



Better outcomes for the most excluded

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BETTER OUTCOMES FOR THE MOST EXCLUDED

EXECUTIVE SUMMARY

This study looked at prevalence, effective interventions, existing mental health services and the perspective of the non-governmental sector in relation to adults with chronic exclusion, or 'chaotic lives and multiple need'. It defined multiple need as having two of the following: mental illness; certain personality disorders; severe alcohol dependence; drug dependence; learning disability and adult neuro-developmental disorders. It defined chaotic lives as having four or more of the following characteristics: difficulty dealing with paperwork; difficulty managing money; no formal qualifications; no confidant; few friends; unemployed; highly mobile; and low income.

There was (and is) a high concentration of multiple need in prisons and in the homeless population. The rate in the adult population in private households was about 3.5%. Numerically, this group was dominated by mental health problems. Most (93%) did not have chaotic lives but many (39%) had low intelligence or problems handling money or paperwork (24%). Nearly one quarter of people with chaotic lives (23%) also had multiple needs; mental illness on its own affected a further 18% and low intelligence 10% of the rest.

A number of evidence based interventions could be applied to the population of people with multiple needs. Of these, the most common appear to be: a growing range of psychological interventions; medication for specific disorders; therapeutic residential care; assertive outreach; and individualised, multi-disciplinary key-working. Although considerable amount of mental health care provision is relevant for people with multiple needs, its effectiveness for them as a distinct group has not been evaluated.

There are well recognised obstacles to delivering formal care to people whose lives are chaotic. This study identified: exclusion around eligibility operating at the boundaries of services; exclusion by neglecting specific needs of certain groups of people eligible for services; and exclusion by omitting to acknowledge or address the

needs of identifiable groups, such as adults with neuro-developmental disorder or low intelligence who do not fit the definition of 'learning disability'.

Exclusion by statutory provision affects the demands on agencies which strive to meet the needs of chronically excluded people. Expertise gained by these agencies could inform improvements in services across the board. The study highlights 10 means by which chronic exclusion may be prevented, reduced or resolved:

1. Seizing opportunities to engage vulnerable young people at transition stages.
2. Early intervention, when primary needs are first identified.
3. Identification and support of young people with certain personality disorders, low intelligence, ADHD or other neuro-developmental disorders.
4. Continuous, appropriate provision which can respond flexibly to user demand.
5. Promoting zero exclusion policies within statutory provision, and providing the skills and back up required to implement these.
6. Re-examining the remit of community mental health services with respect to complex needs.
7. Addressing the needs of identifiable groups who are underserved by current services.
8. Finding ways of delivering evidence based therapeutic interventions to chronically excluded people.
9. Disseminating and applying innovative models in new contexts.
10. Attending to social and cultural needs together with physical and mental health.

Background: the nature of the problem

Policy targeted at socially excluded people has addressed the needs of major groups: people with mental health problems (Mental Health and Social Exclusion, ODPM, 2004) young people with complex needs (Transitions, ODPM, November, 2005) disadvantaged adults (Improving Services, Improving Lives, ODPM, October, 2005) and older people (A Sure Start to Later Life, ODPM, January, 2006). Nevertheless, there remains a minority of troubled individuals who pose a significant burden, both in terms of direct costs to taxpayers because they use a lot of resources with little improvement, and in terms of indirect costs, through family breakdown and crime.

This group includes people who are vulnerable to exploitation by others, or who behave impulsively and get into trouble. Many of the people concerned have difficulty getting on with others, they seem to have a lot of bad luck, they find it hard to cope with life and their personal difficulties increase because they are not dealt with effectively. Often, they turn to alcohol or drugs, and find themselves involved in the criminal justice system. Those without a resilient support network of family and friends, unless they receive prompt help from other agencies, are at risk of homelessness and destitution.

As their problems become more compounded, the services available to these people become fewer and fewer. They do not fit the inclusion criteria of any given service, either because their level of a specific need is not high enough, or because they are disqualified due to the very problems they have (e.g. drinking or drug taking when these are prohibited by the provider). They may have exhausted the formal services to the point where they are explicitly banned. Some feel frustrated and let down to the point where they themselves shun formal services. Generally, these people are well known to the police and to their neighbours. Voluntary organisations, particularly those working with homeless people, may come into contact with them more than statutory services, and an unknown number frequent multiple agencies, without ever seeming to make much progress.

It has been recognised that these problematic groups of people are characterised by 'chronic exclusion'; they find it difficult to access services, services are not well

organised to meet their needs, and when contact is made it is hard to sustain. Secondly, they have needs in a number of domains (health, legal, social etc.) and this has implications for a number of different welfare agencies.

Aims and methods of the research

The aim of this study was, firstly, to identify the numbers of people who have chronic exclusion and to describe their characteristics, including where they are located. We wanted to survey the literature on effective interventions for the groups identified, to learn what therapeutic approaches seemed applicable. We also investigated the extent of NHS provision which might (currently or potentially) address the needs of chronically excluded people. Finally, we wanted to find out how selected NGOs currently work with this client group.

To achieve this, we undertook five distinct activities:

1. Secondary analysis of relevant national surveys to estimate the prevalence and distribution of multiple needs and chaotic lives.
2. Review of the literature on the effectiveness of interventions with people with multiple needs. In the course of this research we also downloaded and read 19 annual reports from leading organisations working with chronically excluded people, as well as a wide swathe of academic and policy-related papers.
3. Analysis of the national mental health mapping data to identify which mental health services are likely to be addressing multiple needs, the scale of provision and where it is located.
4. A telephone survey of senior operational managers of nine leading voluntary organisations to find out how they work, supplemented by reading their publications and evaluation material.
5. A national stakeholders' conference to orientate the analysis.

The approach of this report

This report brings together the information gathered by the methods described above. We recognise that agencies specialising in chronically excluded groups have a huge reservoir of expertise in this respect, which we can only access indirectly and partially in the course of this study. We therefore wish to make our orientation towards this

study explicit here so that it may be taken into account in any recommendations which are drawn from our findings.

Given the backgrounds of most of the contributors, this work is informed heavily by psychiatry and psychology, approached from a bio-psycho-social perspective. By bio-psycho-social we mean that we look for the causes and the solutions to chronic exclusion in biological and psychological as well as social terms. The mental sciences provide the frameworks with which we organise this enquiry: symptoms, diagnosis, treatment and so forth.

The limited time available for this study made it desirable to adopt a restricted approach to the issues surrounding chaotic lives and multiple needs or chronic exclusion. Therefore, we start from the assumption that a large proportion of people with chronic exclusion suffer from identifiable patterns of personality or neuro-developmental impairments which, left untreated, lead to the problematic behaviours associated with chronic exclusion. A further proportion have mental illnesses which are complicated by other features (learning disability, alcohol dependence or drug abuse) that services are not always able to address, so these also go untreated, leading to high levels of social problems and chronic exclusion. An advantage of this 'top down' approach is that it enables us to recommend evidence-based treatment strategies. A disadvantage is that the richness of evidence in the medical and psychological domain can dominate the findings, since less empirical research has been conducted into the social aspects of adults affected by chronic exclusion, the structures which exclude them and the societies which sustain these.

A 'bottom-up' approach to the question of complex needs has been taken in a literature review by Thomson Goodall (2002) in Victoria, Australia. This illustrates how much knowledge about chronic exclusion is held by agencies working in the field. The perspective of agencies with practical understanding of the problems of chronic exclusion forms an essential facet of our enquiry, but the approach which we adopted was to look at the whole population of people with specific characteristics, rather than that part of the population which is known to services.

We therefore defined 'multiple needs' as having at least two of several diagnostic criteria indicative of mental illness, substance abuse, adult neuro-developmental

disorder, learning disability and specific personality disorders. We operationalised this definition using the variables available in a number of surveys, and explored their prevalence individually and in combination. The results are presented in Section 1. At the same time, we reviewed the health care literature about effective interventions with specific clinical groups, so that we could match potential treatments to disorders, to demonstrate where investment in therapeutic services might be most effective (Section 2). The extensive literature identified by our investigations is made available in the bibliography, since time restrictions made it impossible for us to review this literature in depth.

Recognising that NHS-funded services in many areas are already tackling aspects of multiple needs and chronic exclusion, for example through provision directed at assertive outreach for people with mental health problems who are difficult to engage with services, through specialist teams working with homeless people and prisoners, among others, we analysed national mapping data to measure the scope and the scale of existing provision (Section 3). We also interviewed senior executive officers of N voluntary agencies to explore their approach and what they think works (Section 4). The themes for the interview included:

- The schemes they run, their aims and objectives, the outcomes they measure and the costs of services.
- What factors affect access to their services.
- How users can be engaged in the services and how staff can be motivated to work with the most challenging clients.
- What aspects are likely to foster the success of services for this group.

Section 1: Prevalence of multiple needs

We postulated that a significant proportion of the population of adults suffering from chronic exclusion could be identified among those people having more than one ‘primary’ need for which they were likely to need support. We identified six diagnostic categories which were likely to indicate primary needs and **defined multiple need as having any combination of at least two of the following: mental illness; personality disorder; severe alcohol dependence; drug dependence; learning disability and adult neuro-developmental disorders.** The choice of personality disorder (PD) and adult neuro-developmental disorder (AND) is discussed below. Our definition of each diagnostic category used in this analysis is shown in Box 1.

Box 1: Diagnostic definitions

Adult neuro-developmental disorder - attention deficit/hyperactivity disorder, Asperger syndrome and adult autism

Drug dependence – dependent on any drug, including cannabis

Learning disability – IQ of 70 or less

Mental illness – probable psychosis as defined by the survey concerned or neurotic disorder as measured by a score of 12 or more on the CIS-R

Antisocial or borderline personality disorder – restricted here to borderline and antisocial personality disorder categories within the DSM cluster B

Severe alcohol dependence – as measured by an AUDIT score of 15 or more

Adult neuro-developmental disorder

Three inter-related problems are likely to affect a significant proportion of adults with chaotic lives and multiple needs. These are Asperger Syndrome (AS), together with Autistic Spectrum Disorder (ASD) and Attention Deficit/Hyperactivity Disorder (ADHD). These are considered here together as adult neuro-developmental disorders, since all have their origins in early development. Indeed they are more often recognised and treated in children and only recently has their continuity into adult life been widely recognised. Broadly, these problems have an adverse impact on the

ability of people affected to cope independently as adults. Rates of social impairment are high (e.g. difficulty making and sustaining relationships, risky, impulsive decision making, problems with organisation and handling money). Co-morbidities with mental illness, specific learning difficulties, antisocial PD and addiction problems are also well above average. Few, if any, services have been developed to respond to the distinctive needs of adults with neuro-developmental problems. At 0.36%¹, Asperger syndrome is about as common as schizophrenia, while adult ADHD at 3-5%² is at least five times as common as schizophrenia. There is some overlap and the combined prevalence of adult neuro-developmental disorders is not known. Nevertheless, such disorders have a clear and largely predictable impact on the ability of individuals to cope in society. Appendix 1.1 describes current knowledge and how adult neuro-developmental disorder is related to other, primary needs.

Personality disorder

Under the DSM classification of psychiatric diagnoses, personality disorder falls into three clusters, of which Cluster B contains (among others) people who are judged to be antisocial, and those whose mental health problem is defined as borderline. These two groups are over-represented in the prison population and they have a high level of multiple needs (mental illness, addiction problems, offending). Until recent years, personality disorder (PD) was regarded as largely untreatable but there has been a great deal of investment in this field, and new approaches are emerging. For this reason, people with borderline or antisocial PD are treated here as a distinct group with a specific, primary need. Justification for this perspective is given in Appendix 1.2, which describes Cluster B in greater detail, reports some associations with other problems found in recent research and records current knowledge concerning effective interventions.

¹ Ehlers & Gillberg (1993)

² Faraone et al. (2003)

Methods

We explored four, nationally-representative surveys, on learning disability in general,³ and on psychiatric morbidity among: prisoners,⁴ homeless people,⁵ and the general population living in private households.⁶ We restricted our analysis to data from England and used the sample weightings where provided in estimating prevalence. Using secondary analysis of this quantitative data, we investigated what the surveys could tell us about multiple primary needs and social problems in different populations. The reliability of the data may be questioned in several respects. For one thing, it may be assumed that many respondents underestimate or conceal drug use because of the illicit nature of the activity. Self-reported alcohol use may also be underestimated for reasons of social acceptability. Therefore, levels of dependence on alcohol and drugs reported here are probably underestimates. It should also be noted that the surveys reported here were undertaken in different years. The prison data are 12 years out of date, the homelessness data are now nearly 10 years old, and even the survey of private households is somewhat dated. Where more recent, relevant epidemiological studies were available we used their findings to supplement our results.

³BMRB. Social Research and Emerson, E., *Adults with Learning Difficulties in England, 2003-2004* [computer file]. Colchester, Essex: UK Data Archive [distributor], December 2005. SN: 5293.

⁴Office for National Statistics, *ONS Survey of Psychiatric Morbidity among Prisoners in England and Wales, 1997* [computer file]. Colchester, Essex: UK Data Archive [distributor], February 2001. SN: 4320.

⁵Office of Population Censuses and Surveys. Social Survey Division, *OPCS Survey of Psychiatric Morbidity among Homeless People, 1994* [computer file]. Colchester, Essex: UK Data Archive [distributor], March 1997. SN: 3642.

⁶Office for National Statistics, *Psychiatric Morbidity among Adults Living in Private Households, 2000* [computer file]. Colchester, Essex: UK Data Archive [distributor], May 2003. SN: 4653.

Table 1.1: Prevalence of single diagnoses in different populations

| | General population⁷ | Homeless⁸ | Prison⁹ | Learning Disabled population¹⁰ |
|---|---------------------------------------|-----------------------------|---------------------------------------|--|
| | % | % | % | % |
| Mental illness – psychosis | 0.45 | 30.0 | 8.4 male 13.8 female ¹¹ | |
| Mental illness – non-psychotic | 14.0 | 24.2 | 52.8 | |
| Any mental illness | 13.6 | 42.1 | 53.1 | 22.4 [1] |
| Personality disorder (Cluster B) | 1.2 | - | 19.6 | 1 [2] |
| Drug dependence | 3.6 | 8.3 | 29.0 ¹² | 1.0 |
| Severe alcohol dependence | 3.9 | 22.2 | 29.0 | 1.0 |
| Substance (drug or severe alcohol) dependence | 7.0 | 27.0 | 74.7 [3] | |
| Mental illness or substance dependence | 18.4 | 54.6 | - | |

[1] of which psychosis 4.4%

[2] any personality disorder

[3] using AUDIT score of 8+ instead of 15+, so not directly comparable to other rates

⁷Office for National Statistics, *Psychiatric Morbidity among Adults Living in Private Households, 2000* [computer file]. Colchester, Essex: UK Data Archive [distributor], May 2003. SN: 4653.

⁸Office of Population Censuses and Surveys. Social Survey Division, *OPCS Survey of Psychiatric Morbidity among Homeless People, 1994* [computer file]. Colchester, Essex: UK Data Archive [distributor], March 1997. SN: 3642.

⁹Office for National Statistics, *ONS Survey of Psychiatric Morbidity among Prisoners in England and Wales, 1997* [computer file]. Colchester, Essex: UK Data Archive [distributor], February 2001. SN: 4320.

¹⁰Cooper, S.-A. *et al.* (2007) Mental ill-health in adults with intellectual disability: prevalence and associated factors, *British Journal of Psychiatry*, 190, 27-36

¹¹Farrell, M., Boys, A., Bebbington, P., Brugha, T. and Coid, J. (2002) Psychosis and drug dependence: results from a national survey of prisoners, *British Journal of Psychiatry*, 181, 393-398.

¹²One of our project consultants comments: “There are good methodological reasons for thinking the ONS prevalence figure an under-estimate. For example, 55% of prisoners questioned in the 2000 Home Office Criminality Survey reported committing crimes in the 12 months prior to imprisonment that were drug-related (M Ramsey ed Prisoners drug use and treatment: seven studies. Home Office Research Findings 186. London: Home Office).”

Results

We set about measuring the prevalence of each single need, bringing together the most up to date, reliable sources available (Table 1.1). Although the surveys were not all undertaken at the same time, some general inferences are clear:

- Taking psychotic mental health problems together with other mental disorders, mental illness is nearly twice as common among people with learning disability as in the general population.
- Mental illness is widely found among homeless people and prisoners, affecting up to half of these populations.
- Personality disorder is common among prisoners, and also among homeless people, but does not affect a large proportion of people with learning disabilities, compared to the general population.
- Alcohol dependence is five times higher among homeless people and 11 times higher among prisoners than the general population
- These figures indicate that prisoner population has a much higher rate of drug problems than the general population.

This analysis confirmed our expectation that the populations of prisoners and homeless persons would harbour a large number of people with high levels of needs, and demonstrated that in some respects people with learning disabilities did not differ from the general population, such as with regard to PD and substance abuse, with the effect that these combinations of need with learning disability were not likely to contribute significantly to the total number of people with complex needs. We also found that there was no information in the surveys concerning adult neuro-developmental disorders, so they could not be included in the analyses.

Complex needs

Table 1.2 shows the available data on combinations of the previously defined needs. There are a number of gaps in the table, where epidemiological data are not available, notably for adult neuro-developmental disorders (which is not shown) and for the prevalence of PD in the homeless population survey. In addition, we know that changes to these populations have occurred in the interim. For example, custody diversion schemes are likely to have affected the number of people with mental health

problems who find themselves in prison. Local, low and medium-secure psychiatric units were not included in the 1997 survey. According to the adult mental health mapping, as of March 2006, there were 24 local low secure services employing on average 50 staff per unit and supporting approximately 377 bedspaces, while seven local, medium secure services employed on average 121 staff per unit and supported approximately 318 bedspaces for people with mental health problems who might otherwise have found themselves in prison.¹³

With regard to the homeless population, who were accessed in hostels and other forms of temporary accommodation, since 1997 there has been a great deal of public investment in services, which may have altered the profile of those people who remain homeless today. It should also be noted that, more recently, immigration from eastern Europe has affected the make up of the homeless population, with an estimated 15% in London currently coming from Poland, for example (Homeless Link). Nevertheless in 2004 a survey by St Mungo's of 1,534 homeless people found that 40% had a mental health problem, 37% had an alcohol problem and 36% had a drugs problem, with 15% having both mental health and substance use problems – a result which is remarkably similar to the situation in 1994.¹⁴

¹³ North East Public Health Observatory Adult Mental Health Mapping Data for 2005-2006
<http://www.nepho.org.uk/index.php?c=1555>.

¹⁴ *St. Mungo's Big Survey into the Problems and Lives of Homeless People. 50-50 The Big Stat.* St. Mungo's website.

