often dismissed as non-serious. How can this possibly be? We reckon at least part of the explanation is gendered. Anxiety is associated with 'neurosis' and women's pain, and it is unlikely to put anybody (other than the person struggling) at risk. There is a myth that just because many people experience anxiety, it is not serious by definition and therefore should not be a priority. The notion of 'just anxiety' is structured into the National Mental Health Strategy and, unfortunately, is the common parlance of too many decision makers, policy writers and even the consumer discourse. See anxiety disorders.
- 154. **Key workers:** The 'key worker' in a service is responsible for collaborating with the participant in the development of an <u>Individual Program Plan</u> (IPP) that reflects the participant's disability rehabilitation and support needs.



- 155. Language: There is so much we could say about the language of mental health! First, we didn't want to be 'managed' who would? Secondly, we didn't want to be 'treated' (as in 'permanently treated') - who would? Thirdly, we don't want our language coopted. When consumers/survivors started to talk about 'recovery' it became a very important part of our language. What happened next? Bureaucracies and organisations started talking about 'recovery plans' – they stole our concept and rendered it powerless politically. Now we are starting to talk about 'personal transformation'. It will be interesting to see how long it takes for organisations to start talking about 'transformation plans'. More about the language used in this booklet is contained in the introductory notes.
- 156. Leave: During hospital admissions some patients especially in the private mental health sector are sometimes 'given leave' to see a doctor, visit friends, or go to the shops. Often this starts as 'day leave', and later becomes 'weekend leave'. Many of us have experienced really strange meetings before weekend leave where everyone is expected to talk about how they are going to cope with leave. Most people know what to say and what not to say so they won't get their leave revoked. See also AWOL.
- 157. Losing clinical language: This is a phenomenon we have come across when we are working with consumers and clinicians together. Many of us are very conscious of language because we know that language is imperative in relation to the changed relationships we wish to forge with clinicians. Unfortunately, the clinicians who are most attracted to our work are most probably the ones we would not have problems with anyway. The trouble is, the clinicians who take our messages on board sometimes find there is very little left of their clinician-talk once language that is non-patronising, non-judgemental, non-shorthand, non-labelling and non-objectifying is excluded. They feel they can't sabotage their relationships with their peers by losing their common language – and so nothing changes. We would love to see more very senior people who want to embrace our hard-won knowledge, as in most workplaces it is the most senior staff who create the most significantly cultural changes.
- 158. LOTE language/s other than English: A term often used in education. See also <u>CALD</u>.
- 159. Low/high functioning: see high functioning.
- 160. Low prevalence/high prevalence: see <u>high prevalence</u>.
- 161. LSE low stimulus environment: Sometimes within the hectic and chaotic environment of a psychiatric ward we want to go to a place which is quiet and where there is a rest from the cacophony around us -a 'lowstimulus environment' or LSE. Sometimes we are forced to do so.



162. Mainstream services: Psychiatric hospitals used to be big asylums with thousands of mad people completely separated from society. From the 1950s, people started to see madness as a medical 'illness' to be cured, or to be controlled by a new series of drugs. At the same time, institutions became smaller and new ideas 'for entertaining the inmates' were

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introduced. De-institutionalisation began. In the 1990s a huge push towards de-institutionalisation took place in response to the first National Mental Health Strategy. State infrastructure was ill equipped for this rapid change. The term 'mainstream services' was created as a way of positively describing a large-scale push of people out of the big institutions with acreage (expensive to run and worth a lot of money to sell.) Mainstream services are those psychiatric units that are not separate from other hospitals but are annexed on to ordinary ('mainstream') hospitals (usually on the end or out the back, which is unsurprising).

- 163. **Malodorous**: A word meaning 'unpleasant smelling', its use in a clinical setting arises from the way registrars are trained in psychiatric hospitals to do mental state examinations (MSE). They, like all clinicians working in the area of psychiatry, are taught to monitor, watch, and encrypt what they see through medically trained eyes. These observations include what people look like, smell like, and any other physical signs. The word 'malodorous' is most likely to crop up in the first sentence of the admission meeting smell is one of the things that we all notice first because it is the most powerful of our senses. It is also extremely rude to concentrate on it.
- 164. **Management plans:** In many Australian states services use 'management plans' instead of 'treatment plans'. This change of name in Victoria was supposed to herald a change in attitude towards consumers. In the end, however, it has proven to be a euphemism. There is very little difference in the way so-called 'treatment plans' and 'management plans' happen in practice, nor how they are written and enforced. Worse, it is deliberately misleading because these plans are still essentially about 'managing' us using all sorts of rules, regulations, threats, cajoling and so on. Good clinicians can do this brilliantly and it doesn't even feel like 'treatment', let alone 'management'. However, under-skilled clinicians, inexperienced clinicians, burnt out clinicians, and people who just don't care can use this document as a crude enforcer of their will, not ours.
- 165. **Managing clients:** Over and over again, the language used in psychiatry bugs many of us. Many of us do not want our lives 'managed' by others by people we barely know and who only know one sliver of who we are; the small part they see of us as a service recipients. It also draws attention to the fact that we are being asked to 'manage ourselves' and 'allow other people to 'manage' us' at the same time. This is a silly game because the end result is that inevitably people learn how to read the system and play the right hand.
- 166. **Mania**: This word describes a place some of us find ourselves in where our mood is super <u>elevated</u> and we're permanently aroused, busy and sometimes making decisions we later regret.
- 167. Manic: A word used to describe us when our mood is high. We may be getting exhausted but are propelled to keep doing things that are often described as 'inappropriate' and can leave a lot of trouble for us in the future. Experience has taught some of us that mania is not a 'truth' to be witnessed but rather a judgement to be tested. Psychiatrists and consumers disagree all the time about whether we are manic or not. Some of us reflect back after the 'episode' and recognise retrospectively they we were manic. Others of us don't and continue to feel wrongly accused and badly treated, particularly if forced treatment was involved. It's all a balancing act. Psychiatrists can take punitive action (that they may see as protective action) to protect our 'reputations' when they perceive us to be manic. This significantly widens the criteria for enforced detention and treatment. Mania does not mean euphoric or even happy it's about all systems 'go', constantly. This leads for some to grand plans, huge creativity, no sleep, lots of ideas, along with (sometimes) agitation, frustration, anger and confusion. There are two 'types' of mania. Perhaps the psychotic type of mania is more easily recognisable. We can do very strange things in this state. The non-psychotic type of mania is fraught with all the same urgency but without the 'outside reality' traits.
- 168. **Matter:** In legal terms, this word holds a lot of meaning. It's bamboozling at first as everything seems to be a 'matter' and lawyers working with people diagnosed with 'mental illness' don't seem to notice that they are using jargon. It simply means the problem that we have come to the lawyer to help us solve, or the problem we have because someone else has gone to a lawyer about an experience that affects us.
- 169. **MDD major depressive disorder:** Another term used to describe <u>unipolar depression</u>, <u>endogenous depression</u> or <u>clinical</u> <u>depression</u>.



- 170. **Medical model:** The term we us to describe a particular discourse or way of framing emotional distress. The medical model is the dominant way of understanding such distress at this time in history. It came into prominence in the 1950s (not all that long ago) with serious breakthroughs in pharmacology. One of the important drugs to emerge was lithium in Melbourne in 1948. Since that time other discourses to describe emotional distress such as religious explanations, madness, witchcraft, unconscious desires, etc. have gone out of fashion. Some consumers have critiqued the medical model for being too narrow in its focus, too tied to huge multi-national drug companies, unable to explain with deftness and subtlety, not designed to understand the role of trauma, and too busy labelling people to notice that we can do a lot of healing with and for ourselves and our peers. Some consumers have also suggested that the medical model can do people harm and question whether any 'treatment' that is forced on someone against their will is actually 'treatment'. The medical model contains within it the need to 'help' people by doctors and their institutions having a 'duty of care' and that this might include the forcing of psychiatric drugs on to people when they are 'too sick' to know they need them. (See <u>So you have a 'Mental Illness'... What Now?</u>, Our Consumer Place publication, p. 10.)
- 171. **Medication queue:** This is common in most psychiatric hospitals, units and wards. We stand one after another and if we don't come we get rounded up. Many of us hate it because it epitomises the depths to which we have fallen in terms of our grown up, confident, competent status in the world. It is symbolic of being treated like a child.
- 172. **Medication rounds:** 8am, noon, 5pm, 9pm you soon get to know when the medication rounds happen. Staff on psychiatric units are particularly vigilant that we take the medications we are given.
- 173. Meds: Shorthand for medications or medical drugs.
- 174. **Mental health triage scale:** The Victorian Mental Health Branch has recently published a new triage scale that services will be expected to follow. The purpose is to regulate, and hopefully improve, the role of <u>CAT teams</u> and others involved with making decisions about service priority. Everyone can view this scale on the <u>Mental Health Branch website</u> (PDF). From the point of view of people with lived experience, this document may reinforce what we intuitively know that the main criteria for getting access to a service is how much risk you pose rather than what the service can do to help. It's worth having a look.
- 175. **Mental Health Day/Week:** World Mental Health Day is traditionally October 10 each year. The World Federation of Mental Health is responsible for choosing a theme for World Mental Health Day each theme goes for two years. The money and responsibility for organising World Mental Health Day in Australia belongs to the Mental Health Council of Australia (MHCA) (email admin@mhca.org.au, or phone 02 6285 3100). In Victoria, we celebrate the whole of the second week in October as Mental Health Week. Activities are organised by the Mental Health Foundation of Victoria.
- 176. Mini suicidal gesture: This is a term with which many people have problems. Let's pretend that you have had a day where the urge to kill yourself has been unrelenting. The act of self-harming is constant because your mind is full of overwhelming thoughts that you are so useless your family would be better off without you. Over the day you practice every skill you have self talk, breathing, going for a walk, even plunging your arms into freezing cold water. In the end you are forced to converse with your head and make a compromise. You self-harm but it is minor compared with the pain and the struggle. It works in its own way to release the urge and you are relieved; that is, until you see your file, which describes your bravery as a 'mini suicidal gesture'.
- 177. **Mixed state:** This is a term that is used by clinicians to describe a strange mood place where some of us go, where our activity might be exaggerated and 'high' but our actual mood is low.
- 178. **Mobile phone:** In most units, mobile phones are confiscated when you are admitted. The official reason that is mostly given is that the camera component of modern mobiles could breach other patients' privacy. However, another 'worry' is that people who are really 'manic' "may make very inadvisable phone calls" and, for example, lose a lot of money. It is felt these people need to be "protected from their own decisions". The problem is that all of us in the unit are affected by this catchall policy and we are almost entirely cut off from the very community that will enable wellness.