Table 1.2: Prevalence of multiple needs in general population and in disadvantaged populations

| Complex needs | Prevalence homeless 1994 (1) | Prevalence prisons 1997 (2) | Prevalence general population 2000 (3) |
|--|---------------------------------|--------------------------------|---|
| Sample size | 1166 | 3142 | 8580 |
| | % | % | % |
| MI & drug dependence | 4.8 psychosis 1.7 other | 0.3 psychosis 14.0 other | 1.1 |
| MI & alcohol dependence | 10.1 psychosis 3.9 other | 0.8 psychosis 29.5 other | 4.3 |
| MI & substance abuse – drug or severe alcohol dependence | 14.5 | 41.2 | 1.7 |
| MI & AS/BD PD | Na | 0.2 psychosis 11.5 other | 1.0 |
| AS/BD PD & drug or severe alcohol dependence | Na | 7.1 | 0.4 |
| Drug dependence & alcohol dependence | 3.5 | 13.0 | 0.8 |

We then went on to see what we could find out about people with multiple needs compared to the rest of the population, by analysing using the 2000 survey of adults living in private households. We found that people with two or more needs were disproportionately male but not by a large margin (51.3% of those with multiple needs but only 49.4% of the total). They differed systematically from the rest of the population on most social indicators, as shown in Table 1.3. Altogether, 3.5% of the population living in private households had some combination of two needs.

Despite the fact that prisons and the homeless population have high concentrations of the primary and indeed the combined needs shown, the total number of people affected is small compared to the general population. The population in prison is currently about 70,000 (Home Office website, January, 2007). Broad estimates put the number of homeless people at no more than 100,000 (Homeless Link, personal communication January 2007), while the general population of working age adults in England in 2000 (to which the rates in Tables 1.1 and 1.2 apply) was estimated to be 31.8 million. Thus the homeless population is about 0.3% as large as the general population and the prison population is about 0.2% as large. Together they make up about 0.5%. Since the surveys were taken at different times and since we have no definition of chaotic lives and multiple needs which we can apply to all three datasets, it is not possible to estimate what proportion of the total population of adults with chronic exclusion find themselves homeless or in prison. However, our analysis of the prison data (Table 1.1) supports those published by Farrell et al. (1998; 2002), Brugha et al. (2005) and Melzer et al. (2002). Our findings concerning the association between homelessness and mental illness, drug and alcohol use shown in the same table are reinforced by the St. Mungo's (2004) survey cited above. We can conclude with confidence that, within that 0.5% of the population who are homeless or in prison, it is likely that a significant proportion will fit any definition of chronic exclusion.

The next task was to operationalise 'chaotic lives'. In this we were restricted to the available variables in the dataset. Here, the restrictions of the survey should be noted. It included only people living in private households, so it is not representative of homeless people nor those living in prisons, hospitals or institutions. We postulated that literacy and numeracy problems, lack of qualifications, lack of social support,

unemployment, moving around frequently and having low income could all be indicative of a chaotic lifestyle. Table 1.3 compares the rates of these individual problems between people with multiple needs and the rest of the sample. The rates are not representative of the general population because the sub-sample interviewed in greater depth is biased towards people with mental health issues (see footnote to Table 1.3).

Taking a different approach to the same data, to find the people with the most chaotic lifestyles, we gave a score of 1 to each of the following variables. They were not weighted although a case could be made for differential impact on chaotic lives. The overall percentage of respondents to the survey to whom each variable applied is given in brackets:

- Difficulty dealing with paperwork (8.6%)
- Difficulty managing money (4.4%)
- No qualifications (26.2%)
- Feels close to neither a co-habiting adult nor any other adult (0.3%)
- Fewer than two close friends and not spoken to one in past week (1.3%)
- Unemployed (2.7%)
- Moved 3+ times in past year (3%)
- Lowest personal income group (28.2%)

Most of these variables were inter-correlated, as shown by the 2x2 Chi-square tests reported in Table 1.4. The exceptions were: having no confidant was not associated with problems with paperwork, money, having no qualifications, nor being unemployed; having few friends was not associated with moving often nor with having a low income; frequent moves was not associated with paperwork problems nor with having a low income.

Table 1.3: Individuals with multiple needs compared to the rest of the sample who answered these questions¹⁵

| | No multiple needs N 493 | Multiple needs N 102 | p ¹⁶ |
|--|----------------------------|-------------------------|-----------------|
| Difficulty dealing with paperwork | 7.9% | 27.3% | <0.001 |
| Difficulty managing money | 3.6% | 26.5% | <0.001 |
| No qualifications | 26.0% | 35.7% | <0.001 |
| How many adults co-habiting do you feel close to? (mean) | 1.40 | 1.30 | 0.008 |
| How many adults generally do you feel close to? (mean) | 5.90 | 4.23 | <0.001 |
| How many people would you describe as good friends? (mean) | 6.78 | 4.82 | <0.001 |
| How many friends have you spoken to in the last week? (mean) | 5.93 | 4.55 | <0.001 |
| Economically inactive | 30.6% | 37.1% | <0.001 |
| Unemployed | 2.6% | 7.8% | <0.001 |
| Mean accommodation moves in past year | 1.63 | 2.54 | <0.001 |
| Lowest personal income group | 27.9% | 35.5% | <0.001 |

Table 1.4: Correlations for problems postulated as contributing to chaotic lifestyle

| Chi-square tests | paperwork | money | qualifs | confidant | friends | unemp | moves |
|-----------------------------------|-----------|-------|---------|-----------|---------|-------|-------|
| Problems handling money | *** | | | | | | |
| No qualifications | *** | *** | | | | | |
| No confidant | ns | ns | ns | | | | |
| Few friends (<2) & little contact | *** | *** | *** | ** | | | |
| Unemployed | ** | *** | ns | ns | *** | | |
| Frequent moves | ns | *** | *** | *** | ns | *** | |
| Lowest income group | *** | *** | *** | *** | ns | *** | ns |

***Correlation is significant at the 0.001 level (2-tailed)

** Correlation significant at the 0.01 level (2 tailed)

Fisher's exact test applied when any cell had an expected value <=5

¹⁵ The second phase sample included all respondents who satisfied one or more of the screening criteria for psychotic disorder, half of those who screened positive for ASBD PD, but showed no psychotic disorder, and 1 in 14 of the remainder. Only those who agreed to being contacted for a second interview were included in this phase (Bebbington et al., 2004).

¹⁶ T-tests of independent means for continuous variables, Chi-squared tests for binary variables.

The combined chaotic lifestyle score had a maximum of 8 and was 'positively skewed', with 51% of the total sample scoring 0, 30% scoring 1, 15% scoring 2, 4% scoring 3 of a possible 8 and the remaining 0.9% scoring 4, 5 or 6. Nobody scored 7 or 8. We set 4 or more as the threshold for a chaotic lifestyle, given that we were investigating people at the extreme end of this distribution.

We then explored the relationship between those individuals defined as having chaotic lifestyles and those whom we had identified as having multiple needs. People with chaotic lifestyles made up 0.9% of the general population, people with multiple needs made up 3.5% of the population, but the overlap was only 0.2%. So, to find out more about chronic exclusion, we investigated that group which had the former in terms of the latter, and then the reverse.

When we looked into the characteristics of the people with chaotic lifestyles but not multiple needs, we found that there was no apparent association with gender, age nor ethnic minority status.¹⁷ We therefore returned to the diagnostic variables used to define multiple needs (Table 1.1) to see if any of those applied.

Table 1.5 shows the results of a hierarchical breakdown of the characteristics of the people with chaotic lifestyles. Mental illness on its own and low intelligence on its own did account for some of the chaotic lifestyles. Just under one quarter (23%) also had multiple needs. A further 18% had mental illness but did not have multiple needs as we had defined them. Nine per cent had low intelligence (70-79, the threshold for learning disability is below 70, and people with learning difficulties were excluded from the survey). The most common personality disorder among the remainder with chaotic lifestyle was schizoid PD. This is defined as 'A pervasive pattern of detachment from social relationships and a restricted range of expression of emotions in interpersonal settings, beginning by early adulthood and present in a variety of contexts'¹⁸. People with this problem tend to avoid other people, so they are very

¹⁷ Using logistic regression analysis, with chaotic lifestyle as the dependent variable, none of these variables proved significant.

¹⁸ <http://www.psychnetuk.com/clinical_psychology/personality_disorders_schizoid.htm>

likely to turn down help.¹⁹ Having excluded all the people to whom these characteristics applied: multiple needs, mental illness, low intelligence, schizoid PD, there remained four individuals with chaotic lifestyles who had attempted suicide at some time in their life. Perhaps surprisingly, a history of detention in prison did not explain any more chaotic lifestyles after these variables were taken into account.

A similar hierarchical analysis was undertaken to investigate the characteristics of people with multiple needs, as shown in Table 1.6. We found that, leaving aside those people who also had chaotic lifestyles, low intelligence applied to a sizeable minority (39%) of this group, and even allowing for low intelligence, problems handling money or paperwork affected a further 24%. A suicide attempt in the past was the next most common factor, affecting 18% and a residual number (3%) had some form of PD apart from borderline or antisocial. This breakdown helped to explain the makeup of just over 90% of those people who had multiple needs, as compared to 64% of the chaotic lives group.

The two pie charts which follow (Charts 1 and 2) illustrate the results of these hierarchical analyses. They should be seen as exploratory. The following inferences may be drawn:

- About a quarter of people with chaotic lifestyles also have multiple needs (23%).
- Most people (93.5%) with multiple needs living in private households do not appear to have chaotic lifestyles as defined here.
- A considerable proportion of people with multiple needs have low intelligence or problems handling money and paperwork. This analysis does not tell us how far the needs of these groups are addressed.
- The high prevalence of lifetime suicide attempts among people with multiple needs who are of normal intelligence and literacy levels (18%) may indicate an area for suicide prevention.
- Personality disorders other than antisocial and borderline disorders play a part in the lives of people with multiple needs, and schizoid PD may be associated with chaotic lifestyle.

¹⁹ This clearly has implications for the types of services which people find acceptable.

This analysis shows that there is not great overlap between people with chaotic lifestyles and people with multiple needs. It suggests that different response strategies may be indicated if we focus on people with either chaotic lifestyles, or multiple needs, or both.

Individual problem perspective

An alternative perspective is offered if we revert to individual diagnoses, disaggregating the group with multiple needs in terms of specific problems, as shown in Charts 3-5. The categories shown in these bar charts are not mutually exclusive, individuals may fall into more than one 'bar'. Chart 3 shows that the largest sector of people with multiple needs have mental health problems in combination with substance use problems, and that Cluster B personality disorders in combination with another need are also a significant contributor to multiple need. Among the sub group of people with mental illness, anxiety and depression are the most frequent diagnoses, alone, or in combination (Chart 4). Among those who abuse substances, alcohol abuse dominates, whether this is defined as 'dependence' (AUDIT score 8+) or 'severe dependence' (AUDIT score 15+). Illicit drug use is much less common, but of course the legal and social ramifications may be relatively greater, to the extent that a dependence on illicit drugs may be supported by crime, which has a high public profile. The family breakdown and lost employment attributable, by comparison, to dependence on alcohol, causes less public concern. It would be difficult to judge whether drugs or alcohol make a greater contribution to chaotic lives.

Where do they live?

People with chronic exclusion are not evenly spread across the country. Health regional offices at the time of the survey (2000) provide a sufficient level of aggregation to describe where the people with chaotic lives and multiple needs were found. Despite at least one reorganisation since then and with one more planned, these areas have geographical validity and are used here to illustrate the variations in where the target group reside. In the tables which follow, the first column gives the distribution of the unaffected part of the total weighted sample. If the targeted group were distributed in line with the sample, the second column would be the about same. Here, we comment on higher than expected rates. Taking the target group as the 3.5%

of individuals who fit either description, there appears to be a disproportionate number in the Northern & Yorkshire health region and in London, with a slightly higher than expected number in the North West (Table 1.7). If we look at chaotic lifestyle alone (0.9%) the North West seems to have the greatest share (Table 1.8), but if the focus is on multiple needs, then Northern & Yorkshire and London seem to have more than would be expected if the distribution of people with these problems were entirely random (Table 1.9). The narrowest definition, people with both multiple needs and chaotic lifestyle (0.2% of the population) throws the South East into relief. However, the numbers are small in this analysis (30 people affected in total) so the margin of error in Table 1.10 is large.

This analysis shows that the prevalence of the target group varies by location as well as by definition used. Within such large areas as those used here, it seems likely that the majority of people affected will be found in urban centres, but the small numbers in the dataset make further analysis within regions unreliable.

Table 1.5: Hierarchical breakdown of people with chaotic lifestyles

| | N | % |
|---|-----|----|
| | 132 | |
| Multiple needs | 30 | 23 |
| Mental illness (not multiple needs) | 24 | 18 |
| Low intelligence (not multiple needs) | 13 | 10 |
| Schizoid personality disorder (& none of the above) | 12 | 9 |
| Suicide attempt in lifetime (& none of the above) | 5 | 4 |
| Ever in prison (& none of the above) | 0 | 0 |

Table 1.6: Hierarchical breakdown of people with multiple (clinical) needs

| | N | % |
|---|-----|------|
| | 493 | |
| Chaotic lifestyle (score \geq 4) | 30 | 6.5% |
| Low intelligence (not multiple needs) | 180 | 39% |
| Problems handling money or paperwork (& neither of the above) | 109 | 24% |
| Suicide attempt in lifetime (& none of the above) | 85 | 18% |
| Any PD except antisocial/borderline (& none of the above) | 14 | 3% |
| Ever in prison (& none of the above) | 0 | 0 |

Table 1.7: Multiple needs or chaotic lifestyle

| Health regional office | | |
|------------------------|------------|--------------|
| | Not target | Target group |
| N (wtd) | 13426 | 595 |
| | % | % |
| Northern and Yorkshire | 13 | 18 |
| Trent | 10 | 6 |
| West Midlands | 11 | 8 |
| North West | 14 | 16 |
| Eastern | 12 | 11 |
| London | 12 | 16 |
| South East | 18 | 15 |
| South West | 11 | 10 |
| Total | 100 | 100 |

Table 1.8: Chaotic lifestyle alone

| Health regional office | | |
|------------------------|--------|-------------------|
| | Others | Chaotic Lifestyle |
| N (wtd) | 13889 | 132 |
| | % | % |
| Northern and Yorkshire | 13 | 13 |
| Trent | 10 | 8 |
| West Midlands | 11 | 8 |
| North West | 14 | 18 |
| Eastern | 12 | 14 |
| London | 12 | 12 |
| South East | 18 | 14 |
| South West | 11 | 15 |
| Total | 100 | 100 |

Table 1.9: Multiple needs alone

| Health regional office | | |
|------------------------|--------|----------------|
| | Others | Multiple needs |
| N (wtd) | 13528 | 493 |
| | % | % |
| Northern and Yorkshire | 13 | 19 |
| Trent | 10 | 7 |
| West Midlands | 11 | 8 |
| North West | 14 | 15 |
| Eastern | 12 | 11 |
| London | 12 | 17 |
| South East | 18 | 15 |
| South West | 11 | 9 |
| Total | 100 | 100 |

Table 1.10: Both multiple needs and chaotic lifestyle

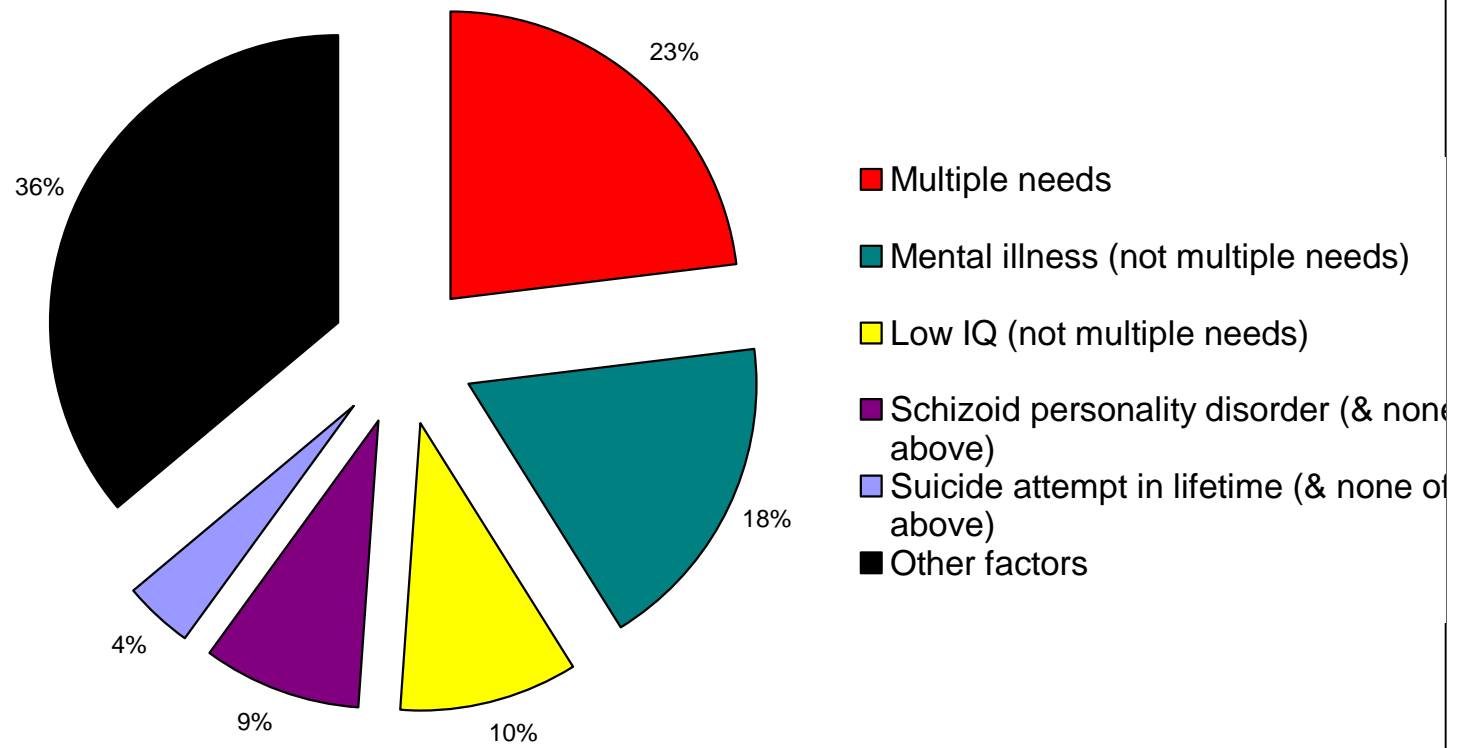
| Health regional office | | |
|---------------------------|---------|------|
| | Neither | Both |
| N (wtd) | 13991 | 30 |
| | % | % |
| Northern and Yorkshire | 18 | 20 |
| Trent | 6 | 17 |
| West Midlands | 8 | 3 |
| North West | 16 | 13 |
| Eastern | 11 | 13 |
| London | 17 | 3 |
| South East | 15 | 20 |
| South West | 10 | 10 |
| Total | 100. | 100 |

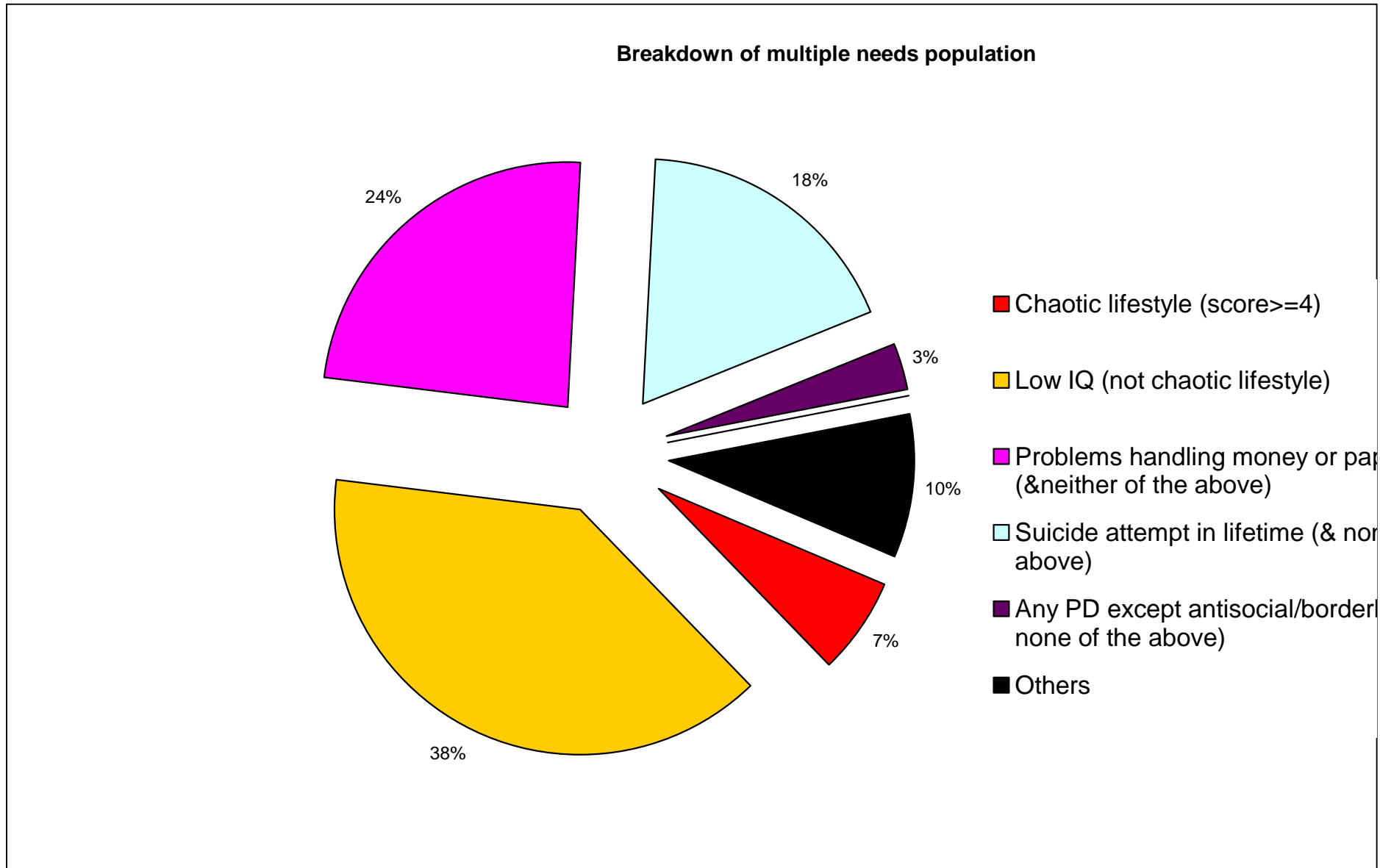
Conclusion

Before moving on to look at effective interventions, it may be helpful to remember here that the secondary analysis of the 2000 survey is not meant to be definitive. The factors taken here to indicate chaotic lifestyle are highly inter-correlated, which may bias our results. We have tried to minimise this possibility by including in our analyses only the highest scores on this measure, less than 1% of the population. This approach does not allow us to take account of current problems with relationships, current involvement of the criminal justice system, rejection by formal services or homelessness, which are all common features of adults with chronic exclusion. Our definitions of needs are limited to the variables available in the dataset. Importantly, they do not include any measure of adult neuro-developmental disorder, which means that a sizeable group of socially disabled people is not included as such in these analyses. This omission may be reflected in the sizeable proportion of people with multiple needs who have low intelligence and problems managing money or paperwork who do not attain a score of 4 or more on the chaotic lives scale.

These limitations mean that the results presented here may be used to illuminate the problems, highlighting some major issues which are associated with chronic exclusion and thereby suggesting means by which solutions might be attempted. They do not rule out other ways of understanding the issues, for instance, in terms of their origins in childhood or as a function of traumatic experiences, however, we do not have data about these factors.

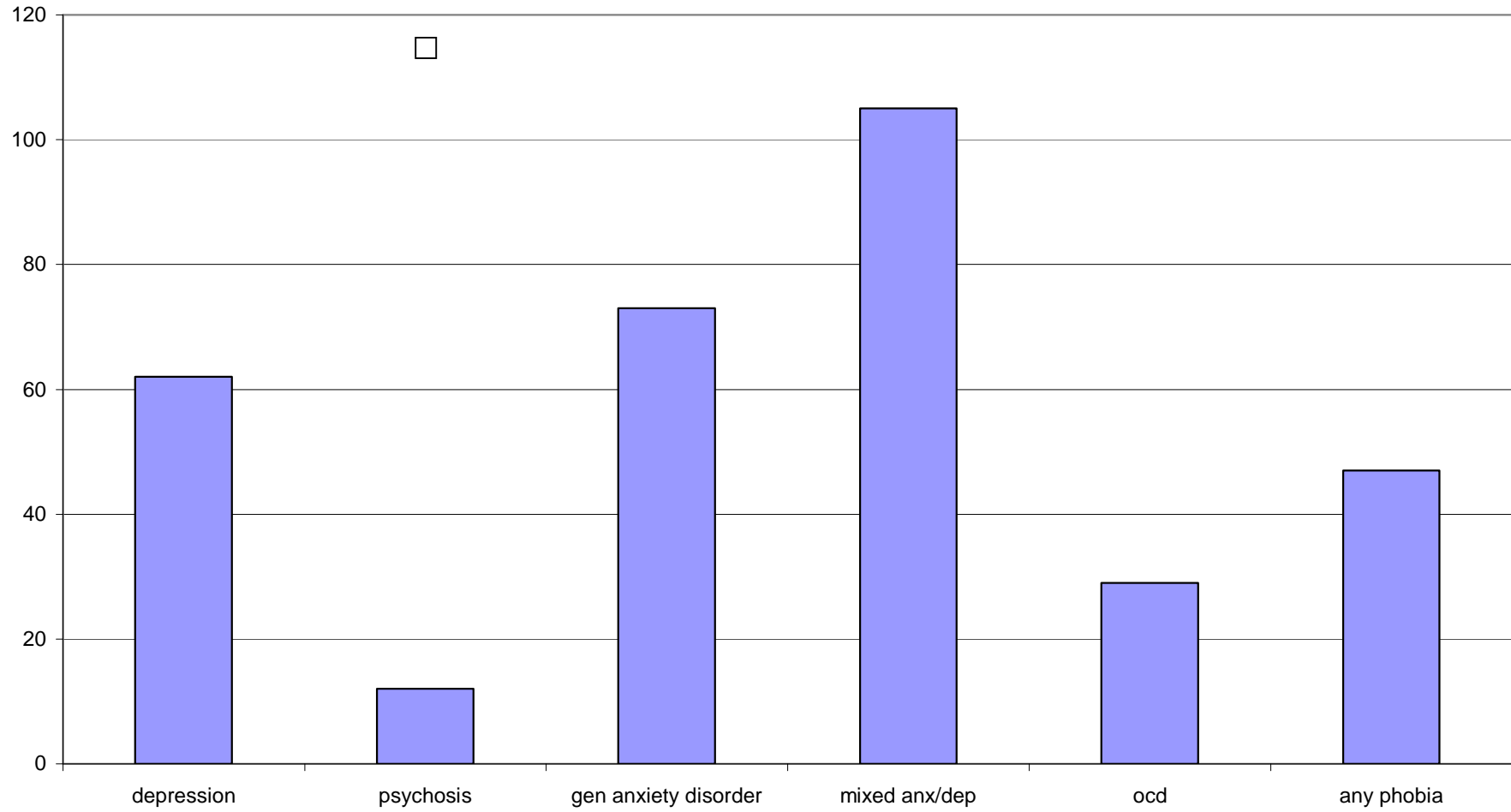
Breakdown of population with chaotic lifestyles



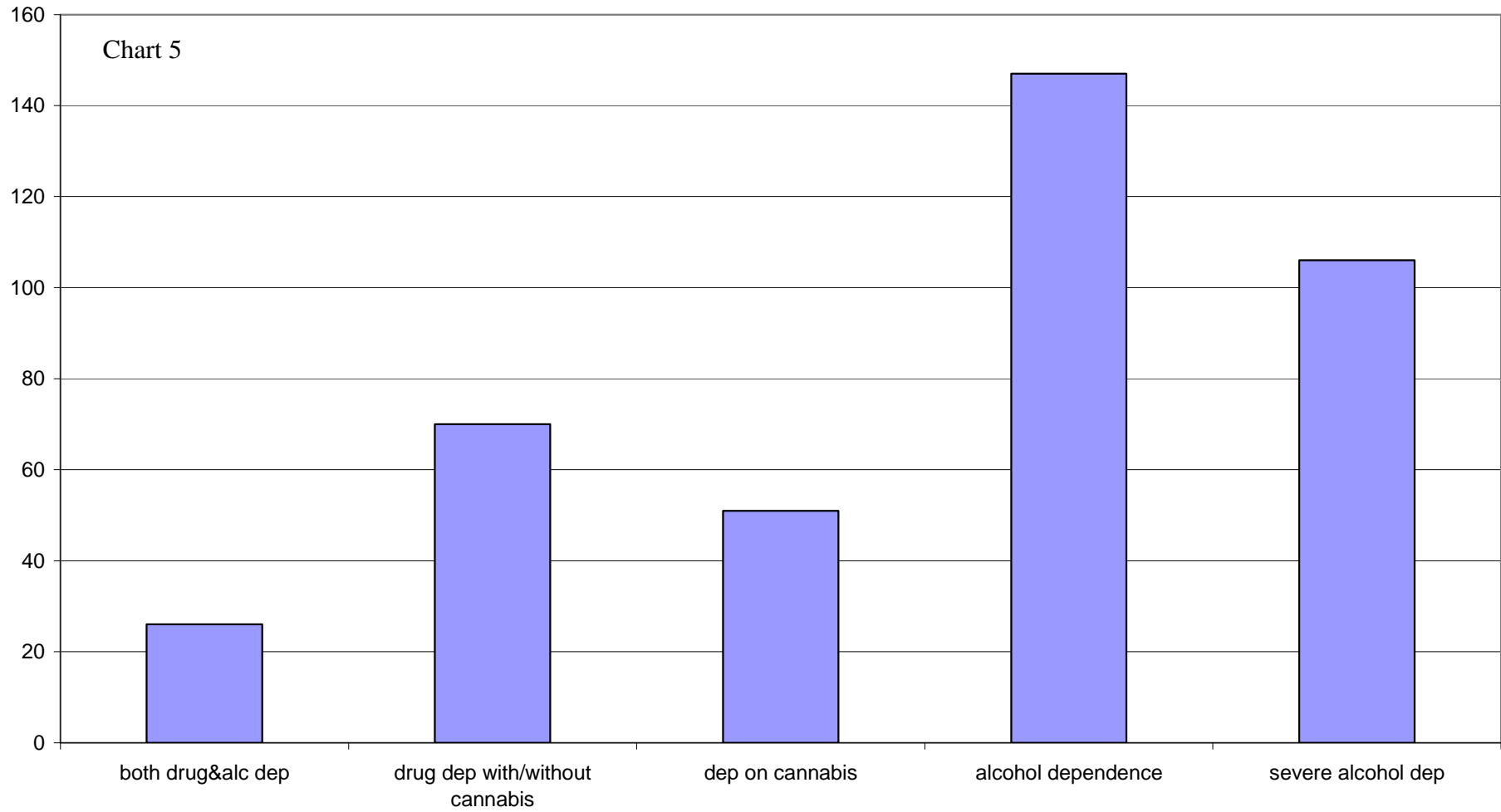


Mental illness breakdown of multiple needs

Chart 4



Substance abuse breakdown of multiple needs



Section 2: Effective interventions

Method

We undertook a search of relevant databases containing evidence on effective health care and criminal justice interventions. Only reviews were included because of the limited time available; individual studies of specific interventions were not included at this stage. Where evidence exists from reviews, evidence from individual studies is likely to be redundant. A review of therapeutic interventions gives a high level of confidence because it incorporates all the available evidence. However, it can be difficult to apply in specific cases because of its level of generality.

The Cochrane database and the Campbell database were ‘hand’ searched, and the York Centre for Reviews and Dissemination was searched electronically, to identify reviews of interventions that were targeted at people with any combination of two of the disorders identified among our main needs. In this way, we targeted our search at treatments suitable for people with complex needs. All interventions which did not exclude people with multiple needs (e.g. substance abuse and mental illness; mental illness and personality disorder) were retained. The abstracts were screened for relevance and applicability; those that passed this screen were obtained and read in greater depth insofar as time permitted. The individual reviews identified and the authors’ conclusions are reproduced in Appendix 2.1.

In parallel with this research activity, a range of potential interventions was drawn up, using information about the activities of organisations working with chronically excluded people including mental health services. This list grew as the review of reviews developed. Two categories of intervention were identified: both individual therapeutic approaches and organisational or service-level approaches (Box 2.1). The next step was to match interventions with evidence, in relation to specific sets of needs. We began by classifying the evidence from reviews and, where this was not found, we turned to the experts in our research group to help us to identify promising interventions.

Results

Table 2.1 shows the results of this analysis. This table has been compiled using an inclusive approach. For some interventions (e.g. music therapy for schizophrenia) the evidence is only slight (Gold et al., 2005). Other interventions are highly specific in their delivery method, e.g. short-term psychodynamic psychotherapy (Abbass et al., 2006). Many have not been explicitly tested on every possible combination of needs, but as far as we are aware the relevant review does not rule out these combinations, so the intervention is included in each row which contains client groups to which it has been successfully applied. As far as we know, none of the reviews listed in the left hand column of references in Table 2.1 included studies where subjects were excluded if they had dual diagnosis.

A ‘review of reviews’ such as that outlined in the left hand column lists meta-analyses of high quality trials. These are the most reliable type of evidence. Where a meta analysis exists for a given category, no evidence of a less reliable type is included here in the right hand column.

However, there are limitations in taking such an approach. For instance, two reviews draw somewhat contradictory conclusions. Lees et al. (2004) found that therapeutic communities (TCs) were effective for people with personality disorders and for mentally disordered offenders, but Smith et al. (2006) did not conclude that they were effective for people with substance abuse problems. This illustrates why a more detailed review of interventions undertaken by experts in the field may be warranted. One of our expert consultants on the project reports that the Smith review should not be used to dismiss TCs because of a number of methodological problems, including the facts that: treatment provision differs between countries, the Smith et al. study is based solely on US studies; none of these compare TC treatment with methadone maintenance, the most common form of treatment for drug use in the UK; problems of allocation and attrition have long been considered too great to allow the randomised control trial (RCT)²⁰ study design of drug treatment in the UK. Using an alternative

²⁰ Study design where treatments, interventions, or enrolment into different study groups are assigned by random allocation rather than by conscious decisions of clinicians or patients. If the sample size is large enough, this study design avoids problems of bias and confounding variables by assuring that

study design, residential rehab (TC) clients have been found to perform better on abstinence indicators at 33-month follow-up than all other treatments groups (McKeganey et al., 2006); choice of outcome measures is crucial. As just stated, TCs do better on abstinence outcomes in our data. But if the outcome is reduction in heroin use, methadone maintained clients do better. Uncertainties around appropriate treatments suggests that it is probably important to maintain a mixed bag of provision.

Implications: what should be available for people with complex needs

Table 2.1 may be read as outlining the potential for helpful interventions based on the available evidence. Some general inferences can be made about what works for people with complex needs. Not all forms of intervention are required for each person affected. However, a service catering for people with these sets of needs at least ought to consider providing (or should have access to) all of the interventions for which there is effectiveness evidence for a significant proportion of their clientele:

SERVICE DELIVERY APPROACHES FOR COMPLEX NEEDS

- Individualised case management
- Assertive outreach
- Integrated, multidisciplinary team working
- Crisis resolution
- Day hospital care
- Therapeutic community/residential rehabilitation
- Individual placement and support model of vocational rehabilitation

SPECIFIC INTERVENTIONS FOR COMPLEX NEEDS

- Medication
- Individual psychotherapeutic counselling
- General psychological therapies: cognitive behaviour therapy, dialectical behaviour therapy, and social problem solving therapy

both known and unknown determinants of outcome are evenly distributed between treatment and control groups. (http://www.mclibrary.duke.edu/training/pdaformat/ebmtermmpda_r.html)

A striking result of this exercise is how much strong evidence exists. Every combination of needs shown in the table has some evidence based intervention which could be applied. Clearly, the ways in which these may be delivered to chronically excluded people need to be explored; this poses a challenge for innovation and experimentation.

Limitations

The clinical perspective of this enquiry has generated a list of interventions with a medical flavour and the terminology used is derived from contemporary NHS provision. Indeed, most of these services are mainly available within the NHS, and the extent to which they may be available to the chronically excluded is discussed in the following sections. There are also a number of services and service approaches in Box 2.1 for which little evidence is available. Some of these are the most innovative and arguably the most attractive to people with chronic exclusion. They include art, creative writing, music, singing and dancing and other constructive activities undertaken individually as well as in groups. These are not on the whole amenable to RCTs, but they have been reviewed elsewhere (e.g. Broadway, 2005).

The exercise has highlighted the need for a review of what works for people with complex needs. It has enabled us to state generally what provision is suitable, but a great deal of work would be required to make more specific recommendations. This ought to take account of contextual factors, including: the service setting; the users' age; social situation; and previous service use. A thoroughgoing synthesis of literature identified here and in the bibliography, a could generate a more detailed and nuanced account of what works for whom.