- 179. **MRC migrant resource centre:** a community-based organisation that provides settlement services for migrants and refugees.
- 180. **MSA mental state assessment:** An assessment of our mental health, tending to follow a bit of a formula, which many of us can predict. This prediction is based on common sense, not manipulation: many of us have got to know the questions so well that we have gained more capacity to use this process to get our needs met or at least understood better.
- 181. **MSTS Mobile Support and Treatment Teams:** Assertive treatment and support designed to allow people to live in the community. These teams provide mobile support and intensive 'care' for people with very complex needs. Clinicians involved in these teams have a lower case load but engage more extensively.
- 182. **Multiple and Complex Needs Initiative:** A service for a very small number of people with very complex, extensive and multiple needs that cut across a big range of services: mental health, drug and alcohol, housing, and children's services, for example. It caters for very few people but provides very intensive support, often following people into prison, or refuges, or hospital admissions. On 31 May 2009, the original legislation underpinning the Multiple and Complex Needs Initiative was replaced with the *Human Services (Complex Needs) Act* 2009. The introduction of this legislation made for a number of changes to the model. The current MACNI model is detailed in the <u>Department of Human Services website</u>.

N

- 183. Narcissistic personality: Often associated with people diagnosed with personality disorders, this term implies we are selfish, self-centred, demanding, vain and compulsively manipulating of staff and other patients to get what we want. It's a judgemental and merciless term. Many of us are hurt or angered by the attitudes this term embraces.
- 184. **Neurotic:** Neurosis is a word that is still bandied around but its meaning has changed over time. Earlier, it was seen as a genuine psychiatric diagnosis, in some ways the opposite of <u>psychotic</u>. It was seen to involve extreme distress but not the classical 'delusions', 'hallucinations' and other hallmarks of 'psychotic illness'. Over recent decades, it has lost its place in psychiatry as a genuine psychiatric diagnosis but it remains (and is common) as a derogatory, dismissive term often accompanied by the word, 'only' and often gendered female.
- 185. **NGO Non-government organisation:** An organisation, usually not-for-profit, that operates independently of government. These include the NGOs that are specifically there to provide services to people diagnosed with 'mental illness'.
- 186. **Non socially-sanctioned self-harm:** Who knows! We found this term in a series of interchanging letters to the editor in the *London Times*. The term was used by a psychiatrist.
- 187. **Non-compliant:** Describes when we make independent decisions to do things that the doctors, the staff, and the system don't want us to do. The system wants us to be both 'compliant' and 'independent'. Quite a hard ask, really.





- 188. **Obs:** Short for observation, this term refers to the number of times your contact nurse must sight you and make sure you're OK. (NOTE: it does not include either speaking with you or listening to you.)
- 189. **OCD obsessive compulsive disorder:** Behaviour involving 'rituals' and ways of doing things that sometimes can completely immobilise us. Like most troubles with anxiety, its seriousness is often underestimated.
- 190. Open ward: A psychiatric unit that is not locked and where you are free to come and go.
- 191. **OT occupational therapist:** A person concerned with promoting health and wellbeing through enabling people to participate fully in the activities of their everyday life.
- 192. **Other clinical populations:** Some of us are continually surprised that the professional literature, and even informal discussions about 'patients', seem to use as complex terminology as possible to describe a concept that is actually quite straightforward. We can only assume that this particular phrase refers to people with different diagnoses.
- 193. Othering: 'Othering' can be seen as any action that renders a person or a group of people different and less than the norm.
- 194. **Outcome measures:** There are primarily two kinds of outcome measures used by psychiatric services: self-rating scales are measurement instruments that we fill in for ourselves, while clinical scales are completed by clinicians and report their perception of our 'progress'. Both these scales can also be used to create a service data set which enables the service to better understand how it is going over time. We are allowed to ask how we have gone on any measurement scale. Some of us keep our own records.
- 195. **Outpatient:** This is a term mainly used in the private sector these days. It refers to those of us who are not inpatients in the sponsoring private hospital but who attend programs and courses provided by the hospital, including <u>outreach</u>. These services are now claimable on private insurance, though are usually only available if our own private psychiatrist has an admitting agreement with the hospital.
- 196. **Outreach**: This is when a mental health worker meets us in our homes to give us support. This might be once a week, once a fortnight or once a month. It is often something that we find useful after we have developed to a degree of wellness that means community services in daily programs or live-in programs are no longer necessary. We still have a 'management plan' (words many of us don't like who wants to be 'managed' by someone 20 years younger than them?).
- 197. **Over familiar**: This is jargon for when services think we are being 'too friendly' with people who are workers and not your friends. Some of us think that this is primarily an issue of power, especially institutional power.

P

198. **PANDA – Post and Antenatal Depression Association Inc:** PANDA offers the following services: helpline support, counselling and information, provided by staff and trained volunteers; resources and information on antenatal and postnatal

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depression and anxiety, and postpartum 'psychosis'; information and referral details for supports and services in your area; information, education and training seminars for professionals and community groups; provision of staff and trained volunteers as guest speakers; community information displays; and regular newsletters for members. See here or phone 1300 726 306.

- 199. Paranoia: Describes a situation where we are feeling very afraid because we are hearing things and seeing very frightening stuff happening but others don't get it because they can't see or hear any of it - it's very real to us but not to them.
- 200. PARC Prevention and Recovery Care Services: These are step up, step-down services for people who are at risk of needing intensive acute unit 'treatment' or who have just experienced a period in an acute setting.
- 201. Passive-aggressive: This term is often used in a derogatory way to describe us. It implies that we tend to get the control we desire by refusing to interact. Some of us experience this not as obtuse refusal to communicate to gain power but rather fear and confusion to such a level that we lose our voice or we're trying to protect other people.
- 202. PDRS Sector Psychiatric Disability Rehabilitation and Support Sector: Well, at least we think this is what the acronym stands for! It has proved very tricky to get everyone to agree on what it means! There are many different services provided by this sector. Some of the big organisations involved in this sector, many of which now oversee many agencies, include MIND Australia, Mental Illness Fellowship of Victoria, Prahran Mission and NEAMI. The sorts of services they provide range from supported housing, to day programs, respite programs, outreach programs, housing programs and opportunities for participants in their programs to be involved in art and a nursery. As we move around the different services we hear lots of news about the programs and what they do well and what they do less well. There are an increasing number of consumers working as consumer consultants and peer support workers, and some are now creeping into management circles as well. These organisations are so different from what they were even a decade ago. From the old lobbying groups with committees of management they have become the fastest growing sector in Victoria with corporate structures and corporate behaviour: using terms and branding and business in confidence, and running services in multiple state and territories.
- 203. PDs 'Personality Disorders': This acronym is like slang; it's dismissive and often accompanied with the words 'only' or 'just'. It often implies, "This person [those people] is a pain in the neck, nothing I try works and they shouldn't be here anyway because they don't have a proper mental illness."
- 204. Peer reviewed: This describes where clinicians and medical scientists have had their research work read and endorsed by their peers, who are, in this context, other researchers/psychiatrists. Actually this holds no real importance in relation to the research but it does hold importance in relation to the status of the study.
- 205. Peer support: Peer support is an idea that has been around for a long time. Originally it was based on the idea that people diagnosed with 'mental illness' led lonely and isolated lives and that if some outside organisation could do a 'bus run' and bring them all together everyone would benefit. After some time, people realised that such events were regularly organised by 'outsiders' and the original concept of talk and friendship was gradually turning into structured rehabilitation activities. There are still remnants of this concept in what are now called <u>psycho-social services</u> provided by non-government agencies.
- 206. Perceive: A term generally reserved for us (not often used by clinicians in relation to themselves). Rarely is our knowledge of ourselves and our lives treated as essential knowledge. It appears that we 'perceive' things and everyone else 'knows' things.
- 207. Perceptions of abandonment: A phrase used to describe people diagnosed with 'borderline personality disorder'. Many people with this diagnosis feel hollow inside and this emptiness can leave us feeling like no one cares about us - that we have been abandoned. It is a very real and very frightening experience that takes work to overcome, especially as most of us with this diagnosis were neglected, abandoned, violated or witnessed violence when we were too young to do anything to stop it. Using the term 'perceptions' suggests that our feelings are not real. This is wrong.