Box 2.1

KEY TO INTERVENTIONS

| THERAPEUTIC INTERVENTIONS | | MODES OF SERVICE DELIVERY | |
|---------------------------|-----------------------------------|---------------------------|---|
| 1 | 1 to 1 counselling/psychotherapy | 21 | Key working/individualised case management |
| 2 | Group counselling/psychotherapy | 22 | Advocacy/mentoring/befriending/peer support |
| 3 | Exercise | 23 | Early intervention |
| 4 | Supported employment | 24 | Crisis resolution/home management |
| 5 | Cognitive behaviour therapy | 25 | Assertive outreach |
| 6 | Medication | 26 | Systemic working |
| 7 | Family therapy | 27 | Therapeutic community/residential treatment |
| 8 | Art therapy | 28 | Multidisciplinary team working |
| 9 | Music therapy | 29 | Day hospitals |
| 10 | Social firms/social enterprise | 30 | Reminders of appointments |
| 11 | Motivational interviewing and CBT | 31 | Alcoholic Anonymous |
| 12 | General psychological therapies | 32 | Staged treatment for dual disorders |
| 13 | Dialectical behaviour therapy | 33 | Integrated treatments |
| 14 | Social problem solving therapy | | |
| 15 | Partial hospitalisation | | |

Table 2.1: Interventions for complex needs (see reference list for full details)

| Complex needs | Interventions for which there is some evidence suggestive of effectiveness from the review of reviews | Interventions for which there is evidence from well designed studies such as RCTs |
|-------------------------|--|--|
| MI & drug dependency | 1 (for common mental disorders) (Abbass et al.) 6 (buprenorphine for opioid withdrawal) (Gowing et al.) 6 (risperidone for schizophrenia) (Hunter et al.) 9 (for schizophrenia) (Gold et al.) 11 (for schizophrenia) (Haddock et al.) 12 (for cannabis) (Denis et al.) 4 (Crowther et al.) 25 (Marshall & Lockwood) 21 (Marshall et al.) 28 (Tyrer et al.) (Drake et al.) (Brunette et al.) 24 (Joy et al.) 29 (Marshall, Crowther et al.) 6 (methadone for opiate addiction) (Marsch) | 33 (first episode psychosis) (Peterson et al.) 33 (Graham) |
| MI & alcohol dependency | 1 (for common mental disorders) (Abbass et al.) 6 (risperidone for schizophrenia) (Hunter et al.) 9 (for schizophrenia) (Gold et al.) 4 (Crowther et al.) 25 (Marshall & Lockwood) 21 (Marshall et al.) 28 (Tyrer et al.) (Drake et al.) (Brunette et al.) 24 (Joy et al.) 29 (Marshall, Crowther et al.) 31 (negative effect) (Kownacki et al.) | 11 (for schizophrenia) (Haddock et al.) 32 (for social anxiety disorder) 33 (first episode psychosis) (Peterson et al.) 33 (Graham) |
| MI & LD | 5 (for aggression) (Hassiotis & Hall) 4 (Crowther et al.) 6 (risperidone for schizophrenia) (Hunter et al.) 9 (for schizophrenia) (Gold et al.) 25 (Marshall & Lockwood) (UK 700) 21 (Marshall et al.) 28 (Tyrer et al.) 24 (Joy et al.) 29 (Marshall, Crowther et al.) | 33 (first episode psychosis) (Peterson et al.) |
| MI & PD | 1 (for common mental disorders) (Abbass et al.) 6 (antidep for BPD) (Binks et al.) 6 (risperidone for schizophrenia) (Hunter et al.) 4 (Crowther et al.) 9 (for schizophrenia) (Gold et al.) 12 (for BPD) (Brazier et al.) 13 (for BPD) (Brazier et al.) 25 (Marshall & Lockwood) 21 (Marshall et al.) 28 (Tyrer et al.) 24 (Joy et al.) 27 (Lees et al.) 29 (Marshall, Crowther et al.) | 1 (Leichsenring & Liebong) (Perry et al.) (Bateman & Fonagy) 5 (Leichsenring & Liebong) (Davidson et al.) 33 (first episode psychosis) (Peterson et al.) |

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| Table 2.1 contd. | | |
|--------------------------|--|---|
| Complex needs | Interventions for which there is some evidence suggestive of effectiveness from the review of reviews | Interventions for which there is evidence from well designed studies such as RCTs |
| MI & AND | 1 (for common mental disorders) (Abbass et al.) 4 (Crowther et al.) 6 (risperidone for ASD) (Jesner) 6 (risperidone for schizophrenia) (Hunter et al.) 9 (for schizophrenia) (Gold et al.) 25 (Marshall & Lockwood) 21 (Marshall et al.) 28 (Tyrer et al.) 24 (Joy et al.) 29 (Marshall, Crowther et al.) | 33 (first episode psychosis) (Peterson et al.) 5 (for ADHD) (Wilens et al., 2000)(Safren et al.) |
| LD & PD | 5 (for aggression) (Hassiotis & Hall); 6 (for BPD) (Binks et al.) 12 (for BPD) (Brazier et al.) 13 (for BPD) (Brazier et al.) | 1 (Leichsenring & Liebong) (Perry et al.) 5 (Leichsenring & Liebong) (Davidson et al.) 14 (Huband et al.) |
| AND & alcohol dependence | 6 (risperidone for ASD) (Jesner) 6 (buprenorphine for opioid withdrawal) (Gowing et al.) 6 (methylphenidate for ADHD) (Faraone et al. 2004) | 5 (for ADHD) (Wilens et al., 2000)(Safren et al.) |
| AND & drug dependence | 6 (risperidone for ASD) (Jesner) 6 (buprenorphine for opioid withdrawal) (Gowing et al.) 12 (for cannabis) (Denis et al.) 6 (methylphenidate for ADHD) (Faraone et al. 2004) 6 (methadone for opiate addiction) (Marsch) | 5 (for ADHD) (Wilens et al., 2000)(Safren et al.) |
| PD & AND | 6 (antidep for BPD) (Binks et al.) 6 (risperidone for ASD) (Jesner) 12 (for BPD) (Brazier et al.) 15 (for BPD) (Brazier et al.) 27 (Lees et al.) 6 (methylphenidate for ADHD) (Faraone et al. 2004) | 1 (Leichsenring & Liebong) (Perry et al.) 5 (Leichsenring & Liebong) (Davidson et al.) 5 (for ADHD) (Wilens et al., 2000) (Safren et al.) 14 (Huband et al.) |
| PD & drug dependency | 6 (antidep for BPD) (Binks et al.) 12 (for BPD) (Brazier et al.) 12 (for cannabis) (Denis et al.) 6 (buprenorphine for opioid withdrawal) (Gowing et al.) 6 (methadone for opiate addiction) (Marsch) | 13 (women - Linehan et al.) Verheul et al., 2003) 1 (Leichsenring & Liebong) (Perry et al.) 5 (Leichsenring & Liebong) (Davidson et al.) 14 (Huband et al.) |
| PD & alcohol dependency | 6 (antidep for BPD) (Binks et al.) 13 (for BPD) (Brazier et al.) 31 (negative effect) (Kownacki et al.) | 13 (women - Linehan et al., 1999; Verheul et al., 2003) 1 (Leichsenring & Liebong) (Perry et al.) 5 (Leichsenring & Liebong) (Davidson et al.) 14 (Huband et al.) |
| PD & convictions | 6 (antidep for BPD) (Binks et al.) 12 (for BPD) (Brazier et al.) 27 (Lees et al.) | 13 (women - Low et al., 2001; Nee & Farman, 2005) 1 (Leichsenring & Liebong) (Perry et al.) 5 (Leichsenring & Liebong) (Davidson et al.) 14 (Huband et al.) |

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| Table 2.1 contd. | | |
|---------------------------|--|--|
| Complex needs | Interventions for which there is some evidence suggestive of effectiveness from the review of reviews | Interventions for which there is evidence from well designed studies such as RCTs |
| Drug dep & convictions | 27 (Perry et al.) (Wilson & Mackenzie) 6 (buprenorphine for opioid withdrawal) (Gowing et al.) 2 (Wilson & Mackenzie) 12 (for cannabis) (Denis et al.) 6 (methadone for opiate addiction) (Marsch) | |
| Alcohol dep & convictions | 31 (negative effect) (Kownacki et al.) | 27 Lipton et al., 2002 |
| Drug dep & alcohol dep | 31 (negative effect) (Kownacki et al.) 6 (buprenorphine for opioid withdrawal) (Gowing et al.) 6 (methadone for opiate addiction) (Marsch) | |
| KEY | ASD – autistic spectrum disorder AND - Adult neuro-developmental disorder BPD - Borderline personality disorder MI - Mental illness LD - Learning disability PD - Personality disorder | |

Section 3: What provision exists in the NHS

Source of data

Since 2001, the Department of Health has funded annual national Adult Mental Health Service Mapping, undertaken by Gyles Glover and colleagues at the Mental Health Observatory, part of the North East Public Health Observatory. This forms part of the annual monitoring of the progress in implementing the National Service Framework for Mental Health. The mapping, which is done on-line, classifies services into 56 carefully defined types, from acute in-patient wards to drop-in centres. Information collected about each individual service item (12,596 in total) varies. For elements of major statutory provision (2,194 units), these include staffing profiles and whole time equivalents and, where relevant, bed numbers. For smaller services, commonly run by voluntary sector organisations, expectations are more modest. The Mental Health Observatory kindly supplied data for this part of our study, which focuses on existing provision that aspires to support adults with complex needs. This dataset relates to the 2005-2006 mapping, so it reflects the state of provision at the end of the financial year, March, 2006.

It should be noted that the mapping dataset was interrogated to identify those services which stated that their target groups included our definitions of multiple needs. In mental health service terms, this means they work with: learning disability with mental illness; dual diagnosis (substance misuse mental illness); or personality disorder. Inclusion in the analysis which follows means that the service has stated that they provide at least one staff member with the multiple need group in their job description or at least one dedicated session per week to the relevant group. For comparative purposes, a table showing all mental health services including those studied here, is given in Appendix 3.1.

Method

The reduced mapping dataset supplied was analysed at the service level. Focusing on the target group, we omitted general, psychiatric residential and inpatient services, on the grounds that chronically excluded people by definition would not find it easy to access this provision. For all other services, the mean number of staff members per team of a given type was calculated. To estimate the capacity of each type of

provision to work with complex needs, this was multiplied by the number of units (Table 3.1). Information on the bed numbers of all inpatient facilities was also analysed but, since length of stay and bed occupancy figures were not available, this is not ranked and does not imply any estimates of capacity (Table 3.2). We investigated the providers of all the services registered with the mapping dataset (statutory, voluntary or private) (Table 3.3). Lacking profiles of caseloads from the mapping data, we also looked at the national survey of adults living in institutions for people with mental health problems²¹ to find out who was accommodated and whether they could be described as having multiple needs.

Results

Table 3.1 gives the existing provision in terms of staff numbers, averaging over all categories of staff (managers, administrators and clinical). Caseload information is not currently collected by the mapping database. Staff numbers could serve as a proxy for the investment in each type of service, although caseloads will vary widely. For example Assertive Outreach (AO) with its prescribed caseload limit per practitioner of 12, is likely to be in contact with far fewer service users than day centres/resource centres, which have a similar level of staffing.

In Table 3.1, asterisks indicate services which might have particular relevance for people with multiple needs, but a question mark could equally well have been used to indicate uncertainty surrounding this assumption, since it is an area for further analysis and investigation. Some services are designated to meet the needs of people for whom conventional psychiatric services fail to cater. AO is one such service. It is meant to work with hard to reach people, including those with dual diagnosis (mental illness and substance abuse). Much of the work is supposed to take place outside of service setting, with 24/7 availability and intensive, long-term, multidisciplinary support. While the penetration of AO services into that group of people who are otherwise chronically excluded is not known, it might be argued that AO could potentially serve a large proportion of the target group who have severe mental health problems. The complete mapping dataset shows 250 AO teams, but only 103 are

²¹ OPCS. Social Survey Division, *OPCS Surveys of Psychiatric Morbidity : Institutions Sample, 1994* [computer file]. Colchester, Essex: UK Data Archive [distributor], September 1996. SN: 3585.)

included in this analysis. This could be because more than half the AO teams do not have dual diagnosis staff or it could indicate that the selected dataset is incomplete; further analysis could resolve this question.

Other services for this group include 11 homeless mental health services and 20 services for people with personality disorders. The coverage of these services is relatively slight; they are small in number if they are compared to 103 AO or 172 community mental health teams. Staff of PD services make up only 1.4% of the numbers shown in Table 3.2, and staff of homeless services make up only 0.7%. Location in relation to the geographical areas of greatest need is therefore desirable. Appendix 3.2 lists the addresses and a brief description of these services, where available.

Table 3.3 lists the providers of all the mental health services in the reduced mapping dataset. From this it is clear that a high proportion of supported housing and care home accommodation for people with multiple needs is provided by the non-statutory sector. The same is true of day centres, advocacy services, drop-ins and service user groups.

Although it may be argued that people living in institutions are by definition not chronically excluded, we know that some of this population have been institutionalised for large parts of their lives and are considerably disabled by this experience. We found a high rate (57.5%) of people with both mental health problems and alcohol problems in the survey of institutions. One third was female (33%). Although all were of working age (16-65), 65% described themselves as permanently unable to work. Fourteen per cent were working and 3% looking for work. Whether they belonged to the 'old long stay' or to a newer, 'revolving door' population of mental health service users, it is of interest to this study to know who is being accommodated in specialist settings. However, it must be borne in mind that this population may have altered since the survey was undertaken in 1993.

For service users with multiple needs, complex packages of support are often required. In addition to clinical and social care (mainly from statutory providers) a large proportion of day and residential services are now provided by voluntary and

private agencies. The nature of this user group demands close integration between all the parties involved. Therefore, systems for joint assessment, sharing information and co-ordinating treatments are of particular relevance to this enquiry. These will be highlighted in Section 4.

Implications

There is a growing awareness of how exclusion affects users of mental health services (ODPM, 2004) and how service structures can create or reinforce exclusion. Some specific services have been developed within the NHS to meet the needs of the most excluded, among them people with PD, homeless service users and the generally hard to help. The most widespread services – AO and CMHTs, could (in principle) be responsible for most people with serious mental health problems, including those with dual diagnosis of learning disability or drug and alcohol problems. We need to know more about the extent to which these services address the needs of chronically excluded people in practice, what barriers they present and how these can be overcome in practice. We understand that a recent trial of dual diagnosis services is as yet unpublished.²²

We also need to know more about the costs and effectiveness of residential options for people with multiple needs. When people are housed, their lives may become less chaotic, but multiple needs persist. Residential services across the board appear to cater for a high proportion of people with mental health problems and alcohol problems. As shown in Section 2, we are not aware of any evidence on the effectiveness of different forms of housing and support.

²² Johnson, S. Thornicroft, G. Afuwape, SA. Leese, M. White, I. Hughes, E. Wanigaratene, S. Miles, H. Craig, T. Co-morbidity Dual Diagnosis Study (COMO) Study Paper 1 - RCT of the effectiveness of training community mental health staff to deliver interventions for comorbid substance misuse (in press).

Table 3.1: Provision for people with mental health problems and multiple needs

North East Public Health Observatory Adult Mental Health Mapping Data for 2005-2006

| | N | Mean WTE staff | Total est. no staff (col. 2 x col. 3) |
|---|-------------|----------------------|---|
| Community Mental Health Team | 172 | 21 | 3612 |
| Assertive outreach* | 103 | 12 | 1236 |
| Day Centres/Resource Centre | 142 | 8 | 1136 |
| Regional medium secure unit | 2 | 426 | 852 |
| Local Low Secure Service - High Dependency Unit | 17 | 50 | 850 |
| Local Medium Secure Service | 7 | 121 | 847 |
| Employment Scheme | 104 | 8 | 832 |
| Crisis resolution* | 43 | 19 | 817 |
| Other community and/or hospital professional team/specialist | 54 | 15 | 810 |
| Drop-in* | 112 | 7 | 784 |
| Home/Community Support Service | 60 | 12 | 720 |
| Voluntary/Private Psychological Therapy and Counselling Service | 33 | 19 | 627 |
| Befriending and Volunteering Scheme | 22 | 27 | 594 |
| Psychological Therapies and Counselling Services (Statutory) | 52 | 11 | 572 |
| Advocacy Service* | 47 | 10 | 470 |
| Advice and Information Service* | 38 | 12 | 456 |
| Outpatient care | 35 | 13 | 455 |
| Education and Leisure Opportunity | 39 | 7 | 273 |
| Specialist Psychotherapy Service | 33 | 8 | 264 |
| Personality Disorder Service* | 20 | 13 | 260 |
| NHS day care | 35 | 7 | 245 |
| Early Intervention in Psychosis* | 18 | 12 | 216 |
| Criminal Justice Liaison and Diversion Service* | 20 | 10 | 200 |
| Emergency Duty Team* | 14 | 12 | 168 |
| Graduate Primary Care/Gateway Workers | 18 | 7 | 126 |
| Homeless mental health* | 11 | 11 | 121 |
| Rehabilitation or Continuing Care Team | 15 | 7 | 105 |
| Crisis accommodation* | 7 | 14 | 98 |
| Psychiatric Liaison services* | 16 | 6 | 96 |
| Primary care mental health service* | 10 | 8 | 80 |
| Prison Psychiatric In-reach Service* | 13 | 5 | 65 |
| Community Forensic Services* | 9 | 7 | 63 |
| Support Time and Recovery Worker | 6 | 8 | 48 |
| Emergency walk in clinics* | 2 | 11 | 22 |
| Mother & baby unit | 2 | 5 | 10 |
| Total | 1331 | 949 | 18130 |

* Arguably the services which come into contact most often with people with multiple needs

Note: Omitted from this table are: services for carers, self-help and support groups, general psychiatric residential services and general psychiatric inpatient provision – all are included in Table 3.3.

Table 3.2: Inpatient and residential mental health provision for multiple needs

| ServiceType | N | Mean no. beds | Std. Devi- ation | Total beds |
|--|------------|---------------------|------------------------|---------------|
| Acute Inpatient Unit/Ward | 73 | 26.1 | 15.85 | 1905 |
| Adult/family Placement Scheme | 12 | 4.3 | 6.55 | 52 |
| Crisis Accommodation | 7 | 19.7 | 32.10 | 138 |
| Hostel | 42 | 13.1 | 11.13 | 550 |
| Independent hospital - mental health establishment | 8 | 37.0 | 27.15 | 296 |
| Local Low Secure Service - High Dependency Unit | 17 | 22.2 | 13.87 | 377 |
| Local Medium Secure Service | 7 | 45.4 | 27.87 | 318 |
| Local Psychiatric Intensive Care Unit | 20 | 7.0 | 3.52 | 140 |
| NHS 24-hour nurse staffed care | 18 | 21.0 | 28.95 | 378 |
| Personality Disorder Service | 20 | 2.2 | 7.14 | 44 |
| Regional medium secure unit | 2 | 158.5 | 4.95 | 317 |
| Registered Care Home (18-65) | 165 | 14.0 | 16.60 | 2310 |
| Registered Care Home (with nursing) for adults (18-65) | 19 | 26.3 | 19.40 | 500 |
| Residential Rehabilitation Unit | 32 | 14.4 | 7.81 | 461 |
| Short-term Breaks/Respite Care Service | 5 | 20.8 | 38.85 | 104 |
| Specialist Psychotherapy Service | 33 | 2.0 | 3.65 | 66 |
| Staffed Group Home | 18 | 6.6 | 4.36 | 119 |
| Supported Housing | 288 | 9.7 | 18.88 | 2794 |
| Unstaffed Group Home | 37 | 5.0 | 7.22 | 185 |
| Total | 823 | | | 11054 |

Table 3.3: Providers of all mental health services for multiple needs

| | Statutory | Voluntary | Private |
|---|-----------|-----------|---------|
| Acute Inpatient Unit/Ward | 73 | 0 | 0 |
| Adult/family Placement Scheme | 11 | 1 | 0 |
| Advice and Information Service | 9 | 29 | 0 |
| Advocacy Service | 6 | 41 | 0 |
| Assertive Outreach Team | 99 | 4 | 0 |
| ASWs not employed in adult mental illness services | 20 | 0 | 0 |
| Befriending and Volunteering Scheme | 4 | 18 | 2 |
| Carer Support Worker | 2 | 1 | 0 |
| Carers Support Group | 1 | 4 | 0 |
| Carers Support Service | 2 | 11 | 0 |
| Community Development Worker - Black and Minority Ethnic | 0 | 1 | 0 |
| Community Forensic Services | 9 | 0 | 0 |
| Community Mental Health Team | 168 | 4 | 0 |
| Criminal Justice Liaison and Diversion Service | 16 | 4 | 0 |
| Crisis Accommodation | 3 | 4 | 1 |
| Crisis Resolution Team | 42 | 0 | 0 |
| Day Centres/Resource Centre | 59 | 83 | 4 |
| Drop-in | 18 | 94 | 1 |
| Early Intervention in Psychosis Service | 17 | 1 | 0 |
| Education and Leisure Opportunity | 18 | 21 | 1 |
| Emergency Clinics /Walk-in Clinic | 2 | 0 | 0 |
| Emergency Duty Team | 14 | 0 | 0 |
| Employment Scheme | 36 | 68 | 4 |
| Gateway Worker | 7 | 1 | 0 |
| GP Counselling Service | 1 | 2 | 2 |
| Graduate Primary Care Worker | 5 | 0 | 0 |
| Home/Community Support Service | 27 | 33 | 11 |
| Homeless Mental Health Service | 8 | 3 | 0 |
| Hostel | 21 | 21 | 1 |
| Independent hospital - mental health establishment | 7 | 1 | 7 |
| Local Low Secure Service - High Dependency Unit | 17 | 0 | 4 |
| Local Medium Secure Service | 7 | 0 | 0 |
| Local Psychiatric Intensive Care Unit | 20 | 0 | 1 |
| Mental Health Crisis Intervention Service | 0 | 1 | 0 |
| Mental Health Promotion Initiative | 0 | 1 | 0 |
| Mother and Baby Facility | 2 | 0 | 0 |
| NHS 24-hour nurse staffed care | 17 | 1 | 1 |
| NHS Day Care Facility | 35 | 0 | 0 |
| Other community and/or hospital professional team/specialist | 41 | 13 | 0 |
| Personality Disorder Service | 19 | 1 | 0 |
| Primary care mental health service | 10 | 0 | 0 |
| Prison Psychiatric Inreach Service | 13 | 0 | 0 |
| Psychiatric liaison service | 16 | 0 | 0 |
| Psychiatric Outpatient Care | 35 | 0 | 0 |
| Psychological Therapies and Counselling Services (Statutory sector) | 52 | 0 | 0 |
| Regional medium secure unit | 2 | 0 | 0 |
| Registered Care Home (18-65) | 112 | 53 | 100 |
| Registered Care Home (with nursing) for adults (18-65) | 11 | 8 | 12 |
| Rehabilitation or Continuing Care Team | 15 | 0 | 0 |
| Residential Rehabilitation Unit | 32 | 0 | 1 |

Table 3.3 continued: Providers of all mental health services listed in mapping database

| | Statutory | Voluntary | Private |
|---|-----------|-----------|---------|
| Self-help and Mutual Aid Group | 1 | 31 | 0 |
| Self-help, Mutual Aid Group for Carers | 0 | 3 | 0 |
| Service User Group/Forum | 2 | 33 | 0 |
| Short-term Breaks /Respite Care Service | 4 | 1 | 2 |
| Specialist Psychotherapy Service | 33 | 0 | 0 |
| Staffed Group Home | 8 | 10 | 4 |
| Staff-facilitated Support Group | 4 | 11 | 0 |
| Support Time and Recovery Worker | 4 | 2 | 1 |
| Supported Housing | 88 | 200 | 71 |
| Unstaffed Group Home | 21 | 16 | 5 |
| Voluntary/Private Psychological Therapy and Counselling Service | 4 | 29 | 3 |
| Total | 1330 | 864 | 239 |

Section 4: Interviews and other sources

The largely quantitative and ‘top down’ approach of the study thus far was validated and informed by our consultation with providers of services to people with chronic exclusion and other people concerned with the issue from a policy or strategic perspective. We had three key sources: systematic, qualitative interviews with a number of senior executives in non-governmental agencies; discussions held at a national stakeholders’ conference in Nottingham on January 30, 2007; and literature collected in the course of the study. Here, we report the method and findings from the interviews, before going on to discuss their implications, reflecting on these in the light of the stakeholders’ conference and other literature.

We are extremely grateful to the individuals who made time for us or who sent materials and to the staff who supported them to do so.

The sample

We interviewed nine senior executives of voluntary organisations and read their annual reports. The selection was opportunistic, depending principally on who could be contacted by the researchers in the time available. Representatives of the following organisations were interviewed: Alcohol Concern, Crisis, Borderline UK, Focus Futures, Framework, Rainer, Rethink, Revolving Doors Agency and St. Mungo’s. Several agencies have national coverage (GB), a few concentrate solely or mainly on London and a couple are regional services. With the exception of Alcohol Concern, all the agencies interviewed work directly with service users, although one does this largely through the Internet. Most are in the fields of housing for vulnerable people, but two organisations specialise in mental health issues (Table 4.1). What follows does not represent the views of any agency or group of agencies and it has not been checked by the respondents. The results reported here are the inferences made by the researchers on the basis of the interviews, and supporting documents.

Table 4.1: Aims of the organisations interviewed

| Aims |
|---|
| Alcohol Concern – to reduce the incidence and costs of alcohol related harm, and to improve the services available to people with alcohol related problems |
| Borderline UK - to provide advice, advocacy, information and support to persons who have been diagnosed or suspect they fit the diagnosis of Borderline Personality Disorder |
| Crisis – to fight homelessness and empower people to transform their lives |
| Focus Futures (Midlands Heart) - housing and practical support for all levels of need |
| Framework Housing – to offer a pathway from street to community with housing and support options at each stage. |
| Rainer – to enable under-supported young people to lead secure and fulfilled lives |
| Rethink – to help people with severe mental illness to recover a better quality of life |
| Revolving Doors – to create opportunities for people caught up in a cycle of crisis crime and mental illness to transform their lives, and to make a compelling case for targeting the causes of revolving door syndrome |
| St. Mungo's – to make sure homeless and vulnerable people can look forward with optimism and improve their quality of life. To house, support and care for vulnerable people in London who have been or are at risk of sleeping rough and homelessness. |

The two mental health agencies cater for carers' needs as well as those of people directly affected by mental health issues, while Alcohol Concern mainly works at the level of strategy and training. These three may be grouped together as 'specialist' agencies, concerned with key, primary needs. By contrast, agencies represented by the rest of those people interviewed all had 'front line' involvement with people experiencing multiple needs, including homelessness and drug problems. Within the front line services, a few agencies target the needs of people who do not fit easily into mainstream services (including, presumably, some of the other front line provision). Such individuals are often barred from services, for violence or for drug use. These agencies form a third subset of interviewees, those who have experience of services or projects within their agencies targeted at the most excluded service users. In the analysis which follows, it may be helpful at times to distinguish between the 'specialist' (N=3), 'front line' (N=6) and within this group the more 'targeted' agencies or projects (N=2).

Services provided to clients

All interviewees emphasised user involvement and progression for clients from less secure and disengaged or vulnerable lifestyles to more secure, integrated lives: "start with engagement, empowerment and befriending." The front line agencies, taken together provided:

- **Housing** - a spectrum of accommodation, from hostels to supported long-term accommodation
- **Individualised support** - link workers/case workers/mentoring/outreach workers
- **A holistic approach** - including learning and skills, work opportunities and activities for leisure and recreation
- **Practical resources** - promotion of physical and mental wellbeing, access to mental health teams, counselling, detoxification and rehabilitation as appropriate

"Get the basics right. Make the service welcoming, then even if people do not engage they will have had a good experience and in our experience are more likely to approach us again."

Several agencies, including those specialist ones, offer: policy advice concerning the needs of their own client groups as well as research, evaluation and consultancy on service development. Some work with volunteers. Partnerships with housing, probation, antisocial behaviour teams, health and welfare agencies are vital to front line agencies. These links help to procure appropriate referrals, to enable onward referrals and to ensure the sustainability of the agencies concerned: “Local mental health teams know they can’t fob us off and if they do put some effort in they can get a decent service.” “If I have a CPN desperate to get their person in, I will be putting the pressure on saying how are we going to manage ... when it all kicks off at 11pm on Friday night ... they can’t just leave the person to us and walk away. But it does mean that for the first time the individual has got high quality accommodation and 24-hour quite intensive support with a package that starts to meet those multiple need issues.”

Obstacles and challenges

People with a history of arson, and Schedule 1 offenders pose particular problems for all services because of the risk management issues. Apart from these groups, the front line and specialist agencies said that the hardest to help client groups are:

- young people with multiple ‘risk factors’ (e.g. homeless, no family support)
- people who use drugs (three agencies) “One of our biggest problems is with the reluctance of drug users with serious health problems – e.g. deep vein thrombosis – to go into hospital.”
- people with a dual diagnosis of mental illness and substance use problems (two agencies)
- people with severe physical disabilities
- people who are not eligible for benefits, e.g. asylum seekers
- people who commit violent acts
- people with a severe mental illness
- people with a learning disability
- people who are not IT literate (from a service based largely on the Internet)

The front line agencies which were already targeting these hard to help groups said that the greatest challenges for their services come from:

- People with personality disorders
- People with lower level learning disabilities
- Young people who do not want to engage with services
- Black and minority ethnic groups who don't engage
- People with unchecked drug issues and poor mental health present a challenge both in managing their behaviour and in managing the legalities around dealing and supply of drugs: "If they leave the hostel they end up on the street or in a psychiatric ward or in prison."

These agencies face specific obstacles to meeting clients' needs. Sometimes this is due to a lack of knowledge about the service, so that referrals are not made when appropriate; sometimes there is insufficient capacity to meet all the demands made on the service. Clients can be turned down if they pose persistent threats to staff; this may be related to a personality disorder, in which case a mental health assessment is sought.

Strategies for success

From a strategic perspective, interviewees recommended that agencies seeking to address chronic exclusion:

- Identify the group they mean to target and tailor their service accordingly
- Focus on what they want the service to achieve
- Employ and support competent staff and relevant specialists
- Foster support from the local authority and funders
- Develop excellent links with community and statutory bodies
- Set outcomes that are realistic for the time scale they have to work with.

What works well – features of an effective service

The agency respondents did not appear to disagree in any way about the features of an effective service. It should maximise accessibility, being available 24/7, offering choice, and being flexible in approach. The agency 'attitude' or ethos should be non-judgemental, characterised by consistency and 'stickability': "Always keep the door open even when support has been turned down. Be clear with people that they are always welcome back."

The staff should have good ‘people skills’ and an empathetic attitude, but there should be clear boundaries between staff and users. The stakeholders also agreed that the relationship with the key worker is fundamental to engaging adults with chronic exclusion, and added that there should be a ‘safety net’ for people moving between different agencies, with good information sharing protocols.

There was a lot of emphasis on the need for user-led services, asking people what they want rather than telling them what they may have. Such services treat people as individuals, structuring responses to meet their particular needs. In the arena of chronic exclusion, several people commented on the importance of being able to respond to a window of opportunity, to catch people at the right time, when they have some motivation to seek and use the help available. When this has been achieved it was seen to be important to focus on what is motivating them at that time, and to do this with sufficient intensity of intervention: “skimp on this and you don’t even get on the first rung of engagement”. At the same time, the stakeholders flagged up assessment as a potentially problematic area, when more than one agency needs to be involved.

‘Theories of change’

There were embryonic ‘theories of change’ underlying a couple of responses, such as “engage people’s trust and engage them with a sense of hope that there is a way forward ... give people a sense of purpose and social inclusion if you like” and “[r]estore some of the absent ‘protective factors’ – give them skills, praise, encouragement and recognition and be clear that it’s about changing behaviour”. This would be an area for further study with agencies which succeed in meeting the needs of chronically excluded adults: why do they do what they do, what are the mechanisms which effect change for the better? If a wider circle of people had been interviewed, other issues might have included harm minimisation, personal responsibility, reducing stigma and competing theories of need. For instance, the stakeholders’ discussion touched on the relevance of Maslow’s hierarchy, which prioritises meeting basic needs ahead of emotional and social ones. Some argue that, for chronically excluded people, it is essential (and possibly a greater priority than meeting basic needs) to address the emotional and social aspects of exclusion. This may explain why so much success seems to follow from approaches that espouse

creative arts (e.g. Street Opera, karaoke) which affect individuals' confidence and self esteem. The stakeholders saw 'relationships' as a key change agent, but that shared activities could be a means whereby these flourished. Unfortunately, some funding sources place an emphasis on therapy to the exclusion of individual and group activities designed to build community. These questions could not be resolved here but are highlighted for future reference.

Discussion

In working with these individuals, the inter-agency dimension is clearly vital, but this drew less attention from our interviewees. There is a body of research on inter-agency and inter-disciplinary working which could be brought to bear on planning new services, together with the insights to be gained from our companion study undertaken by Roger Bloor and colleagues.

One interviewee pointed out that it is important not to define adults with chronic exclusion solely in terms of 'dual diagnosis': "don't cast the net so wide in terms of who's got multiple needs that we lose any meaning to it." A crucial, additional qualification is that a person should also be excluded from available housing services. There is a danger of overwhelming provision with every service user with drug problems in addition to mental health issues. This is accentuated by the perception on the part of one, London front line agency that "mental health provision is inadequate" and they are not equipped to deal with these issues. Elmore, a service in Oxford, acknowledges that, in addition to having multiple or complex needs, an appropriate user of their service should have one of the following:

- being very chaotic to the extent that conventional services cannot cope;
- not fitting the referral criteria of other services or being barred from them;
- having a distrust of statutory services/refusal to engage with them.

The stakeholder conference concurred with these as indicating the group whose interests concerned it, and added that, once an individual met these criteria, there should be no exceptions.

Section 5: Discussion and implications

Over the course of this analysis, a picture has emerged from the literature and the evidence assembled from providers. It is a picture of a pathway to chronic exclusion which can be traced through a person's lifetime. This pathway, together with the points at which a vulnerable person may be diverted from a life course of chronic exclusion, is described here to set the scene for some inferences to be drawn from the research.

From the bio-psycho-social orientation of this research, chronic exclusion can be seen as the outcome of specific sets of factors, many of them already operating in childhood and adolescence. These factors interact with existing health and welfare service systems to exclude a small minority of adults. Some of the biological, psychological and social factors are at play from birth. Neurological deficits and problems such as autism or learning disabilities can be detected in the early years and are largely biological in origin. At the same stage, maladaptive behaviour can develop in the early years, this may manifest as disruptive behaviour or conduct disorder, posing challenges for parents and teachers. The third set of factors is social: emotional or physical trauma such as abuse or neglect can have a lasting affect on children. These biological, psychological and social elements can divert children from a normal developmental process, with a lasting effect on their intellectual attainment, skills acquisition, emotional resilience and social interaction.

Windows of opportunity to intervene to minimise the impact of these factors arise during school years, but resources are limited and access may be biased towards families which have higher incomes and social status. Intervention at this stage might be seen as a means to prevent later problems, and it is the focus of another stream of research under the *Reaching Out* policy initiative. Advisers on the present study drew attention to the potential of Children's Centres in implementing appropriate remedial plans and to the need for mental health promotion in schools as an ongoing part of the curriculum.

Children who are made vulnerable by the factors discussed face a difficult adolescence and early adulthood, with the challenges of work, independent living and

sexual maturity. Particular risks apply to those whose support structures are weak, as indicated by having inadequate family support (e.g. having been in the Looked After system) or having few friends. Additional problems, like physical disability or chronic ill health, further complicate the transition from adolescence to adulthood for these young people.

This is a stage when vulnerable youths have a higher probability of drug and alcohol abuse, sexual exploitation, homelessness, destitution and criminal involvement. Young adulthood is also a critical period for some mental health problems, such as schizophrenia, whose onset in males is common in early adulthood. Some voluntary agencies see their role as intervening with young people before these behaviours become irreversible patterns. Help at this stage is designed to offer alternatives, minimise harm and resolve problems before they escalate. The benefits of intervening with young people are very likely in time to outweigh the costs if they pre-empt a lifetime of chronic exclusion.

Department of Health policy recognises that early intervention can have long term benefits for people experiencing psychosis for the first time, and teams have been set up in most mental health services in recent years to provide this form of care. They might benefit from lessons in engaging young people from the voluntary sector. They could also be extended to early or first onset of other mental health problems in vulnerable young people, which might avert some of the risks which are especially acute at this stage.

However, when help (formal or informal) is not at hand or when what is on offer fails to have an effect on the underlying problems, individuals embark on life courses characterised by substance use, crime, prison, homelessness, physical and mental ill health. For the vast majority of these people, in the UK, the state provides a fairly comprehensive safety net: minimum income, housing, social work assistance, and health care exist for most citizens. Although there may be exclusionary effects from having recourse to these services, they keep most people from destitution.

Adults with chronic exclusion fall through the safety net of state provision. More correctly, they are forced through. This is often because the provision has explicit

eligibility criteria which they are unable or unwilling to meet. These barriers are numerous but the most common are probably substance use, violence and being an immigrant who is ineligible for social security benefits. Implicit obstacles also exist – opening hours for health and social services, language barriers, and racism which can deter people from obtaining the resources to which they are entitled.