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- 208. **Permission:** When we are in a locked ward we have to ask permission to do just about anything. This generally means attracting the attention of a nurse and waiting till someone is free to accompany us. However, it is not as simple as this often you have to wait and wait until you even sight your 'contact nurse' and then s/he makes a decision about priority. This is where a couple of skills come in handy. The first is 'being a good patient' and the second is 'glass-knocking techniques'. There is also the 'squeaky wheel' effect (the squeaky wheel gets the grease; i.e. the noisiest, most annoying person, gets the attention) but this can land you in even deeper trouble and might not be worth it. Although we can laugh at this with our renowned black humour, it is actually very belittling and simply bad for your mental health to be constantly supervised and needing to ask permission from people half your age.
- 209. **Personal Helpers and Mentors Programs PHAMS:** PHAMS is funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). It is a program which has been taken up by some clinical services but mostly by the <u>PDRS Sector</u>. Some of us were quite upset about the way these positions were created with minimal consultation with consumers, especially consumers with experience of consumer politics and leadership qualities; consumer expertise should have been used to provide advice on how to get the program up. In some places it is all working out for the best; in others it is struggling. Different organisations have made totally different calls on whether 'their' staff should be 'allowed' to disclose their consumer status and whether the PHAMS workers should or should not have consumer mentors paid of course. It does seem odd to not allow people to disclose their consumer status because this is, and has to be, THE most important knowledge they bring to the position. Enforced non-disclosure forces consumers into an unauthentic position, which we just know everyone will see through anyway or, at least, find patronising.
- 210. **PHACS Primary Health and Community Support:** Provided by the Department of Health, these include community health centres, centres against sexual assault, innovative services for homeless youth, dental health services, some community-based mental health services and some community-based drug treatment services.
- 211. **Placebo:** This is the name that is given to a look-alike drug that has no actual active ingredients but looks like a real pill. It is used in medical drug trials to try and minimise bias by both patient and researcher/clinician. See also <u>blind trials</u> and <u>double-blind trials</u>.
- 212. Planning for the future: Many of us who have had experiences that have distressed us and sometimes left us using psychiatric services quickly realise that the buzz theme seems to be 'planning'. We are told we have to plan for <u>day leave</u> and then plan for weekend leave. We have a '<u>management plan</u>', a '<u>treatment plan</u>', a '<u>recovery plan</u>', an '<u>individual service plan</u>' and an <u>IPP</u> ('individual program plan')!! Those of us who are disorganised by nature find all this planning a bit bothersome. The potential with all this planning, however, is to forget that the world doesn't pivot around us. One woman, as part of a dialectical behaviour therapy group, wanted to talk about two fundamentally important issues for her: childhood sexual abuse and the feminist critique of much contemporary psychology. She had this idea of the group getting together independently to plan an action for <u>Mental Health Week</u>. Much to her surprise and then disgust, this important planning for the future was labelled as '<u>therapy interrupting behaviour</u>' and she got into trouble.
- 213. **Positivism:** Refers to a 'perspective' on the world which looks through the lens of a science methodology that many people are convinced is far superior than any other way of knowing that it is only through positivist research methods that are rigorous, like double-blind trials, that true evidence to support different treatments can be achieved. As people who have experienced 'mental illness' first hand, we have a much more generous approach to knowledge. Many of us desperately want positivist researchers to look at the things they look at and come up with some different ways to make our lives easier. However, as consumers, we can also see a gaping big hole in the positivist approach. How many of us have been asked to fill in the 'eenie, meenie, miney, mo' questionnaires, which we immediately see through as dumb and that don't ask the questions that we know need to be asked?
- 214. **Power:** It is now oft said, and somewhat clichéd, but it is true that those who have power don't know it and those who don't have it know it. Power is a central concept for many consumers. Not all consumers use the language of power, or for that matter the language of politics, to describe their involvement in the mental health system. Indeed both power, and (particularly) 'politics', scare some people, usually because they associate politics with what happens in Canberra and the



notion of power frightens them. Nonetheless there is no way we can proceed with our journey to revolutionise psychiatry by the people power of ordinary consumers unless we fight the power imbalances that presently mean that the control of most things in psychiatry lie with the economically and politically powerful. In mental health, these include government at both state and federal level, large pharmaceutical companies, organisations such as the Mental Health Council of Australia, which have inadequate consumer representation, powerful professional individuals, and professional associations such as Royal Australian & New Zealand College of Psychiatry. See also <u>critical mass</u>.

- 215. Powerlessness: As consumers, we are relatively powerless. We walk into a room 'owned' by the clinicians, we interact with their secretaries, we sit in the chair that doesn't face the clock, we do not control the situation even though it's our story spilling out all over the room (in half an hour we know another person's story will have replaced ours). Some of us want to please and many of us feel constrained in what we can say. This is powerlessness. At a collective level, we are also disempowered. We have a fragile status. In meetings where there is only one, or even two, consumers we don't get heard. Often we are given time to speak but this is not the same as being heard. Relative powerlessness means we have to fight twice as hard to get heard and then we are likely to be accused of being shrill – making too much noise. This is because people who have power fundamentally don't get it. There have been examples of projects set up to purposely even up the power balance. Frequently those who are used to power feel uncomfortable and are irritated by the exercise, which they then perceive as a waste of time. They may try desperately to regain their power advantage by attacking the process. Some ideas for disempowered groups include: holding meetings in our own spaces and refusing to go to the space of the powerful; inviting government reps and bureaucrats to come to us; or trying to sit in our psychiatrist's chair instead of the patient's one (it feels really weird; and beware: your psychiatrist may want to psychoanalyse you for suggesting such a deviant manoeuvre!). We should always try for 'critical mass' - it's not always possible but it changes the power relationship significantly – fight to have as many consumers as there are professionals in the room or as many consumers as there are policy staff and so on. If you're at a conference and in a break out group offer to take the notes. There is considerable power in the pen. These are just a few strategies you can use. It's a good idea to brainstorm more.
- 216. **Precious belongings:** Very few staff seem to understand the dilemma faced by some of us in relation to the objects in our lives that represent love, spiritual renewal and moving towards health the dog, our home, our family, our things. Most units in public hospitals have one safe, into which goes your money, keys, medications, artefacts, and any precious and symbolic items, along with any connection with the things that matter to us. You may then be able to access them for half an hour each day. Expect this and plan for it. The reality of living for 10 days (or whatever) with people who may be decimated by poverty, illicit drugs and homelessness is that you won't be able to make your room 'pretty' or 'spiritually safe'.
- 217. **Presentation**: This is a perception only but it is a powerful one. Within the first hours of our admission we will be introduced to an admitting psychiatrist (whom we may never see again). A large part of the assessment is this consultant's judgements about how we 'present'. This is sometimes not based on science but rather on social class, levels of education, ethnicity, gender, whether we are in jail and so on. Psychiatric registrars are taught to make their first assessment comment about what they 'perceive' when the 'patient' enters the room. This is, of course, a perception based as much on their prejudices as anything else: "Ms Stein presented as a rather plain looking women in her 30s". However, in many parts of psychiatric service, it is only patients who 'perceive', while staff 'know' or, at least, 'put forward a hypothesis'.
- 218. p.r.n. pro re nata: Latin for 'when required'. It describes where we have been prescribed a medication which we can ask for and have when we need it. It's not always as straightforward as it may seem. Firstly, although it means 'when required', there will be a limit to the number we can have in a day. It's a good idea to ask what this limit is. There will also be a time that needs to elapse before we can have our next dose often four-hourly. Again, ask. This leaves you more in control of your own circumstances. p.r.n. medications can also be misused, with some staff threatening to refuse drugs if people behave in certain ways and threatening to provide drugs if people behave in other sorts of ways. This is not within the spirit of the way these drugs are designed to be used. The other thing to note is that in an environment where surveillance is supreme, we may try to do without optional medications so it looks better in our records. This is understandable but it really is OK to take them if you think you need them.



- 219. **Prodromal:** Describes early symptoms before it is possible for clinicians to make a diagnosis.
- 220. **Prognosis:** Describe what doctors think your middle to long-term health status is likely to be a guess based on the clinician's experience. In mental health we have a history of clinicians giving overly pessimistic prognoses. Over the last 50 years, since the medicalisation of madness, people have been virtually institutionalised because of consistently stultifying prognoses.
- 221. **Promiscuous**: Some of us become very promiscuous when we are 'manic', prompting in ourselves mixed reactions. Some quite enjoy it and suffer few consequences particularly very shy people who have a chance to experiment in ways they would never have under 'normal' conditions. Others do what we later feel to have been outrageous and then have to put a lot of work into building bridges between old friends and sometimes spouses. Psychiatrists get worried by this one.
- 222. **Psychobabble:** This term is a wonderful three-headed beast. First, the term 'psychobabble' was informally used by clinicians to describe us when we were (in their eyes) 'psychotic' and speaking in a way that seemed random and did not make any sense. This became, and is now more formally known as, 'a flight of ideas' or 'word salad'. Next, the professionals upped the ante on the quasi-experts who were entering the field that the traditional clinicians wanted to claim as their own. 'Psychobabble' came, for clinicians, to describe the use of their psychological language by populists and self-help writers. These imposters the non-clinicians were accused of using specific, very important, very proper words out of context and not having the proper qualifications and education to be using them. Now, quite appropriately, consumers are claiming this word as our own, using it to describe the acronyms, the long technical words, the words that means several things at the same time, the judgemental terminology that should be dumped from the lexicon, the words that depersonalise and objectify people, the terms that exclude, terms that judge harshly, terms that empower professionals at our cost, and stuff that is just plain silly, along with language that it's helpful to understand. We don't really care where the words or terms come from psychologists or populists or ourselves: We just call the whole lot 'psychobabble' because that is precisely what it is!
- 223. **Psychomotor agitation:** This is how we are described when we seem to be undertaking a series of unintentional purposeless motions because we are stressed and anxious. Things like pacing and maybe pulling clothes on and off are sometimes seen as indicative of psychomotor agitation, although it could also be menopause!
- 224. **Psychomotor retardation:** This is sometimes called 'psychomotor impairment'. It is when clinicians perceive us to have a slowing down of the way we think and our physical movements.
- 225. **Psycho-social disability:** The terms we use to describe ourselves as a group vary widely. In Australia the most common term is 'consumer'. In other countries the 'official' terms range from 'user' to 'psych survivor'. The worldwide lobby group for us is called the World Network of Users and Survivors of Psychiatry (WNUSP). However, there is always a tension about whether we fit within 'health' (defined broadly) or 'disability'. Belonging to one or the other has different and contrasting advantages and disadvantages politically. A very important place for us is at the United Nations and in that place we go under the label of People with Psycho-social Disabilities. There are people in Australia who see much greater advantages for us to be known as Australian citizens with psycho-social disabilities. Some of this is to do with the relative power and influence of the combined disability sector, rather than the situation where we're out on our own in a mental health balloon. Others disagree primarily because of the perceived (some would definitely say real) pecking order of the disability sector where people with acquired brain injury, intellectual disability and psycho-social disability are frequently fighting to see which group is on the bottom. Others of us simply don't relate to the idea that they have a disability. See also <u>consumer</u>.
- 226. **Psycho-social rehabilitation:** The provision of psycho-social rehabilitation is a key component of all <u>Psychiatric Disability and Rehabilitation and Support Services</u> (PDRSS). <u>VICSERV</u>, the peak body for psycho-social rehabilitation in Victoria, maintains that it is informed by belief in the potential of every individual to change.
- 227. **Psychotherapy:** 'Talking therapy' as compared to 'drug therapy' (although they can be used together). There are many forms of psychotherapy, but it is very hard to access any of them in the public mental health system. Furthermore, the rapid



turnover of staff in <u>Area Mental Health Services</u> makes it very hard for those of us who need long-term types of intervention based on ongoing relationships.

- 228. **Psychotic:** Used to describe those of us who are perceived to be showing signs which are interpreted by clinicians as not 'being in touch with reality'.
- 229. PTSD post-traumatic stress disorder: There are two types of post traumatic stress disorder. At this point in time one is recognised officially and the other is not. The first type was first identified, if not named, after soldiers started returning from World War I. Many were freaked out by the horror they had witnessed to the point that they became barely able to function. It's an extreme anxiety disorder which is characterised by flashbacks, strange and unexplainable behaviour, and failure to connect with people in the same way they did before the trauma. Although it became strongly associated with war veterans, many people experience these things following other types of trauma such as domestic violence, violent muggings, abduction, ransom or armed robbery. (This is one of many experiences that makes a farce out of Australia's silly classification system that declares anxiety disorders to be high prevalence and there, by definition, in the non-serious basket. People struggle mightily with this condition.) The second form of post traumatic stress disorder is complex post traumatic stress disorder, a diagnosis named by Professor Judith Herrman in the USA. This describes a group of people, 75% 90% women, who have histories of traumatic childhoods. What differentiates this group of consumers from people with post traumatic stress disorder is that the start of the trauma happened long before we had developed into adults hence the complexity. Sometimes we develop with really strange ways of coping with the world often ways that worked for us as children but don't work as adults. Many women (and a few men) who have complex post traumatic stress disorder are presently labelled with 'borderline personality disorder' a judgemental and unhelpful label for many.
- 230. **Public phones:** In hospital, these are our only link to our own community (<u>mobile phones</u> are not allowed), but most public psychiatric units only have one or two wall phones that we can use. There are problems with this set up. Phones are usually placed near the nurses' station so some people can be monitored, but the result is we all lose our privacy. Due to the high turnover rate in public psychiatric units, people usually don't know each other so one person will answer the phone, yell out your name (which you may or may not hear) and then wander off, leaving the phone and your caller hanging. Sometimes it takes 10 calls before someone can get through to you. Also, people often get really angry when the ridiculously small number of public phones means they can't receive a call they are expecting due to them all being in use by others.
- 231. **Publicly funded private psychiatrists:** Visitors from overseas are often amazed at our health system. Folks from America are blown away by how generous it is; those from New Zealand are bemused that we have publicly funded private psychiatrists. We now also have publicly funded private clinical psychologists. The New Zealanders are right: we have created a problem for ourselves. Even though Medicare pays the bulk of our bill, psychiatrists and clinical psychologists assume all the rights of being private operatives. This causes a grossly inequitable distribution of both clinical groups. Those of us in the western suburbs of Melbourne and rural and regional areas miss out, especially if we have 'high prevalence' issues that don't get past the front door of the <u>Area Mental Health Services</u>. Some of this slack is picked up by public health services (not mental health specific) which have the resources to concentrate a little on so-called 'high prevalence' experiences. Unfortunately, though, we lost many of these during the early 1990s. It's one of those tragedies you look back on and wonder, 'How can we possibly have let that happen?'

Q

232. **QA – quality assurance:** One of the significant wins for the consumer movement in Australia has been that people diagnosed with 'mental illness' began getting permanent places in our quality assurance bodies very soon after we got our





toes in the water of consumer participation. Hospitals have now learnt that with every audit there will be a consumer auditor who will have as much influence as other auditors and may very well ask questions from leftfield. Some of the consumers who fill these positions are our most experienced leaders. For more information, go to the <u>National Quality Council's</u> webpage.

- 233. **Qualitative research:** This is jargon for research that denounces <u>positivism</u> and understands reality to be subjective rather than objective. The researcher is sometimes more likely to interact with us and our stories and there is an understanding in 'good' qualitative research that we are experts in our own lives. The process is an 'inductive' one (see <u>here</u>), which means that the logic goes from understanding individuals through observations and/or conversations to then making informed 'guesses'/ generalisations about a community or a group or a population. Like so much of the activity that is done *on* us or to us, qualitative research can be 'good' and life enhancing for participants and it can be 'bad' and life challenging. Just because a study is in the camp of qualitative endeavour does not imply that the ethics are consumer perspective, consumer-including or consumer-respectful. However, there are some quality qualitative researchers who do good work. There are many different ways of doing qualitative research. See <u>positivism</u>.
- 234. Quantitative research: The philosophy behind quantitative research is positivism. It is based on an assumption that reality is objective rather than subjective and that the researcher can be neutral and separate from the research process. Double blind trials and randomised control trials are both examples of quantitative research methods. The logic is deductive rather than inductive (see here). This means that there is a top-down approach, one that most of us are familiar with. It starts with a defined theory (known by the researchers) from which a hypothesis (educated guess) is drawn. This is followed by formularised, non-evolving, regulated, usually large-scale observations or testing which are recorded again in pre-defined formulaic ways. Confirmation of the hypothesis is sought by interpretation of these observations and tests by independent experts' and then, generally, publication of the results in peer reviewed (very prestigious) learned journals. Although this represents the methodologies of choice by the medical industry, it can also be useful for us (because it is well respected by those who have the money we want and sometimes can also be used to give us certainty and confidence in something we already strongly believe in). It's important to be realistic about what type of research will bring what type of outcomes. For all its obvious values, quantitative research is not always the most useful research method for what we want to do. The problem for us is often either economic or political or both. Consumer research is already difficult to fund, and when what we want to do isn't quantitative, the problem is doubled. In the main, at this point in time, quantitative research determines what is and what is not seen as 'the truth' is in the psychiatric system. See also: randomised control trials, double-blind trials.

R

235. **Raft of services:** Describes a range of available services. This is another bureaucratic term that is trying to get at the idea that services are designed to be both separate 'logs' (i.e. stand-alone), with their own brand and different functions, but are bound together with other logs to make a raft. The transference/sharing of confidential information is usually not the main aim of this concept, it is more about organisations and bureaucracies not pulling against each other.