From the perspective of this explanation of social exclusion, taken together with the findings of this study, the following issues are raised for consideration:

The role of statutory services

Under the current system, statutory services can fail to prevent, create or sustain chronic exclusion. Children's services and the education system clearly play a part in diagnosis and remediation of specific problems in childhood. There is a wide recognition of the importance of effective parenting both in preventing behaviour problems and in resolving them. For a number of children, the optimal approach will be to co-ordinate educational and parental input with specific inputs, including speech therapy, psychology and psychiatry. To the extent that children in need fail to obtain the required services, the risk of chronic exclusion is increased.

The problem of transition from education to adult life is created to some extent by age-specific health and social care services, which mean that people who are compelled to change because of their age fail to meet the inclusion requirements of the equivalent adult service. Such requirements may stipulate, for example, for any age group having an IQ below 70 to access intellectual (learning) disability services:

“Service boundaries represent a major problem for staff in mainstream intellectual disability services. Many health staff attempt to defend an intelligence level boundary around 70: acknowledging its arbitrary nature, they nevertheless fear that extending services to people in the borderline (up to IQ 80) range will overwhelm their small service. If generic services were to include people in the borderline range, cursory inspection of population data such as that given in WAIS-III (1998)²³ demonstrate that a service designed for 2% of

²³ Wechsler Adult Intelligence Scale-III . UK (1998). London: The Psychological Corporation.

the population would be attempting to support 9%. This is clearly an impossible task.”²⁴

We found that, among those with chaotic lives and multiple needs, there was a substantial group of people who had low intelligence but not, by definition, learning disability. Insofar as this group may seek help but be turned down, their exclusion is increased by services. However, the chapter cited goes on to point out that such boundary disputes may not operate outside statutory services:

“Palmer & Hart (1996) cite a court of appeal as having no interest which side of IQ 70 a person falls, preferring to use more qualitative judgements to identify people who have ‘significant impairment of intelligence and social functioning’. Xenitidis et al (1999) are not unusual in describing a specialist service for people with ‘mild intellectual disability and challenging behaviour’ which includes people within the borderline and low average ranges of intelligence (IQ 70-84). Thus while the inclusion or otherwise of people outwith the classification is a major issue for mainstream intellectual disability staff, it causes no problem for tertiary national services that attract external funding.”²

Many other examples are known of this type of exclusion by statutory services, which might be called ‘boundary’ exclusion, caused by eligibility criteria. Boundary exclusion may be generated by any resource-limited system: welfare benefits, housing social care or health. Rather than rehearse the evidence here, we ask: can boundary exclusion by statutory provision be reduced? If for example existing services were have some accountability for excluded groups, might they be able to be more flexible in some cases (e.g. make exceptions for people with PD or low intelligence)? This could conceivably absorb some of the need for help, or at least prevent some people from becoming chronically excluded. Alternatively, or additionally, is there a need for distinct developments to meet the needs of people with borderline intelligence who are at risk of chronic exclusion? Does the third sector offer more inclusive models?

Primary care providers are likely to encounter a high proportion of people with chronic exclusion. Frischer et al. (2004) report that the rate of various forms of

²⁴ Clegg, J.A. (2004) How can services become more ethical? Pp91-108 in Lindsay, W. Taylor, J. & Sturmey, P. (eds) Offenders with Developmental Disabilities. Chichester: John Wiley.

psychiatric illness in combination with substance use problems is increasing 10% per year in England and Wales, and that the patients are getting younger. This raises questions about effective liaison. Is it possible that some people become excluded as a result of boundary disputes between primary and secondary care? Psychiatric liaison services have a part to play in this respect, it is not known how effectively they engage with chronically excluded groups.

A high proportion of people with chronic exclusion were found to have mental health problems, often in combination with substance use or personality disorder. Community mental health teams and assertive outreach teams are the most numerous forms of mental health provision, with national coverage. They are meant to include treatment for dual diagnosis (mental illness and substance abuse). The Policy Implementation Guide published by the Department of Health in 2003, *Dual Diagnosis Good Practice Guide* states that: “Individuals with these dual problems deserve high quality, patient-focused and integrated care. **This should be delivered within mental health services.**” (p4, Executive summary, bold in the original). Our evidence from front line agencies is that mental health services for their clients with dual disorders are not adequate. The perspective of specialist drug and alcohol services on this user group was not obtained by this study, and more needs to be known about the current provision of dual diagnosis treatment within mental health services.

Where a service fails to engage with people who do qualify for help on most counts, this might be called exclusion by neglect. We are not in a position to evaluate mental health services, but these findings raise questions about matching statutory services to needs. Several of the experts who commented on this study emphasised the point made by the voluntary organisations that it is hard to get mainstream mental health services, including Assertive Outreach teams, to engage with patients who have dual diagnosis, multiple needs or chaotic lives without a lot of effort on the part of the voluntary organisations. The reasons for this lack of engagement with the most needy need to be investigated. For instance, it raises questions about the capacity of statutory services to work with people who present challenging behaviour. What skills do these teams have for working with disruptive clients, and where do they draw the line? The answers to these questions will have implications for the numbers of

people who are allowed to pass through the statutory ‘net’ and become chronically excluded.

A third type of exclusion by statutory services is exclusion by omission. This is illustrated by the lack of services for adult neuro-developmental disorders. Psychosocial therapies are likely to benefit this group of people and medication is effective in adult ADHD. The National Institute for Clinical Excellence has included adult ADHD within the remit of the current ADHD Guideline update, but there is no recognition of the needs of this group in the Mental Health National Service framework. There are also implications for training of staff in health, social care and criminal justice systems. Another example of omission is the limited implementation of psychological therapies which are effective in the treatment of PD. Dialectical behaviour therapy, for instance, is only provided in a few places.

Problems facing the voluntary sector

The voluntary sector is presently the last resort of people whose needs are not met by statutory provision. Agencies at the front line include not only those which expressly target adults with chaotic lives and multiple needs, but also those organisations whose mission is to support people who are homeless, ex-prisoners or who have mental health problems; groups where the rate of chronic exclusion is high. We found that the voluntary sector has particular problems helping some groups of individuals, notably people who have personality disorder or who have mental health problems and abuse substances. Physical and learning disabilities also present problems for targeted services, while young people and people from black and minority ethnic groups may be especially difficult to engage.

Effective interventions for key groups need to be made more widely available.²⁵ Such interventions include psychosocial therapy for people who have personality disorder

²⁵ A forthcoming report by Fischer et al., *Drug user involvement in treatment decisions: final report*, York: Joseph Rowntree Foundation, is understood to touch on these issues from a user perspective.

or dual diagnosis, medication for adults with ADHD, or any of the other potential interventions identified in Table 2.1. Several obstacles present themselves:

Limited resources – the real availability of some interventions (e.g. problem solving therapy, dialectical behaviour therapy) is extremely limited.

Poor co-ordination with statutory providers – even where provision exists, there may not be sufficient links nor effective co-ordination between voluntary and statutory providers.

Appropriate service delivery modes – knowledge about approaches which are suitable for hard to help individuals which resides mainly in the voluntary sector, but which may also be found in statutory services, needs to be encapsulated so that effective strategies to engage people long enough to help them may be replicated.

What works for whom - there is no agreement about whether multiple needs are best addressed in sequence or in tandem, and a formal, systematic review of treatments for combinations of mental health-related needs, such as that shown in Table 2.1, needs to be undertaken.

Service organisation and co-ordination

How can effective psychosocial therapies be integrated with provision targeted at people with chronic exclusion? Clearly, conventional, delivery modes based in clinics with appointment systems will not work. Could some generic therapeutic services identified in Section 3 be offered incentives to address the needs of this group? Could front line agencies be enabled to access relevant services more effectively? Do new, specialist services need to be developed to fill the gaps in the system?

New approaches to care

We found that there some organisational aspects of care which are effective for some people with mental health problems and other needs: individualised case management: assertive outreach, integrated, multidisciplinary team working, crisis resolution, day hospitals, therapeutic communities, and the individual placement and support model of vocational rehabilitation. Some of these approaches are already evident in the way that front line agencies work with their clients and their strategies for engagement discussed in the preceding section. From the statutory side, early

work on readiness to treat, for instance, offers a psychological perspective on engagement with services.

Might some services for adults with chronic exclusion be enhanced by developing tried and tested approaches to care, such as input from a range of professions, day hospitals instead of inpatient treatment, therapeutic communities, and supported employment?

What provision?

In the preceding paragraphs we have focused on ‘how’ services can be organised and delivered to avoid exclusion and meet needs. There is also a question of ‘what’ constitutes a substantial intervention with chronically excluded people. We have detailed clinical systems and interventions in Table 2.1. There appear to be a growing number of social and cultural activities, as reviewed by Broadway (2005). Thirdly, there are innovative projects whose experience constitutes a distinct philosophy of care. Two examples are given here.

The Elmore project, which targets people who fall through the service ‘net’, practises what has been called ‘unassertive outreach’ (Everitt & McKeown, 2006, p27). At Elmore, the client’s wishes are prioritised, which means that street homelessness may be tolerated at times. The scheme is also unusual because it follows its clients wherever they end up; sleeping out, in prison, or in hospital. This is seen as a means to solve some of the boundary issues which bedevil statutory services.

Revolving Doors Agency’s Link Worker Schemes represent a large initiative designed to respond to the needs of people in contact with a criminal justice agency, many of whom have chronic exclusion (O’Shea et al., 2003). The schemes support people outside of mainstream services, linking them in to formal services where needed. They receive referrals from police stations courts and prisons in their respective localities. The practical help provided (e.g. housing, benefits, GP care) is seen as key to engagement for clients. They do not close cases; their engagement is open-ended, although clients may disengage. In addition, Link Worker Schemes have succeeded in breaking down inter-agency obstacles to co-ordination and it is reported that they reduce re-offending.

These tried and tested approaches offer models within it might be possible to deliver other evidence based interventions.

Under-served groups

People with some learning disability or neuro-developmental disorders seem likely to make up a significant proportion of the chronically excluded. Although effective interventions exist, at least for adult ADHD, this group is really not served by the NHS, and local authority provision is devoted largely to children with these problems or to adults whose housing and support are publicly funded. Before recommending specific responses, it would be helpful to find out how far this group do figure in the population of chronically excluded people and among those at risk of exclusion (e.g. homeless, prisoners, young people leaving care). Epidemiological evidence on the prevalence of these problems among these groups is needed.

Conclusion

In conclusion, this study indicates that better outcomes for adults who are affected by chronic exclusion may be attained by attending to several critical issues.

1. Seizing opportunities to engage young people, at transition stages (leaving school or college, moving on from the Looked After system, from custody or hospital).
2. Early intervention, when primary needs are first identified, rather than a watch and wait approach, which can allow them to become compounded.
3. Identification of vulnerable adolescents and young adults, notably those with certain personality disorders, low intelligence, ADHD or other neuro-developmental disorders.
4. Continuous, appropriate provision: open-ended services, which can respond flexibly to user expressed needs as well as anticipating problems and acting to minimise harm.
5. Promoting zero exclusion policies within statutory provision, and providing the skills and back up required to implement these.
6. Re-examining the remit of community mental health services with respect to complex needs.

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7. Addressing the needs of identifiable groups who are underserved by current services.
8. Finding ways of delivering evidence based therapeutic interventions to chronically excluded people. This may require a long-term, stepped approach.
9. Disseminating and applying innovative models in other contexts (different target groups, different agency lead, different problem area) and evaluating these.
10. Attending to social and cultural needs together with physical and mental health.

Appendix 1.1

Taking account of adult neuro-developmental problems

Three inter-related problems are likely to affect a significant proportion of adults with chaotic lives and multiple needs. These are Asperger Syndrome (AS), together with Autistic Spectrum Disorder (ASD) and Attention Deficit/Hyperactivity Disorder (ADHD). These are considered here together as adult neuro-developmental disorders, since all have their origins in early development. Indeed they are more often recognised and treated in children. Broadly, these problems have an adverse impact on the ability of people affected to cope independently as adults. Rates of social impairment are high leading to isolation or conflict with authority. Co-morbidities with mental illness and addiction problems are also well above average. Few if any services have been developed to respond to the distinctive needs of adults with neuro-developmental problems. Those who receive support as children and adolescents may be left to fend for themselves when they grow too old for this provision, at a time in life when other perilous transitions also have to be negotiated. In many ways they are typical of people who are chronically excluded.

ADHD in adults

Adult ADHD is a largely unrecognised and untreated condition in adults that contributes significantly to both psychiatric morbidity (McGough et al., 2005; Masi et al. 2006) and a more general burden on society. Brasset-Grundy and Butler (2004) found that, controlling for demographic factors, ADHD was significant independent risk factor for a wide range of social disadvantages, addiction problems, involvement with the police and even homelessness. Interestingly, it increased the likelihood of alcohol problem in men and the likelihood of drug problems in women. Adult ADHD is frequently found in combination with other problems, being identified in 30-50% of patients with substance use disorder (Garland et al., 2001; Konig et al., 2007) while strong associations have been found between ADHD and pathological gambling (Specker et al., 1995, Sood et al., 2003) . Among young, male prison inmates at least 45% (Rosler et al., 2004) showed residual ADHD symptoms.

“A key question is the number of children with ADHD who continue to show ADHD in adult life. Studies that followed children identified with ADHD, as well as controls, into adulthood have been included in a meta-analysis of 32 publications (Faraone et al al, 2006). When the ADHD samples included only those who met full diagnostic criteria for ADHD the rate of persistence was approximately 15% at age 25 years. However, the rate was far higher –approximately 65% – when individuals fulfilling the DSM–IV definition of ADHD in partial remission were included, referring to the persistence of some symptoms associated with significant clinical impairments.” (Asherson et al., 2007, 5).

“The disorder in adults is not as well studied as it is in children. However, there are sufficient data and unanimous agreement among clinical experts on the validity of the adult diagnosis. Although there is evidence that ADHD symptoms show an age-dependent decline, there is no evidence that the disorder disappears in adolescence and adulthood, and considerable evidence that in the majority symptoms persist and are frequently associated with clinical and psychosocial impairments. Furthermore, it is well established that ADHD symptoms in adults show the same responsiveness to

stimulant and non- stimulant medications as that seen in children (Faraone et al al, 2004; Simpson & Plosker, 2004).

Childhood ADHD often persists into adulthood, either as a categorical diagnosis or as persistence of symptoms which contribute to poor social adjustment, personality problems and psychiatric comorbidity. Many young people currently treated with stimulants will continue this medication into adult life, requiring psychiatric advice. Many children with ADHD go unrecognized and may present in adulthood for the first time. Mis-specification of the diagnosis currently leads to inappropriate, ineffective and protracted interventions by psychiatrists and general practitioners. Furthermore, adults with untreated ADHD use more healthcare resources because of smoking-related disorders, increased rates of serious accidents and alcohol and drug misuse.” (Ascherson et al., 2007, 4-5)

Asperger syndrome and autism

Epidemiological studies have found Asperger syndrome to be more prevalent than autism: 36 per 10,000 (Ehlers & Gillberg, 1993) with Asperger’s, compared to 20 per 10,000 with autism (Wing & Gould, 1979). There is a growing body of literature on Asperger syndrome, in particular, addressing issues of diagnostic boundaries and diagnostic assessment measures (Klin, 2005; Campbell, 2005; Fitzgerald & Corvin, 2001). To date, there is no clear agreement of distinction between Asperger syndrome and high functioning autism. However, researchers are starting to take a view that they are the same disorder, that is, all part of the autistic spectrum (Frith, 2004). The diagnosis of Asperger syndrome remains controversial in terms of its distinction from autism, but is considered to be clinically valuable. Diagnosis often occurs in late childhood or adulthood, often preceded by other diagnoses.

“Asperger’s syndrome is a form of autism, a condition that affects the way a person communicates and relates to others. A number of traits of autism are common to Asperger’s syndrome including:

- difficulty in communicating
- difficulty in social relationships
- a lack of social imagination and creative play

However, people with Asperger’s syndrome usually have fewer problems with language than those with autism, often speaking fluently, though their words can sometimes sound formal or stilted. People with Asperger’s syndrome do not usually have the accompanying learning disabilities associated with autism; in fact, people with are often of average or above average intelligence.” (National Autistic Society, <<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=212&a=3580>>, accessed 9 February 2007).

Asperger’s has been implicated in criminal behaviour but there is a possibility that this association may be an artefact of the publicity given to the disorder in a relatively small number of cases. Nevertheless, some features of Asperger’s make it a cause for concern. People affected may lack insight. They may be unable to see inappropriate behaviour as others do. An apparent lack of awareness of outcome allows people to behave impulsively, with little consideration of the consequences. Poor appreciation

of social rules makes interactions with other people problematic, while misinterpretation of relationships can result in their being exploited by others.

Implications of adult neuro-developmental disorders for chronic exclusion

Asperger syndrome is about as common as schizophrenia, and adult ADHD is at least five times as common as schizophrenia. Such disorders have a clear and largely predictable impact on the ability of individuals to cope in society. Once young people leave school they are faced with a new set of challenges as they strive for independence. It is likely that people affected by adult neuro-developmental disorders will find it difficult to adapt to such changes. They may encounter considerable obstacles, and without significant support they may suffer from mental health problems or social difficulties. Given their disability profile, the patterns of co-morbidity, and the lack of relevant specialist services, these people are very likely to make up a proportion of those who have chaotic lives and multiple needs. However, we have insufficient epidemiological information reliably to estimate the prevalence of adult neuro-developmental disorders in the UK population, much less the absolute prevalence of co-morbidity. This is a major gap in the evidence needed to estimate the prevalence of chronic exclusion and the most effective responses to the needs of the people affected.

Appendix 1.2

Taking PD into Account

In 2003, NIMHE published *Personality Disorder: No Longer a Diagnosis of Exclusion*. This report, which outlines how public services ought to respond to the needs of individuals with personality problems included a survey of service users, which highlighted the following points. Numbers refer to paragraphs in the original document.