³ Shaw J & Epstein M (1997) *The Rat Speaks Back: A Consumer Perspective of the Research Process,* The *Mental Health Services Conference, Book of Proceedings,* 1997 (available on the Our Consumer Place website – www.ourconsumerplace.com.au)

- 236. Randomised control trial (RCT): A form of <u>quantitative research</u>, informed by <u>positivism</u>. An experimental design used for testing the effectiveness of a new medication or a new therapeutic procedure. Individuals are assigned randomly to either a treatment group (using the experimental treatment/therapy) or the <u>control group</u> (using a <u>placebo</u> or standard therapy) and the outcomes are compared. The trial is strengthened by 'blinding' or masking (single-blind, double-blind or triple-blind study) and cross-over design. <u>Double blind</u> trials are a form of randomised control trials. <u>Standard medical thinking</u> suggests that: "RCT is the most accepted scientific method of determining the benefit of a drug or a therapeutic procedure. It represents the best evidence available, which is integrated into the final decision about the management of a condition by healthcare practitioners in what is called <u>evidence-based</u> healthcare". See also <u>double-blind trials</u>, <u>positivism</u>, <u>quantitative research</u>, <u>control group</u>, <u>evidence-based</u>.
- 237. **Reactive depression:** This is a term that is used to describe an experience of very low mood that is caused by something identifiable that has happened in our life. See also *exogenous depression*.
- 238. **Recommended/scheduled/sectioned:** These are all terms for being held in psychiatric facilities without our consent and 'treated' against our will.
- 239. **Recovery plan**: This is similar to a 'treatment plan' or a 'management plan'. It is a very good example of how organisations and bureaucracies can get pulled into changing their language in name only in response to our criticism. In reality, in most places, there is not much difference between a 'treatment plan' or a 'management plan' or a 'recovery plan'. They constitute the official commentary on the 'treatment' and progress of the patient/client/participant. Some of us obtain our files through <u>Freedom of Information</u> legislation and are quite surprised, sometimes bereft, and sometimes very angry at what we see in 'our' plans. Sometimes they are, in principle, created collaboratively between participant and worker, but in practice this rarely happens. It is interesting that the workers often tend to 'blame' this on a lack of interest on the part of the client, while, if gently pushed, the client will often talk about issues to do with power on the whole, they know where they stand, despite the hyperbole of 'client-centred' 'care'.
- 240. Rehabilitation: Rehabilitation/recovery/transformation these concepts are being thrown around in a big tug of war for ascendency. Up until 10 or so years ago the term that was relatively un-problematically used was 'rehabilitation'. People with 'mental illness', especially people who were seen to have 'real' or 'serious' 'mental illness', were seen to have fallen out of society and what was needed was a simple program to rehabilitate them and get them up to the bottom steps of society's staircase to 'success'. At this stage there were very limited thoughts about even the most basic paid work opportunities and even living independently was off the screen. It was the consumer movement worldwide that started to question the idea of rehabilitation as limited and holding people back from gaining any sort of fulfilling life. Consumers around the world introduced this new, outrageous concept of 'recovery'. By this people were talking about a chance for real change outside the square of present rehabilitation services which were deemed to be patronising, controlling, underexpecting, burnt out and less useful than they should be. Consumers championed the idea of recovery and were particularly interested in peer support towards recovery. What happened in reality was that the services slowly co-opted the term 'recovery' and rehabilitation services didn't change all that much other than to have new signs outside pointing visitors to Recovery Services instead of Rehabilitation Services. It became politically correct to talk about 'recovery', even though most people didn't believe in it or understand it. Over the past few years there has been a new idea coming from the international consumer movement, transformation, and we're trying to work out how to keep control this time. This is hard. Our capacity to protect our concepts from social co-option is limited. The theory behind the thinking on transformation is that what others see as a 'break down' can be understood as a 'break through'; that is, there is a positive that can be found. In the same vein we question why we would want to go back to who we were before 'an episode' or 'a break down'. Both rehabilitation and 'recovery' assume we need to go back to where we were before this awful thing happened to us, to get better and start again with all the old assumptions and knowledge. Well no, actually. Some of us want to find exciting new selves as a result of these experiences. The support we crave is support to transform ourselves into new selves that may be all sorts of things: less likely to fall in a hole again, more creative, more accepting, less self-hating, able to play the piano or not too scared to climb a mountain. Without venerating the pain of mental distress, it's important to recognise and salute those consumers who have used sometimes terribly difficult experiences to try and catapult themselves into new, rewarding, challenging, different lives.

- 241. **Resilience:** This is a term that is presently in vogue, involving a suggestion that some young people bring to their adult lives 'psychological capital', which comes both from some sort of genetic loading and early life experiences. It's a good idea; however, we have to be careful that we don't start to see ourselves as 'failing resilience' as well as everything else. Once you start talking about resilience the story changes subtly as the responsibility for our predicament is seen to be whether we have or lack resilience.
- 242. **Respite**: This is a term that describes the ways we find 'to get away from it all'. Sometimes our families and friends want to shoot through for a while to let us get on with our lives. In this instance they get respite from us. Sometimes we want to shoot through to escape the familiar that's driving us mad! So, we look for respite opportunities. Everyone needs respite from the stresses in their lives as often as possible. People diagnosed with 'mental illness' are no different.
- 243. **Rigid thought patterns:** Often associated with people diagnosed with 'personality disorders', this term implies we obtusely refuse to change 'for the better', as perceived by clinicians. Because of this we are seen to challenge everything and be a challenge.
- 244. **Rigour:** Rigour is a jargon term used to describe scientific research that is considered 'good', sophisticated and most likely to get closest to 'the truth'. From a <u>consumer</u> perspective, these criteria are often seen to be biased towards certain sorts of science philosophy (<u>positivism</u>) and certain sorts of methods (<u>quantitative research</u> including <u>double-blind trials</u> and <u>randomised control trials</u>). It is certainly possible for other sorts of small er-scale, reflective, <u>qualitative research</u> methods to be very rigorous but often this slides under the radar of those companies and organisations that fund research because they do not carry the same prestige. We all strive for the greatest rigour possible; it's just that we define rigour differently. Some traditionally 'rigorous' science claims that the best way towards rigour is to objectify the process and create the role of neutral independent researcher. Some of the research that consumers are interested in puts the researcher back into the research and argues that it's better to be honest and say where we're coming from (for example, a consumer perspective) than pretend we don't see things through a certain set of experiences, including a person's training as 'a researcher'). This is a different definition of rigour. Neither is right nor wrong. The problem is that one definition of 'rigour' is dominant, powerful and gets funded (often by drug companies) whilst the other is not and does not. For more information on research design see <u>here</u> (PDF 183kb).
- 245. **Risk**: Over the past 10 years, public psychiatry has moved its emphasis from 'treating the sick' to protecting the community from 'risk'. Our society has given the social institution of psychiatry the responsibility of looking after 'ill' people and protecting the community from harm. This is a tall order.

S

- 246. **Safe times:** This term is used to describe what times patients can get their belongings out of the ward safe in a psychiatric unit. In many <u>acute units</u> it's not wise to keep special belongings and money on the ward. Things disappear.
- 247. **Sample:** When used in the context of research, the 'sample size' describes how many people are actually involved as 'subjects'. When undertaking drug trials and other <u>positivist</u> research, the researchers try to entice as many 'subjects' as they possibly can. The greater the number of 'subjects', the more the research will be seen as 'good' science.
- 248. **Scale or tool:** A scale (or, sometimes, tool) is an instrument not like a ruler or a tambourine, but a test-like set of questions that have been carefully thought through by the sorts of clinicians who like doing these sorts of things. Over time, as more and more people are asked to do the test, the clinicians get closer and closer to seeing some patterns in the information they are getting back and can start to analyse it. When clinicians create a scale, it often becomes a document that other



qualified people can use. The people responsible for refining the scales spend a lot of time trying to work out ways they can defeat our cheating but they haven't met the full force of consumers yet! Some of us are critical of what we call the 'eenie, meanie, minie, mo' research methodology. Sometimes this is because we are research weary and at other times it is because we can see very easily through the 'trickery' (or the dumb questions), even when we know that this sort of research is the only way to go in order to get an evidence base for our work. This certainly doesn't apply to everyone, but those of us who use services may find it annoying when this is the only sort of research that the organisation is involved in. It doesn't drill down and look at the experiences of everyday life.

- 249. **Scheduled:** This is another term for being held against your wishes, and treated against you wishes, in a psychiatric facility. See also <u>sectioned</u>.
- 250. **Seamless services:** This term was fashionable 20 years ago and has recently come back into vogue. Basically it is bureaucratic speak for different parts of complex service systems to be linked so that the left hand and the right hand always know what the other is doing, and consumers with complex needs who move across these systems can get a more co-ordinated system of 'care'. This could mean links from drug and alcohol services to mental health services, or links and knowledge from child welfare agencies to mental health agencies. Consumers have very different attitudes to this concept. Some of us (particularly those who are sick and tired of telling our story, over and over again) are thrilled that our psychiatric files will be more readily available for workers in other agencies with whom we interact. On the other hand, some of us are horrified by the lack of confidentiality that comes with this. Some people will fight for their right for confidentiality to be maintained. A good quote about 'seamless services' came from a consumer, David Meyer, who told a group of bureaucrats his interpretation of the slogan: "I know what it means! It means that services seem to be something but they are less than what they seem!" See also <u>raft of services</u> and <u>silos</u>.
- 251. (a) Se arch: When we first enter a psychiatric hospital there is often a search of our belongings to make sure we are not bringing in substances that could be used for an overdose, or sharp objects for cutting ourselves or others. This can feel totally intrusive and horrible but when we find the 'right' nurse, someone who recognises that this is intrusive and prison-feeling and says so, or someone who is able to communicate in adult-to-adult conversation the reasons for this invasive behaviour, or someone who is intuitively respectful, it can be affirming and make us feel safe. Some of us are also regularly searched when we come back from day leave or weekend leave. It is really unpleasant and might be necessitated by a clinician's 'duty of care' but this duty only includes invasion of our privacy in a way that does no harm.
- 252. **Seclusion:** Describes when we are locked up in a room on our own, supposedly so that we are protected from self-harm, or where staff are worried we might hurt others. It is sometimes used as punishment or in cases when we are considered too demanding, or if there is violence, or people are being annoyed by stuff that we are doing. Occasionally we may choose to use seclusion rooms to get away from others and the ward for a while.
- 253. **Secondary consultations:** A secondary consultation is when a specialist service provides local <u>Area Mental Health</u> teams with specific advice about the services we receive. The idea is to enable us to be 'treated' locally. Secondary experts can help local teams arrange treatment plans for those of us who have special 'needs' that require expert input. Ideally these plans should include the active involvement of local staff, secondary consultants as well as us with a supporter of our choosing (though this isn't that common). Secondary consultation can also take place in the private sector.
- 254. **Secondary diagnosis:** This is when clinical staff believe they have enough clinical evidence to diagnose us with two different 'mental illnesses' but one is seen to be the dominant problem and the other a lesser or secondary problem. See also *diagnostic traits*. When using the <u>Diagnostic and Statistical Manual</u> (DSMiv) the clinician counts the number of symptoms you exhibit and ticks them off against a checklist. If you don't have enough to have a secondary diagnosis the clinician might record that you show traits of this condition.