- 40. No mental disorder carries a greater stigma than the diagnosis “Personality Disorder”, and those diagnosed can feel labelled by professionals as well as by society. There was a strong feeling that many professionals did not understand the diagnosis, and often equated it with untreatability.
- 41. Those with personality disorder have been described as “*the patients psychiatrists dislike*”, and many reported being called time-wasters, difficult, manipulative, bed-wasters or attention-seeking. Some felt that a more appropriate description would be “attachment-seeking”. They felt blamed for their condition and often sought basic acceptance and someone to listen to them. They sought to gain legitimacy rather than being told “you’re not mentally ill”. Some preferred terms such as “emotional distress”.
- 42. ‘Antisocial personality disorder’ was felt to be even more stigmatising, and there was concern that the “dangerous and severe personality disorder” label would be wrongly applied, and lead to an inappropriate use of compulsory detention.
- 44. There was strong agreement that there are not enough services available for people with personality disorder. In the main, experiences of general adult mental health services were negative. Unhelpful attitudes from staff were encountered, who would see “just the label”, and were often prejudiced about the condition, and belittling or patronising in manner. Although the benefits of CPA being required were acknowledged, the experience was that procedures were often not followed or not helpful.
- 45. The different attitudes in adolescent services, compared with adult ones, towards intervention and treatability were striking. Early intervention was highlighted as crucial to the prevention of major deterioration in personality disorder. The need for specific services covering an age range of about 15 -25 was suggested. “*Had I been helped when younger I would not have got this bad.*”
- 46. Users felt that there needs to be acknowledgement by professionals that personality disorder is treatable: a negative experience on initial referral to a psychiatrist makes engagement less likely. There was also general agreement that endings of therapeutic relationships were often not addressed adequately. Also, once people show any improvement, services can be removed; this can discourage improvement.

“There is a link between hurting yourself and getting support and treatment. It is hard to resist self-harming behaviour when, you know if you do it, you will get treatment.”

Definitions of personality disorder

DSM-IV (1994) defines personality disorder as: ‘an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment’ (p. 629). In DSM, disorders that commonly co-occur are grouped in three clusters: Cluster A: odd or eccentric (paranoid, schizoid, and schizotypal); Cluster B: dramatic or flamboyant (antisocial, borderline, histrionic, and narcissistic); and Cluster C: anxious or fearful (avoidant, dependent, and obsessive-compulsive).

ICD-10 (1992) defines personality disorder as: ‘deeply ingrained and enduring behaviour patterns, manifesting themselves as inflexible responses to a broad range of personal and social situations. They represent either extreme or significant deviations from the way the average individual in a given culture perceives, thinks, feels, and particularly relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems in social functioning and performance’ (p. 200).

The personality disorders are listed in Appendix 1 comparing the two major diagnostic systems. It should be noted that the diagnosis of personality disorders is controversial. The wide range of criteria and their co-occurrence in many individuals means that categorisation is difficult. Generally, people diagnosed with PD do not conform to easily-recognisable types identifiable from symptoms. Instead, they are judged by their behaviour, which introduces a source of error (gaining reliable information about past behaviour) and which is clearly a function of circumstances. Treatments are relatively new, and can encounter staff prejudice against their effectiveness, as noted by service users above. The emphasis on PD of mental health policy signalled by *No Longer a Diagnosis of Exclusion* needs to be understood as a response to criminal justice issues as well as to mental health issues.

Table 1 shows the relationship between Cluster B PD and a range of other components of multiple exclusion. This suggests that PD is a common factor in many people who are chronically excluded. It is followed by a case study of ‘B’ to illustrate the sort of issues which are implicated in the diagnosis.

Table 1: Cluster B Personality Disorder Odds Ratios²⁶

| Cluster B personality disorders and: | OR (Confidence Interval) | Statistical significance | Note |
|--------------------------------------|-----------------------------|-----------------------------|------|
| Functional psychosis | 7.44 (2.20-25.2) | p<0.01 | A |
| Affective/anxiety disorder | 20.3 (5.70-71.6) | p<0.001 | A |
| Drug dependency | 1.87 (0.57-6.11) | Ns | A |
| Alcohol dependency | 4.21 (1.69-10.5) | p<0.05 | a |
| Convictions | 10.6 (2.72-41.3) | p<0.001 | b |
| Local authority care before age 16 | 6.00 (1.77-20.4) | P<0.05 | b |
| Institutional care before age 16 | 18.0 (3.87-83.8) | p<0.001 | b |

(a) adjusted for gender, age, social class and marital status

(b) adjusted for gender, age, social class, marital status, alcohol misuse, drug dependency, any affective/anxiety disorder, functional psychosis

Definition of odds ratio

The ratio of the odds of having the target disorder in the experimental group relative to the odds in favour of having the target disorder in the control group (in cohort studies or systematic reviews) or the odds in favour of being exposed in subjects with the target disorder divided by the odds in favour of being exposed in control subjects (without the target disorder).

²⁶ After Coid, J., Yang, M. Tyrer, P., Roberts, A. and Ullrich, S. (2006) Prevalence and correlates of personality disorder in Great Britain. *British Journal of Psychiatry* **188**, 423-431.

Example of a Cluster B patient

BB is a 22 year old unemployed single woman whose two children were adopted shortly after birth. In the early hours of Saturday morning, B (who was well known to the psychiatric service as someone suffering from a Cluster B PD) had been admitted to the local acute psychiatric ward from the Accident and Emergency Department. She had slashed both her wrists following a row with her ex-boyfriend. This was the latest in a long series of violent relationships with men. None lasted more than a few months. B had become pregnant on five occasions but only two of these had gone to term. On both occasions the infant had been removed into care to be adopted shortly afterwards, as B was not considered to be a fit mother.

B herself had been the product of a short-lived relationship. Her mother had many partners subsequently, some of whom had sexually abused B. It was not clear whether mother had been aware of this as B was growing up. The latter had been noted to be intelligent when assessed at primary school but had played truant from an early age and been expelled for violence to a teacher when at secondary school. By this time she was already abusing both alcohol and 'soft' drugs. This behaviour escalated after leaving school to include heroin addiction. To feed this habit B had prostituted herself on a number of occasions.

At interview on the psychiatric ward, B was noted to have multiple scars on both arms and some on her abdomen. She described herself as feeling 'empty and dead inside' - feelings that were relieved in the short-term by her self-harming. She intermittently heard 'a male voice' inside her head but there was no evidence of a major mood disorder or of psychosis. On the ward she quickly settled into the routine not appearing unduly depressed. She made friends with the younger patients there and was continually asking favours of the younger staff members, sometimes being intrusive and sexually inappropriate. She left the ward on her third day and returned with cannabis, which she encouraged other patients to share. She was discharged on account of this after it was discovered since there were no reasons to consider compulsory detention. She has been referred for an outpatient assessment for psychotherapy.

NIMHE (2003) Personality Disorder: No Longer a Diagnosis of Exclusion, Gateway ref. 1055, p10.

Treatments

In recent years, a great deal of effort has been made to identify effective interventions for people with PD, but the evidence is patchy. “Duggan et al. (2005) found just 29 methodologically acceptable randomised controlled trials of treatments for people with personality disorder: 16 psychopharmacological treatments (10 for borderline, 2 antisocial, 1 avoidant, and 3 mixed personality disorders) and 13 psychological treatments (7 for borderline, 1 antisocial, 2 avoidant, and 3 mixed personality disorders). Clearly, this body of treatment research is strongly biased toward borderline personality disorder.” (31-32) A thorough review of treatments can be found in a chapter prepared by Mary McMurrin for an edited book in preparation: M. McMurrin K. Soothill, M. Dolan, & P. Rogers (Eds), *Handbook on Forensic Mental Health*. Cullompton, Devon: Willan.

Knowledge in the field of treating PD is evolving rapidly, and the review cited above is already undergoing revision. The findings are incorporated in our report on effective interventions. There is also a growing amount of practice knowledge, gained from clinical experience. Rex Haigh summarises this in two tables reproduced below, from *Services for People with Personality Disorder: The Thoughts of Service Users* (2002), reproduced in *Personality disorder: no longer a diagnosis of exclusion* (22).

Helpful features for personality disorder services

| | |
|--|---|
| Early interventions, before crisis point | Focus on education and personal development |
| Specialist services, not part of general MH | Good assessment/treatment link |
| Choice from a range of treatment options | Conducive environment |
| Individually tailored care | Listens to feedback and has strong voice |
| Therapeutic optimism & high expectations | from service users |
| Develops patients' skills | Supportive peer networks |
| Fosters the use of creativity | Shared understanding of boundaries |
| Respects strengths and weaknesses | Appropriate follow up and continuing care |
| Good clear communication | Involves patients as experts |
| Accepting, reliable, consistent | Attitude of acceptance and sympathy |
| Clear and negotiated treatment contracts | Atmosphere of “truth and trust” |
| <i>...can make people feel respected, valued and hopeful</i> | |

Unhelpful features for personality disorder services

| | |
|--|--|
| Availability determined by postcode | Dismissive or pessimistic attitudes |
| Office hours only | Rigid adherence to a therapeutic model in cases where it becomes unhelpful |
| Lack of continuity of staff | Passing on information without knowing a person |
| Staff without appropriate training | Long-term admissions |
| Treatment decided only by funding/availability/diagnosis | Use of physical restraint and obtrusive levels of observation |
| Inability to fulfil promises made | Inappropriate, automatic or forcible use of medication |
| Critical of expressed needs (e.g. crisis or respite) | Withdrawal of contact used as sanction |
| Staff only respond to behaviour | Long-term admissions |
| Staff not interested in causes of behaviour | |
| <i>...can make people into "career psychiatric patients"</i> | |

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Table 2: DSM-IV and ICD-10 Personality Disorder classification compared

| DSM-IV | ICD-10 |
|--|--|
| Cluster A | |
| Paranoid Distrust; suspiciousness | Paranoid Sensitivity; suspiciousness |
| Schizoid Socially and emotionally detached | Schizoid Emotionally cold and detached |
| Schizotypal Social and interpersonal deficits; cognitive or perceptual distortions | No equivalent |
| Cluster B | |
| Antisocial Violation of the rights of others | Dissocial Callous disregard of others; irresponsibility; irritability |
| Borderline Instability of relationships, self-image, and mood | Emotionally unstable (a) Borderline - Unclear self-image; intense, unstable relationships (b) Impulsive - Inability to control anger; quarrelsome; unpredictable |
| Histrionic Excessive emotionality and attention- Seeking | Histrionic Dramatic; egocentric; manipulative |
| Narcissistic Grandiose; lack of empathy; need for admiration | No equivalent |
| Cluster C | |
| Avoidant Socially inhibited; feelings of inadequacy; hypersensitivity | Anxious Tense; self-conscious; hyper- sensitive |
| Dependent Clinging; submissive | Dependent Subordinates personal needs; needs constant reassurance |
| Obsessive-compulsive Perfectionist; inflexible | Anankastic Indecisive; pedantic; rigid |

Appendix 2.1

Review of reviews: Authors' conclusions

| THERAPEUTIC INTERVENTIONS | | |
|--|--|--|
| Review | Title | Results and authors' conclusions |
| A Hassiotis, I Hall. (2004) | Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with learning disabilities | D irect interventions based on cognitive-behavioural methods (modified relaxation, assertiveness training with problem solving, and anger management) appear to have some impact on reduction of aggressive behaviour at the end of treatment but not at follow up (up to six months) as rated by individuals and their carers. The existing evidence on the efficacy of cognitive behavioural and behavioural interventions on outwards directed aggression in children and adults with ID is scant. There is a paucity of methodologically sound clinical trials. |
| Bower P, Rowland N. (2006) | Effectiveness and cost effectiveness of counselling in primary care | Counselling is associated with modest improvement in short-term outcome compared to usual care, but provides no additional advantages in the long-term. Patients are satisfied with counselling. Although some types of health care utilisation may be reduced, counselling does not seem to reduce overall healthcare costs. |
| Perry A, Coulton S, Glanville J, Godfrey C, Lunn J, McDougall C, Neale Z. (2006) | Interventions for drug-using offenders in the courts, secure establishments and the community | Limited conclusions can be drawn about the effectiveness of drug treatment programmes for drug-using offenders in the courts or the community. This is partly due to the broad range of studies and the heterogeneity of the different outcome measures presented. Therapeutic communities with aftercare show promising results for the reduction of drug use and criminal activity in drug using offenders. Standardisation of outcome measures and costing methodology would help improve the quality of research conducted in the area. |
| CA Binks, M Fenton, L McCarthy, T Lee, CE Adams, C Duggan. (2006) | Pharmacological interventions for people with borderline personality disorder | Pharmacological treatment of people with BPD is not based on good evidence from trials and it is arguable that future use of medication should be from within randomised trials. Current trials suggest that the positive effect of antidepressants, in particular, could be considerable. Well designed, conducted and reported clinically meaningful trials are possible and needed with, perhaps, the question of antidepressant versus placebo being addressed first. |

| Therapeutic interventions contd. | | |
|---|---|---|
| Review | Title | Results and authors' conclusions |
| CA Binks, M Fenton, L McCarthy, T Lee, CE Adams, C Duggan. (2006) | Psychological therapies for people with borderline personality disorder | This review suggests that some of the problems frequently encountered by people with borderline personality disorder may be amenable to talking/behavioural treatments but all therapies remain experimental and the studies are too few and small to inspire full confidence in their results. These findings require replication in larger 'real-world' studies. |
| Jeffery DP, Ley A, McLaren S, Siegfried N. (2000) | Psychosocial treatment programmes for people with both severe mental illness and substance misuse | There is no clear evidence supporting an advantage of any type of substance misuse programme for those with serious mental illness over the value of standard care. No one programme is clearly superior to another. The problems posed by substance misuse in the context of severe mental illness will not go away. The current momentum for integrated programmes is not based on good evidence. Implementation of new specialist substance misuse services for those with serious mental illnesses should be within the context of simple, well designed controlled clinical trials. |
| Haddock G, Barrowclough C, Tarrier N, Moring J, O'Brien R, Schofield N, Quinn J, Palmer S, Davies L, Lowens I, McGovern J, Lewis S (2003) | Cognitive-behavioural therapy and motivational intervention for schizophrenia and substance misuse - 18-month outcomes of a randomised controlled trial | This is a single RCT. Patient and a nominated carer allocated to either CBT, motivational intervention and routine care, or routine care alone. Inclusion criteria were a diagnosis of schizophrenia, schizoaffective disorder or delusional disorder, plus diagnosis of substance dependence or misuse. Patient had to be living with a carer. 36 pairs were randomised. Compared with routine treatment, the integrated programme of cognitive-behavioural therapy (CBT) combined with motivational intervention (MI) for patients with psychosis and substance use resulted in significant improvements in patient functioning. In addition, the benefits persisted for up to 18 months. The experimental intervention was no more costly than routine care (RC), and there was a high probability of it being cost-effective. The study sample was small and was not representative of the study population, but overall, the internal validity of the effectiveness estimates is likely to have been high. The benefits attributed to the intervention may have been due to additional contact time per se, as the study design did not control for the additional staff time allocated to the intervention group. |
| Brazier J, Tumor I, Holmes M, Ferriter M, Parry G, Dent-Brown K, Paisley S (2006) | Psychological therapies including dialectical behaviour therapy for borderline personality disorder: a systematic review | There is some evidence that 1. DBT is more effecting than treatment as usual to treat chronically parasuicidal and drug dependent borderline women, 2. DBT more effective than client centred therapy for BPD, 3. partial hospitalisation is more effective than treatment as usual to treat BPD. Overall efficacy of psychological therapies is promising; however at this stage the evidence is inconclusive. Results should be |

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| | | |
|--------------|-------------------------------------|---|
| Not Cochrane | and preliminary economic evaluation | interpreted with caution as not all studies were primarily targeted to borderline symptoms and there were considerable differences between the studies. |
|--------------|-------------------------------------|---|

| Therapeutic interventions contd. | | |
|--|--|--|
| Kownacki RJ, Shadish WR | Does Alcoholics Anonymous work: the results from a meta-analysis of controlled experiments | The randomized trials suggest that AA at best does no better than alternatives and in some cases may do significantly worse. |
| Hawton K, Townsend E, Arensman E, Gunnell D, Hazell P, House A, van Heeringen K (1999) | Psychosocial and pharmacological treatments for deliberate self harm | 23 RCT's were identified of psychosocial and/or psychopharmacological treatment versus standard or less intensive types of aftercare for patients who had recently engaged in self harm. There was a trend towards reduced repetition of deliberate self harm (DSH) for problem-solving therapy compared with standard aftercare, for additional provision of an emergency contact card. Significantly reduced rates of further self-harm were observed in single small trials for depot flupenthixol vs. placebo in multiple repeaters and for DBT vs. standard aftercare. Results are limited by insufficient numbers of patients in trials. Therefore there is insufficient evidence to recommend a specific clinical intervention after DSH. |
| Duggan C, Adams C, McCarthy L, Fenton M, Lee T, Binks C, Stocker D.(2006) | A systematic review of the effectiveness of pharmacological and psychological treatments for those with personality disorder | Overall the evidence to justify intervening in this group was found to be weak although some approaches showed promise. That there is so little evidence in intervening in those with antisocial personality disorder is of concern, given its high prevalence and political sensitivity. There is an urgent need therefore to fund properly designed and powered randomized trials in this area if it is to advance scientifically. |
| Abbass AA, Hancock JT, Henderson J, Kisely S (2006) | Short-term psychodynamic psychotherapies for common mental disorders | For general, somatic, anxiety and depressive symptom reduction and for social adjustment, outcomes for most categories of disorder showed significantly greater improvement in the treatment than the control groups, maintained in medium and long term follow up. There was only a small amount of data for each category, so results should be interpreted with caution, also there was variability in treatment delivery and quality. |
| Gold C, Haldal TO, Dahle T, Wigram T (2005) | Music therapy for schizophrenia or schizophrenia-like illnesses | Four RCT's were included, which compared music therapy with standard care or other psychosocial interventions for schizophrenia for 1 – 3 months, with 7 – 8 sessions. Music therapy added to standard care was superior to standard care alone for global state, and continuous data suggested some positive effects on general mental state, negative symptoms and social functioning. These latter effects were inconsistent across studies and depended on the number of sessions. |

| Therapeutic interventions continued | | |
|--|--|---|
| Gowing L, Ali R, White J (2006) | Buprenorphine for the management of opioid withdrawal | Interventions involving the use of Buprenorphine to manage opioid withdrawal for withdrawal signs and symptoms, completion of withdrawal and adverse effects were compared with control of reducing doses of methadone, alpha2adrenergic agonists, symptomatic medications, placebo, or different Buprenorphine based regimes. Compared to clonidine, Buprenorphine is more effective in managing symptoms of withdrawal, patients stay in treatment for longer, and are more likely to complete treatment. There is no significant difference in incidence of adverse events but patients on clonidine may be more likely to drop out due to adverse events. Severity of withdrawal is similar for Buprenorphine and methadone, but withdrawal symptoms may resolve more quickly with Buprenorphine. There is a trend towards completing of treatment being more likely with Buprenorphine than methadone. |
| Jesner OS, Aref-Adib M, Coren E (2007) | Risperidone for autism spectrum disorder | Meta-analysis was possible for outcomes of irritability, repetition and social withdrawal, and some evidence of the benefits of Risperidone were apparent. However there were adverse events the most prominent being weight gain. These studies had small sample sizes and there was not a single standardized outcome measure. Long-term follow up is also lacking and is necessary to assess long-term benefits versus risks. |
| Joy CB, Adams CE, Lawrie SM (2006) | Haloperidol versus placebo for schizophrenia | From 3 trials, more people allocated haloperidol improved in the first six weeks of treatment than those allocated placebo. From 8 trials, there was a difference favouring haloperidol over 6-24 weeks. Half of those entering studies failed to complete even the short trials but at 0-6 weeks 11 studies found a difference that marginally favoured haloperidol. Haloperidol does seem to cause adverse movement disorders such as acute dystonia, parkinsonism and akathisia, at least in the short term. Where there is no treatment option the use of haloperidol is justified. If a choice is available an alternative antipsychotic will have less likelihood of adverse events. |
| Hunter RH, Joy CB, Kennedy E, Gilbody SM, Song F | Risperidone versus atypical antipsychotic medication for schizophrenia | In the short term, Risperidone was more likely to produce an improvement in the positive and negative symptoms scale than haloperidol (9 RCT's). A similar result was found in the longer term (4 RCT's). Risperidone was more likely to reduce relapse at one year compared to haloperidol (1 RCT). Those given Risperidone had significantly fewer movement disorders than those receiving older antipsychotics. (10 RCT's). but were more likely to have significant weight gain (4 RCT's). |