- 255. **Second opinion:** This is usually arranged at our request, although sometimes a doctor may request it. It usually occurs post diagnosis when we want another clinician's opinion. Sometimes we seek an alternative opinion on treatment options, or when we are locked up against our will. It's a systemic safeguard but often clinicians 'close ranks' and tend to agree with the original decision that has been made.
- 256. **Sectioned/scheduled/recommended:** This is a term that is commonly bandied around the sector and has come to have a meaning independent of its original source. Everybody just talks about a 'Section 10' or 'Section 12' or 'being sectioned'. Originally the terms come from the *Mental Health Act 1986*. We are on the cusp of a new *Mental Health Act* becoming law so it will be interesting to see what happens to the much-used terms currently in vogue. Being 'sectioned' means being locked up and held and treated against one's will. This cannot just happen without a legal framework that framework comes from the Act mentioned above. There are requirements under the Act that must be fulfilled. It is strongly advis able to visit the Mental Health Legal Centre website here even if you don't see a locked ward in your sights at the present time download a copy of their booklet that explains all your rights under the *Mental Health Act* that come into play if you are ever threatened with being sectioned (or scheduled). Important information can also be found on the website of the Victorian Government here.
- 257. **Section 8:** Section 8(1) of the *Mental Health Act* outlines the five criteria that must **all** be present to enable <u>CAT teams</u> or others to commend you for the involuntary treatment. They are:
 - the person appears to be mentally ill; and
 - the person's mental illness requires immediate treatment and that treatment can be obtained by the person being subject to an involuntary treatment order; and
 - because of the person's mental illness, involuntary treatment of the person is necessary for his or her health
 or safety (whether to prevent a deterioration in the person's physical or mental condition or otherwise) or for
 the protection of members of the public; and
 - the person has refused or is unable to consent to the necessary treatment for the mental illness; and
 - the person cannot receive adequate treatment for the mental illness in a manner less restrictive of his or her freedom of decision and action.

It seems very straightforward but in practice it is not. All these requirements are interpretative, though they masquerade as fact. For starters, we know that whether we have an 'illness' or not is not straightforward – we're not just talking about differences in opinion between patients and clinicians, but also differences in opinion between clinicians. The <u>DSMiv</u> is not scientific and doesn't even pretend to be; it involves ticking boxes off a checklist – and not all will agree if an item on the list should be checked or not. It's a cruel fact that sometimes the more we know and the more we fight against and the more determined we are that we really do not have all five criteria for involuntary admission, the more likely it may be for others to judge the criteria fulfilled. Sometimes it's sensible to just go with it – possibly you'll get out quicker.

- 258. **Section 10:** Comes from Section 10 of the *Mental Health Act 1986* and gives the police the ability to transport us from the community or from our homes for examination against our will. The term is meaningless to most people.
- 259. **Section 12:** This document is signed to hold us against our will. There are important limitations to Section 12 (a part of the *Mental Health Act*) it's a good idea to find out what you can about this important piece of legislation (if you can bear to plough through it). The Mental Health Review Board has an excellent website see here. See also recommended, scheduled or sectioned.
- 260. **SECU Secure Extended Care Units:** These provide secure inpatient treatment and care for people with severely scary experiences, and associated behaviour that rattles people, and where there is a fear that it will rattle other people in the community. See also <u>CCUs.</u>



- 261. **Secure wards**: Describes closed, locked, involuntary wards or units.
- 262. **Self-control**: This is something any of us can supposedly lack but it is rarely understood within the context of psychiatric settings that are nearly always controlling and where we get mixed messages that we have to try to navigate through. For example, in psychiatric acute units, everything is closely monitored and controlled. We are rarely given choices and it is within these environments that some of us burst out with frustration which is later documented as 'lack of self-control'. The other aspect of mental health services is that the power differential, particularly in acute units, is so great, and the communication necessities so warped, that assertion no longer works and we turn to the squeaky wheel approach to communication.
- 263. **Self-harm:** Self-harm is where we deliberately hurt ourselves. There may be many reasons why we do it. It is very rare that we self-harm for attention or to manipulate others. This concept often gets mixed up with 'suicide attempt' but those of us who 'self-harm' know it is very different. We sometimes 'self-harm' so we don't suicide.
- 264. **Self-management**: This term is sometimes used interchangeably with <u>self-control</u>, although it does not have the overtone of 'acting out' and losing it! Nonetheless, the principles are the same. Psychiatric services are weird places. We are, at the same time, both expected to 'obey the rules' (and we are often asked to sign a contract to this effect) and manage our own lives. Apart from being patronising, these terms are impossibly antithetical. You can't sign away all your control and at the same time take responsibility to manage your life. We think that perhaps the desired outcome from the service is that we self-mage in a way they approve of!
- 265. **Self-medicating**: This is jargon for trying to control our horrible internal experiences by using illicit drugs or alcohol.
- 266. **Service delivery**: This term simply means that a mental health service such as a hospital or <u>Area Mental Health</u> clinic is providing you with assistance or a service of some kind. The term seems to imply that this 'service' is, by definition, good and wanted. This is untrue in psychiatry. Many people are forced to receive services they do not want.
- 267. **Shallow or exaggerated emotions:** This is actually an expression of someone else's judgment. It's their perception (remembering that only people diagnosed with 'mental illness' have <u>perceptions</u>; somehow clinicians just seem to know!)
- 268. SHIFT Service for the Homeless, Intellectually Disabled, Frail and Transient: A Victorian program, operating state-wide.
- 269. Short-acting and long-acting: Describes how long medications stay in our system (body).
- 270. **Silos:** In mental health, the term 'silo' is often used to envisage the different bureaucratic institutions creating their own limited view of the world because they are locked in their own grain silo and can't see out. Many of us push for a breaking down of these silos, which restrict our lives. A very good example of this was in the creation of the *Disability Act 2006*, which commenced on July 1, 2007. The Act was specifically designed to protect the human rights of people with a disability, but in a deplorable act of 'siloism', people with psychiatric disabilities were excluded from its reaches because we were managed by a different bureaucracy than people from other areas of disability or, this is what we were told. See also <u>raft</u> and <u>seamless services</u>.
- 271. **SMI serious mental illness:** Generally used to describe psychotic illness, this is a term that is challenged by some consumers who believe the seriousness of our experiences are being belittled and ignored.
- 272. **Somatoform disorders:** Describes the experiences of people who really believe they have a physical (or some forms of mental) disorder and yet all the scientific tests and examinations already completed show that there is no medical signs or symptoms. Pressure is sometimes put on doctors and others to do a lot of tests, which they begin to believe will go absolutely nowhere. Often those of us who are experiencing these weird 'non-illnesses' cannot take a medical 'no' for an answer and we keep feeling symptoms even though no illness seems to be present. This collection of disorders challenges the system of physical health and often we become 'well known' which generally means, "watch out, here she comes again". It is horrible to be treated like this and plays right into our anxiety levels, which are so often at the core of our real



suffering. Sometimes people with so-called 'somatoform disorders' have proved the physical health system wrong and new forms of scientific research have shown they did indeed have what they had been claiming all along; it's just that it hadn't been known to science at that time. Somataform disorders are gendered – women are much more likely to be diagnosed in this way. The most common form of somatoform disorders is 'hypochondria'.

- 273. **Splitting:** This is a term often used to describe people diagnosed with 'borderline personality disorder'. It is supposed that those of us with this diagnosis are able to make different members of 'our' treating team dislike each other. It's seen as a 'severe' form of manipulation. Many of us with this diagnosis and quite a few clinicians find the concept ridiculous.
- 274. **SRV social role valorisation:** "The major goal of SRV is to create or support socially valued roles for people in their society, because if a person holds valued social roles, that person is highly likely to receive from society those good things in life that are available to that society, and that can be conveyed by it, or at least the opportunities for obtaining these" see here.
- 275. **Staff turnover:** The staff turnover in <u>Area Mental Health Services</u> is extraordinarily high. This makes it almost impossible to take on anyone who needs long-term work.
- 276. **Step up, step down services:** Describes services that are available for a few people in Victoria to enable us to have a smoother transition between <u>acute hospital</u> stays and 'the community' (whatever this means). People, usually people diagnosed with psychotic illness who use public services, can go to a step up service which is 'in the community' and not 'an institution', where it is hoped that sufficient support can be provided to enable people to avoid an escalation of the most terrible of their psychotic experiences. These 'step up' services are usually run by <u>psychiatric disability rehabilitation support services</u> (PDRSS). Step down services are for people discharged from acute units but who are deemed to still need quite intensive support 'in the community' before 'going home' (which might be back to a residential unit). One of the reasons this concept was designed was that recent statistics of completed suicides in Victoria showed that there was a danger period immediately after acute unit discharge step down services were designed to try and arrest this. There are a few important considerations:
 - a. In Victoria these services are called <u>Prevention and Recovery Care Services</u> (PARCs). They are a recent addition to psychiatric services and mark a new era in, perhaps questionable, bonding between the non-government sector and the clinical sector.
 - b. It is possible that the group of people engaging with PARCs might not represent the breadth of people completing suicides after discharge.
 - c. Large non-government PDRSs are making a lot of money out of taking on the increasing number of step up, step down services;
 - d. Government services are saving money because people are being discharged from acute services earlier so there is a cost cutting aspect to these new services;
 - e. PARCs free up acute unit beds in public psychiatric services. This is either good or bad depending on where we come from and where we want to go.
- 277. (a) Study: This is a common word clinicians use to describe a piece of research in medicine including psychiatry. It is almost exclusively used in psychiatry to describe a type of positivist research. This term was coined by philosopher Auguste Comte and basically means that the only knowledge worth knowing is that which comes from logic, science and mathematics. Most 'studies' compete to prove their rigour (good science) through a positivist perspective. This includes drug trials but also research to create an evidence base for certain treatments. Consumers often find that the positivist mantle negates the sort of evidence that makes sense to us intuitive, reflective, consciousness-based, and narrative-based evidence, for example. We often endorse methods that are more sophisticated than just counting things and we tend to be critical of over-reliance on the knowledge that comes from positivist research. An assumption of researcher neutrality which accompanies positivism (and other research philosophy as well) is criticised as fantasy. To uncritically assume the relatively powerful researcher/s and their institutions (and often drug company funders) are neutral is to many of us a political con.



This mirage of neutrality-as-researcher enables dominant knowledge to reproduce its power base and maintain its stranglehold on what constitutes 'real' knowledge at the expense of the relatively powerless which, in this case, is us. Sometimes institutions, mainly hospitals and universities, publicly call for participation for people to take place in studies; other times clinicians may recruit patients to take part. If we are approached by our psychiatrist (or anyone else) to take part in a study it is often difficult to say no but it's really important to know that we can and we should say no if we have any worries at all. Sometimes studies, especially when psychologists have a part to play, can be extremely tedious. They can consist of huge numbers of questionnaires and other instruments (measurement tools) and, for many of us, the repetitive ticking and crossing of boxes can be overpowering. Also, it often feels like we've resorted to an 'eenie, meanie, miney, moe' method of option selection out of sheer frustration and at this point the whole exercise can feel stupid and very unscientific. However, there are some studies that we can be very committed to and join in with relish. See also <u>drug trials</u>, <u>randomised control trials</u>, <u>double-blind trials</u>, <u>informed consent</u>, and <u>subjects</u>.

- 278. **Subjects, objects, cohorts, individuals and people:** As people who use mental health services, it is likely that we will be asked at some time or other to take part in a <u>drug trial</u> or a research project into other therapies. It's a good idea to think ahead about your ethics and values in regard to these trials so that you don't get caught on the hop when you are having a very stressful time in a hospital setting. The most important thing to remember is that if you take part in a <u>study</u>, you offer your participation in good grace and are doing them a substantial favour. If they take you for granted, are rude, or keep you waiting for ages, you have every right to complain. This activity has nothing whatsoever to do with your 'treatment' so they are obligated to treat you with the utmost courtesy. Remember, regardless of the words that are used, we are people. We are not *objects, subjects, part of a cohort* or representative of any particular population of research participants. Don't sign anything you don't understand. They'll just have to wait. There is generally a chief investigator and s/he will be the one with the track record. Get a mate to look her/him up. They can't do anything without your <u>informed consent</u>. In order to approach you and other people, the researchers would have had to get their research design past a research committee and an ethics committee. This is much easier to achieve if the research design is comfortable, fashionable or powerful.
- 279. **Suffers from absent insight:** Surely this depends on whose insight one thinks is the true, good insight? There must be a sanctioned position in order for one to proselytise one set of beliefs about what constitutes the 'correct' insight. Furthermore, we are not sure about the inclusion of the word 'suffers' in this phrase. Is it a suggestion that those with certain sorts of knowledge automatically suffer from not having the same insight as the norm? An alternative view is that it may be quite exciting for our different insights to be acknowledged. See <u>insight</u>.
- 280. **Suicidal ideation:** This term describes thinking and thinking about killing ourselves (different from <u>self-harm</u>). We are often quizzed about this and it is not always taken seriously. Most often it is followed by questions about whether we have a specific suicide plan and whether we have a history of so-called 'serious' suicide attempts, for example.
- 281. **Support worker:** Another name for a 'key worker' in the <u>Psychiatric Disability Rehabilitation and Support Services</u> (PDRSS) sector.
- 282. **Supportive psychotherapy:** Supportive psychotherapy is only one of many different approaches to psychotherapy. Psychotherapy is different from <u>behavioural</u> and <u>cognitive</u> therapy because it contains elements of reflection in a 'safe environment', and (usually) a respect for issues we carry from damaged pasts. Through this approach, those of us who hate group work usually don't have to endure it. Another positive for some of us is that we can work at our own pace. There are some people who hate all forms of psychotherapy. Some of us feel that we are expected to go on for months and months without any significant changes in our lives. Others of us find great hope in psychotherapy as we become involved in a healing relationship. In all the different forms of psychotherapy the relationship with the therapist is key to the success of the therapy. This is very different from 'behavioural therapy' regimens which appeal to some and not to others. The most important thing when it comes to 'treatment' approaches is for us to hold on to our personal power and trust our intuition. Just because someone has diagnosed you with a 'mental illness' doesn't mean that you can't make meaningful choices about what works for you and what does not.
- 283. **Surg:** Shorthand for surgery.



- 284. **Symptoms:** Many of us don't speak very much about 'symptoms' any more. We have made this decision as we have become increasingly dissatisfied with the 'medical model' being the only socially acceptable explanation of our lives. Instead of thinking of ourselves as having 'always bad' symptoms, we are starting to think and write about experiences experiences which can be either good or bad but which we, by definition, have a role in creating.
- 285. **Syndrome:** A syndrome is, in 'medico-gabble', different from an 'illness', which is different again from a 'disorder'. The term 'syndrome' comes from the Greek and describes where a group of symptoms occur together in a way that seem to indicate a pattern, but that this pattern is not yet adequately enough understood to be described as an 'illness' or 'disorder'. 'Experts' don't yet know why they occur together or the aetiology (reason they occur in one person and not another).

Τ

- 286. **Take down:** This is a horrible euphemism. It describes where a whole heap of clinicians jump on us and throw us to the ground usually to lock us away in a <u>seclusion</u> unit.
- 287. **Taking instructions**: A legal term which means that whenever possible, the legal advocate must do what the person they are representing wants them to do (not what they the legal advisor thinks would be in the best interest of the person diagnosed with a 'mental illness'). The <u>Mental Health Legal Centre</u> estimates that about 95% of the time, legal advocates representing a person before the <u>Mental Health Review Board</u> are able to get instructions from their client. When you think about it, this says heaps. The clients of the Mental Health Legal Centre (appearing before the Mental Health Review Board) are usually consumers on community treatment orders. These are people that the general public might dismiss as 'seriously disabled' and yet they are nearly all able to give the solicitors who are representing them cogent instructions about how they want their case argued. The alternative to taking instructions is to make decisions in their client's 'best interest', with a built-in assumption that the person no longer has 'insight' into what is in their best interest. The Mental Health Legal Centre lawyers are rarely forced to take this action. This language can also be found outside legal determinations, when we are held against our will and the medical officer presents their case about our status as involuntary patients, they may use the language of 'in the best interest' to justify their paternalism.
- 288. **Team leader:** In both non-government and government services, a team leader is someone who is responsible for 'the team'. In mental health services, both <u>acute</u> and community-based, the teams are known as 'multidisciplinary teams' to designate they are made up of <u>clinicians</u> from the five major clinical groups: psychiatric nurses, psychologists, occupational therapists, social workers, and psychiatric registrars.
- 289. **Termination of therapy:** This is a less than respectful way of describing that a therapeutic relationship is coming to an end. Traditionally, people find this process hard. This is totally understandable. These relationships, particularly some forms of psychotherapy, might be very useful, but the glue that holds them together is power and none of it remains with the 'client'. Where therapy is coming to an end, clinical psychologists and others have protocols to try and make the situation easier for 'their' clients, but too many of them don't understand that this is not just about the interpersonal relationship it's also about much bigger social structures. For example, where are the rituals to give us back the personal power that we have trustingly given them as a gift, to hold for us in trust until they are OK to give it back and we are OK to accept it?



- 290. 'The mentally ill': This is (unfortunately) a frequently used term, both in the community and in services. Some of us would like community members and, particularly, community leaders to show their respect for us by using what we call 'person first' language. Instead of saying, 'the mentally ill' we'd like everyone to remind each other that we are people before we are an illness. We are never a walking psychiatric diagnosis. The language we prefer is people with a diagnosis of 'mental illness'; or people diagnosed with 'schizophrenia' or people who hear voices. If we all did this one little thing, huge changes in community attitudes are likely to follow.
- 291. **The narcissistic personality:** Another of those terms which is experienced by many of us as judgemental. Many clinicians agree but interpret this judgement differently. It can sound aurally distasteful. It is used to describe those of us who clinicians have found to be self-centred and selfishly demanding.
- 292. **The program:** The timetable of activities which is planned for us in certain situations. It can happen when we're on an <u>acute unit</u>, in an outpatient environment run by private psychiatric hospitals, and when we're participants in special programs run by state-wide services such as the Eating Disorders Program or the Personality Disorders Program. Sometimes, especially in public psychiatric units, there are minimum opportunities for organised activities. In other locations, especially some priva te psychiatric hospitals, people get 'programmed' out! Many people have complained that they feel patronised and infantalised by these programs, whilst others genuinely appreciate the freedom from intolerable boredom that they offer. Many of us question their therapeutic value and suspect that the main beneficiaries are the ward staff who can get rid of us for an hour! See *therapised*.
- 293. **The suicidal patient**: This is a crude (and rude) way of thinking about people who are struggling with life and death. It also reflects the very common form of address which takes the person out of the equation. It is much more respectful to call us people who struggle with suicide.
- 294. **The very large NGOs:** Refers to organisations like the Brotherhood of St Lawrence, Wesley Mission and The Salvation Army, who work in areas of severe disadvantage and with people who live on the streets with virtually nothing. We know that many people served by these organisations are people diagnosed with 'mental illness'.
- 295. **Therapised:** A condition some of us contract from both inpatient and outpatient facilities. It refers to a condition that develops when every aspect of our lives seems to attract therapeutic interventions, both wanted and often unwanted. We're not sops for therapeutic inventions! It can all be overdone and sometimes leaves us wrung out and exhausted, wondering what has been achieved by it all. This is a particular problem in private psychiatric hospitals it's like the hospitals feels they have to justify the money they are getting from our private insurance companies by constant therapisation (though, of course, some stuff is useful). Often the most useful stuff is the informal interaction, wandering into the occupational therapist's room on our own and just being ourselves in a creative place.
- 296. **Therapy-interfering behaviours:** A term used in <u>dialectical behavioural therapy</u> (DBT) which is one of the preferred therapies in the treatment of '<u>borderline personality disorder</u>' and is very structured and very rigid (like everything else, some consumers love it and others hate it). The term is accusatory, which is horrible. For many people labelled with 'borderline', being blamed and accused simply compounds the shame that already derides us each step we make in life.
- 297. **This cohort of difficult females:** This terrible phrase came from a distinguished medical journal. There is, perhaps, room to give writers a bit of licence, given their audience. Nonetheless, it is an excellent example of how language that is primarily disrespectful can, and does, dribble down into the attitudes of clinicians. Clinicians are given a vocabulary very early in their training. This language comes from learned journals and texts as well as being learned through mentoring by experienced clinicians. The group that was being described in this case was a group of women diagnosed with 'borderline personality disorder'.
- 298. **Thought blocking:** This is when we interrupt our train of speech before completion e.g. "Am I early?", "No, you're just about on ...". At an extreme degree, after blocking occurs, some of us find it hard to recall the topic we were discussing. This is also known as getting older!
- 299. **Thought disordered:** This is generally seen to be associated with those of us who are diagnosed with 'schizophrenia' and it describes when our speech, language and communication doesn't make sense to others. There are many different ways clinicians describe specific types of 'thought disorders'.
- 300. **Time out:** This describes a situation when clinicians want us to calm down. It is the same term that parenting books use to help parents deal with toddlers. That says a lot really. We may use this phrase ourselves when we wish to 'get somewhere quiet' when we are in an <u>acute unit</u>. This is an entirely different proposition.



- 301. **Traits:** Used to describe clinical features that are sort of like an add-on to our first diagnosis. For example, we might have a diagnosis of 'bipolar affective disorder (BPD) with borderline personality disorder traits'. This means that there are some signs of 'BPD' but there are not enough to make a differential diagnosis.
- 302. **Transfer:** Sometimes we are transferred from one unit to another, one hospital to another, or from an emergency department to a psychiatric hospital.
- 303. **Transference:** A term used in <u>psychotherapy</u>, particularly in psychoanalytic psychotherapy, which occurs when we project on to the therapist feelings we hold that are meant for someone else who is important in our lives. It is neither unhealthy nor unusual and psychodynamic therapy uses these feelings as helpful phenomena to examine. Transference and counter-transference are neither good nor bad; like all feelings, they just are. We mustn't add them to our list of things to feel ashamed of. However, every psychotherapist must recognise they have an overwhelmingly more powerful position in a every clinical relationship they are part of. With this power comes the responsibility to manage transference and counter-transference and protect us from harm. (See also <u>counter-transference</u>.)
- 304. **Treatment plan:** This is the formal document that is written about us (often using the shorthand jargon articulated in this publication). There is much talk about making these open documents that we are able to read and write in and in which we can proffer different explanations for our behaviour than those given by clinicians. In truth, this rarely happens. With our permission, carers under the *Mental Health Act* can now discuss our treatment plans with clinicians. Sometimes clinicians forget we are real people and that many of us have well-practised 'crap detectors'. Even when we can't see what changes have been made in terms of our 'management', within half a day we'll have guessed it from changed staff behaviour. If you are booked for a hearing before the Mental Health Review Board you have a right, under the Mental Health Act, to see your treatment plan before the hearing. An advocate can go through the plan with you if you want.
- 305. **Treatment resistant:** This is another one of those silly terms where we get blamed for the fact that the medical 'treatment' we are given doesn't work! We are described as 'treatment resistant' rather than the 'treatment' being described as not useful.



- 306. **UDS urine drug screen:** Checking (often daily) on the urine of those of us who have come into hospital with illicit drug issues.
- 307. **Unipolar:** Shorthand for 'real' chemical depression that is not 'just' caused by grief or life events. See also <u>endogenous</u> <u>depression</u> and <u>clinical depression</u>.
- 308. **Unit manager**: The person in charge of the inpatient unit. The unit manager has to take responsibility for what happens on the unit. A good unit manager will also be seen by patients, be humble, be a good role model for staff, and manage stressful times without adding to the stress. See also *charge nurse*.



309. **VACCHO – Victorian Aboriginal Community Controlled Health Organisation:** A body representing all ACCHOs in Victoria, which provides direction on Aboriginal health policies and supports local initiatives.





- 310. **VEOHRC Victorian Equal Opportunity and Human Rights Commission:** The Victorian equivalent to the national HREOC (Human Rights and Equal Opportunities Commission). The <u>Victorian Equal Opportunity and Human Rights Commission</u> is an independent statutory body with responsibilities under three laws: *Equal Opportunity Act 2010*; *Racial and Religious Tolerance Act 2001*; and the *Charter of Human Rights and Responsibilities*. The *Equal Opportunity Act 2010* makes it against the law to discriminate against people on the basis of a number of different personal characteristics, including psycho-social disability. For more information see <a href="https://example.com/here-new-more information-new-more informatio
- 311. **VICSERV:** The peak body for the entire non-government mental health sector in Victoria. This is the sector that has the greatest ballast at the moment and it's worth a phone call just to find out a bit more about what is offered phone 03 9519 7000 or visit http://www.vicserv.org.au/.
- 312. **Voluntary hospital admission:** This is when we come into hospital of our own accord. This can be true, however it also can be a case of 'come in voluntarily or we will <u>section</u> (force) you'. Voluntary hospital admissions are common particularly in the private sector and many of us are grateful for them. It is also frustrating and distressing for some of us who are on pensions or little income and cannot afford private health insurance that the public system can rarely find room for voluntary admissions. See also <u>informal patient</u>.

W

- 313. Wilfully immature: This is a judgement, a supposition and a perception. It is not a truth. It's a guess that gets reified through the process of record keeping and the creation of a new human being in the likeness of a medical god. How do you judge immaturity? Behaviour might just be a reaction to a horrible hospital setting or being locked up. Many of us become institutionalised very quickly, even the supposedly 'high functioning' mob of us. Wilfully? This is just clinical-speak for, 'I don't get it...'.
- 314. **Word salad:** Associated with those of us with very challenging experiences of 'schizophrenia'. It describes what clinicians perceive as incoherent speech consisting of both real and imaginary words.



315. **YEP – Youth Early Psychosis program:** Provides an early intervention service for young people between 16 and 25 who are experiencing, or at risk of, a first episode of 'psychosis'. YEP services provide treatment and support over the first few years after someone seems to have experiences that are describes as 'psychotic'. This is controversial for several reasons. Some people question the wisdom of such an early use of powerful drugs even before a definitive diagnosis is made. They also worry about labelling people so young with 'psychiatric descriptions' that are easily misunderstood by the community. There is also a community concern (and concern of some consumers) about 'medical imperialism', i.e. turning every possible reaction to distress or trauma into something medical rather than something that is best understood by the community as it would be in so many other societies. See the *Youth Early Psychosis Status Report - March 2007*(PDF 402kb).