| SERVICES DELIVERY & ORGANISATION | | |
|---|--|--|
| Review | Title | Results and authors' conclusions |
| Marshall M, Lockwood A. (1998) | Assertive community treatment (ACT) for people with severe mental disorders | Those receiving ACT were more likely to remain in contact with services and were less likely to be admitted to hospital than those receiving standard care. They were more likely to remain in contact with services, were less likely to be admitted and spent less time in hospital than those receiving hospital based rehabilitation. They spent fewer days in hospital than those receiving case management. ACT is a clinically effective approach to managing the care of severely mentally ill people in the community. |
| Marshall M, Gray A, Lockwood A, Green R. (1998) | Case management for people with severe mental disorders | Case management ensures that more people remain in contact with psychiatric services (one extra person remains in contact for every 15 people who receive case management), but it also increases hospital admission rates. Present evidence suggests that case management also increases duration of hospital admissions, but this is not certain. Whilst there is some evidence that case management improves compliance there is no evidence that case management improves outcome on any other clinical or social variables. |
| Tyrer P, Coid J, Simmonds S, Joseph P, Marriott S. (1998) | Community mental health teams (CMHTs) for people with severe mental illnesses and disordered personality | Community mental health team management is not inferior to non-team standard care in any important respects and is superior in promoting greater acceptance of treatment. It may also be superior in reducing hospital admission and avoiding death by suicide. |
| Joy CB, Adams CE, Rice K. (2006) | Crisis intervention for people with severe mental illnesses | Five studies were included, none of which purely investigated crisis intervention, all used a form of homecare for acutely ill people which included crisis intervention. 45% of the crisis/home care group were unable to avoid hospital admission during the treatment period. Home care may however help avoid repeat admissions. Crisis/home care reduces the number of people leaving the study early, reduces family burden and is more satisfactory to patients and families. Home care crisis treatment, coupled with an ongoing home care package, is a viable and acceptable way of treating people with serious mental illnesses. |

| SERVICES DELIVERY & ORGANISATION contd. | | |
|--|---|--|
| Marshall M, Crowther R, Almaraz-Serrano A,et al. (2003) | Day hospital versus admission for acute psychiatric disorders | Nine RCT's were identified comparing day hospital versus inpatient care for people with acute psychiatric disorders. Day hospital treatment was feasible for 23% of those in inpatient care. People randomised to day hospital care spent more days in day hospital care and fewer days in inpatient care. Those suitable for day hospital care showed a more rapid improvement in mental state but not in social functioning. Caring for people in acute day hospitals can achieve substantial reductions in the numbers of people needing inpatient care, whilst improving patient outcome. |
| Crowther R, Marshall M, Bond G, Huxley P. (2001) | Vocational rehabilitation for people with severe mental illness | Supported employment is more effective than Pre-vocational Training in helping severely mentally ill people to obtain competitive employment. There is no clear evidence that Pre-vocational Training is effective. |
| Brunette M F, Mueser K T, Drake R E (2004) Not Cochrane | A review of research on residential programs for people with severe mental illness and co-occurring substance use disorders | In residential treatment programmes, greater levels of integration of substance abuse and mental health services are more effective than less integration. Research suggests that residential programmes should be flexible, supportive, low intensity and offered for long periods of time. |
| Drake R E, Mercer- McFadden C, Mueser K T, McHugo G J, Bond G R (1998) | Review of integrated mental health and substance abuse treatment for patients with dual disorders | Studies of adding dual-disorders groups to traditional services, studies of intensive integrated treatments in controlled settings, and studies of demonstration projects have yielded disappointing results. However, 10 recent studies of comprehensive, integrated outpatient treatment programmes provide encouraging evidence of the programme's potential to engage dually diagnosed patients in services and to help them reduce substance abuse and attain remission. Outcomes related to hospital use, psychiatric symptoms and other domains are less consistent. Several programme features appear to be associated with effectiveness; assertive outreach, case management, and a longitudinal, stage wise motivational approach to substance abuse treatment. |
| Reda S, Makhoul S. (2001) | Prompts to encourage appointment attendance for people with serious mental illness | A simple prompt to attend clinic, very close to the time of the appointment may encourage attendance, and a simple orientation-type letter, 24 hours before the clinic appointment, may be more effective than a telephone prompt. This simple intervention could be a more cost effective means of encouraging compliance at first |

| | | |
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| | | attendance, but supplementing these data with the results of large, well designed, conducted and reported randomised studies would be desirable. |
|--|--|--|

Appendix 2.1

| SERVICES DELIVERY & ORGANISATION contd. | | |
|---|--|--|
| Lees J, Manning N, Rawlings B (2004) | A culture of enquiry: research evidence and the therapeutic community | Included 8 RCT's. Inclusion criteria were post-treatment or in-treatment outcome of therapeutic community treatment in secure or non-secure democratic therapeutic community settings for people with personality disorders or mentally disordered offenders. Heterogeneity was largely accounted for by differences between types of community. The overall summary odds ratio provides evidence for the effectiveness of therapeutic community treatment for personality disordered patients. |
| Smith, LA, Gates S, Foxcroft D. (2006) | Therapeutic communities for substance-related disorder | Seven randomised controlled trials comparing therapeutic community with either another therapeutic community, another treatment or no treatment. Differences between studies precluded meta-analysis. There was little evidence that therapeutic communities offer significant benefit in comparison with other residential treatment, or that one type of therapeutic community is better than another. Prison therapeutic community may be better than prison on its own or mental health treatment programmes to prevent reoffending post release for inmates. Methodological limitations of the studies may have introduced bias and firm conclusions cannot be drawn due to limitations of existing evidence. |
| Jamtveldt G, Young JM, Kristoffersen DT, O'Brien MA, Oxman AD | Audit and feedback: effects on professional practice and healthcare outcomes | 118 RCT's were found of audit and feedback of clinical performance that reported objectively measured professional practice in a healthcare setting, or healthcare outcomes. Low baseline compliance with recommended practice and higher intensity of audit and feedback were associated with greater effectiveness across studies. When audit and feedback are effective, the effects are generally small to moderate. This does not support mandatory or unevaluated use of audit and feedback as an intervention to change practice. |
| Marshall M, Crowther R, Almaraz-Serrano AM, Tyrer P (2001) | Day hospital versus outpatient care for psychiatric disorders | There is only limited evidence to justify the provision of day treatment programmes and transitional day hospital care, and no evidence to support the provision of day care centres. |

Single studies: Authors' conclusions

| Single studies of THERAPEUTIC INTERVENTIONS | | |
|--|--|--|
| <p>Haddock G, Barrowclough C, Tarrier N, Moring J, O'Brien R, Schofield N, Quinn J, Palmer S, Davies L, Lowens I, McGovern J, Lewis S (2003)</p> | <p>Cognitive-behavioural therapy and motivational intervention for schizophrenia and substance misuse - 18-month outcomes of a randomised controlled trial</p> | <p>Patient and a nominated carer allocated to either CBT, motivational intervention and routine care, or routine care alone. Inclusion criteria were a diagnosis of schizophrenia, schizoaffective disorder or delusional disorder, plus diagnosis of substance dependence or misuse. Patient had to be living with a carer. 36 pairs were randomised. Compared with routine treatment, the integrated programme of cognitive-behavioural therapy (CBT) combined with motivational intervention (MI) for patients with psychosis and substance use resulted in significant improvements in patient functioning. In addition, the benefits persisted for up to 18 months. The experimental intervention was no more costly than routine care (RC), and there was a high probability of it being cost-effective. The study sample was small and was not representative of the study population, but overall, the internal validity of the effectiveness estimates is likely to have been high. The benefits attributed to the intervention may have been due to additional contact time per se, as the study design did not control for the additional staff time allocated to the intervention group.</p> |
| <p>Healey A, Knapp M, Marsden J, Gossop M, Stewart D (2003)</p> | <p>Criminal outcomes and costs of treatment services for injecting and non-injecting heroin users: evidence from a national prospective cohort survey</p> | <p>Re-analysis of longitudinal observational data on a national sample of heroin addicts referred to treatment. Examines only crime reduction as outcome of treatment. Treatment programmes examined – methadone prescribing, inpatient NHS drug dependency units, residential rehab units. Treatment selection is needs based. Increasing time in treatment (and therefore treatment cost) had a mean crime prevention effect on clients referred for community based methadone treatment, specialist drug dependency units and residential rehabilitation programmes. There was a significant interaction between client injecting status and time in treatment. All programmes were effective but treatment was more effective among non-injectors, with no difference in treatment costs between the groups. Outcomes were at one year only, longer term follow up is needed, and also health and quality of life outcomes should be examined.</p> |

| Single studies of THERAPEUTIC INTERVENTIONS | | |
|--|---|--|
| <p>Kroger C, Schweiger U, Sipos V, Arnold R, Kahl K, Schunert T, Rudolf S, Reinecker H. (2006)</p> | <p>Effectiveness of dialectical behaviour therapy for borderline personality disorder in an inpatient setting</p> | <p>Unselected comorbid population seeking 3 month inpatient treatment. Assessed for frequency of comorbidity at admission and at 15 month follow up. Psychopathology was significantly reduced post treatment and at follow up. The results of other studies which support the efficacy of DBT can be generalized to an inpatient setting and to patients with borderline personality disorder with high comorbidity.</p> |
| <p>Reda S, Makhoul S. (2001)</p> | <p>Prompts to encourage appointment attendance for people with serious mental illness</p> | <p>There is evidence that a simple prompt to attend clinic, very close to the time of the appointment may encourage attendance, and a simple orientation-type letter, 24 hours before the clinic appointment, may be more effective than a telephone prompt. This simple intervention could be a more cost effective means of encouraging compliance at first attendance, but supplementing these data with the results of large, well designed, conducted and reported randomised studies would be desirable.</p> |

Appendix 3.1

All mental health services included in the mapping database

| Title | N |
|---|-----|
| Acute Inpatient Unit/ Ward | 488 |
| Adult/family Placement Scheme | 40 |
| Advice and Information Service | 336 |
| Advocacy Service | 246 |
| Assertive Outreach Team | 250 |
| ASWs not employed in adult mental illness services | 115 |
| Befriending and Volunteering Scheme | 139 |
| Board and Lodging Scheme | 36 |
| Carer Support Worker | 74 |
| Carers Support Group | 181 |
| Carers Support Service | 286 |
| Community Development Worker - Black and Minority Ethnic | 46 |
| Community Forensic Services | 44 |
| Community Mental Health Team | 823 |
| Criminal Justice Liaison and Diversion Service | 111 |
| Crisis Accommodation | 60 |
| Crisis Resolution Team | 263 |
| Day Centres/Resource Centre | 687 |
| Drop-in | 356 |
| Early Intervention in Psychosis Service | 127 |
| Education and Leisure Opportunity | 187 |
| Emergency Clinics / Walk-in Clinic | 23 |
| Emergency Duty Team | 111 |
| Employment Scheme | 469 |
| Gateway Worker | 42 |
| GP Counselling Service | 93 |
| Graduate Primary Care Worker | 86 |
| High secure psychiatric hospital | 2 |
| Home/Community Support Service | 316 |
| Homeless Mental Health Service | 63 |
| Hostel | 191 |
| Independent hospital - mental health establishment | 44 |
| Local Low Secure Service - High Dependency Unit | 70 |
| Local Medium Secure Service | 27 |
| Local Psychiatric Intensive Care Unit | 94 |
| Mental Health Crisis Intervention Service | 19 |
| Mental Health Promotion Initiative | 61 |
| Mother and Baby Facility | 24 |
| NHS 24-hour nurse staffed care | 100 |
| NHS Day Care Facility | 177 |
| Other community and/or hospital professional team/specialist | 220 |
| Peri-natal Mental Illness Service | 23 |
| Personality Disorder Service | 22 |
| Primary care mental health service | 138 |
| Prison Psychiatric Inreach Service | 68 |
| Psychiatric liaison service | 140 |
| Psychiatric Outpatient Care | 336 |
| Psychological Therapies and Counselling Services (Statutory sector) | 334 |
| Regional medium secure unit | 18 |

Better Outcomes for the Most Excluded Final Draft

| | |
|---|------|
| Registered Care Home (18-65) | 888 |
| Registered Care Home (with nursing) for adults (18-65) | 156 |
| Rehabilitation or Continuing Care Team | 82 |
| Residential Rehabilitation Unit | 191 |
| All mental health services ... continued | |
| Self-help and Mutual Aid Group | 294 |
| Self-help, Mutual Aid Group for Carers | 44 |
| Service User Group/Forum | 296 |
| Short-term Breaks / Respite Care Service | 92 |
| Specialist Psychotherapy Service | 112 |
| Staffed Group Home | 188 |
| Staff-facilitated Support Group | 156 |
| Support Time and Recovery Worker | 37 |
| Supported Housing | 1776 |
| Unstaffed Group Home | 194 |
| Voluntary / Private Psychological Therapy and Counselling Service | 354 |

Appendix 3.2

NHS Homeless Mental Health Projects working with dual disorders as at March 31 2006

1. Stoke Homeless Mental Health Project

Potteries Housing Association/ Stoke on Trent SSD
Homeless and Dual Diagnosis outreach service.
The Dudson Centre
Hope Street
Hanley,
Stoke on Trent
01782 683168
8.30am to 4.30pm Monday to Friday

2. The Scrine Foundation (formerly Canterbury Open Christmas)

A full-time RMN will work 37 hours per week
covering all the targets as
above.

The Scrine Foundation
Canterbury Open Centre
Palmer House
13 Station Road East
Canterbury
Kent CT1 2RB
01227 464904

The project is 24hr support. Mental Health
Specialist worker is 09.00 to 17.00 hrs Monday - Friday.

3. Homeless Team

Lancashire Care NHS Trust
5 Camden Place
Preston
01772 562242
Mon to Fri 8am to 4pm

4. Housing A&R Team

LB Bromley
via CMHTs / ACT / Rehab

5. Community and Tenancy Support

Local Authority Community Services
Activities include access to day centres, training and education and independent living
Housing Centre, Civic Offices
St Nicholas Way

Sutton

SM1 1EA

020 8770 5468

Housing Authority Homeless Persons Unit

Monday to Friday, 8.40am - 5.15pm

Support to enable service users to live independently in the community, engaging in daytime activities and support to maintain tenancy.

6. START Team

South London and Maudsley NHS Trust

Southwark PCT

First floor

Master's House

off Renfrew Road

Dugard Way

SE11 4TH

020 7840 0653

9am - 5pm, Monday - Friday

Multi-disciplinary community mental health team for homeless people. The Team uses an assertive outreach approach to engage people with mental health problems who have difficulty accessing mainstream services. An assessment service is provided as well as case management for people with severe and enduring mental health needs. Workers from the voluntary sector receive training about mental health issues.

NHS Personality Disorder Provision as at March 31 2006

1. The Brenchley Unit

The Courtyard
Pudding Lane
Maidstone, ME14 1PA
01622 776330
01622 776339

9 - 5 Tue, Wed and Friday

Staff also present Mon & Thurs, but these are not Therapeutic Community days.
Therapeutic Community which offers treatment to patients with S.P.D on 3 days per week for 18 months. Per programme and after care groups also.

2. Therapy Services for People with Personality Disorder

Francis Dixon Lodge
Gipsy Lane
Leicester
LE5 0TD
0116 2256800
0116 2255959

Trudy.Cornes@leicspart.nhs.uk

Mon - Fri 9:00 - 17:00 for callers.

24 hours 5 days per week for inpatients (Mon - Fri weekday service inpatient service)

Day Hospital/out-patients Mon - Fri 9.00 to 5.00

Personality Disorder Service providing a Monday-Friday residential programme, day programme including women only service on Tues/Thur. In addition provides an outpatient assessment and treatment service as well as liason and consultancy services to staff in other areas.

3. Intensive Psychological Treatment Services

York Clinic, Thomas Guy House
47 Weston Street
London
SE1 3RR
020 7188 3257
020 7407 5117

Weekdays 9am to 4pm

IPTS offers structured therapy programmes based on a Therapeutic Community model, mainly focused around group-work. There are currently two main programmes, a three day a week Intensive programme, and a one day transition and Support Programme.

4. Regional Personality Disorders Service

Claremont House
Off Framlington Place
Newcastle upon Tyne
NE2 4AA
0191 282 4547

Monday - Friday 9.00am - 5.00pm

Regional service providing: support for people aged 18+ years with mental health problems; and borderline personality disorders. This service also provides in house support for staff.

5. North Hampshire Personality Disorder Service

DBT Service
Terry Wilcox
Bridge Centre
New Road
Basingstoke
Hampshire
RG22 7PJ

Consultant Psychiatrist

Specialist service for treatment of patients diagnosed as having a PD using DBT Techniques

6. Complex Needs Service

Barton House,
Addenbrookes Hospital
Cambridge
CB2 2QQ

Specific Links with probation and Area Social Services team
9-8 Monday to Friday - on call evenings to 10 and weekends

7. Rotunda Therapeutic Day Programme

109 Great Mersey Street
Liverpool
L5 2PL
0151 207 2176 0151 207 4122

Social services, Voluntary Sector e.g. Whitechapel project

9 am - 5 pm

Group therapy for people with personality disorders living in the community.

8. Halliwick Personality Disorder Service,

Haringey Psychological Therapies Service

Halliwick Psychotherapy Department

St Anns Hospital

St Anns Road

London N15 3TH

0208442 6093 or 6528

Any healthcare professional, adolescent services, children and families, crisis

9.00-4.30

The Specialist Personality Disorder Service is part of the Psychological Therapies Service. It comprises a Day Unit and an intensive Outpatient Programme for the treatment of Personality Disorder patients.

9. Henderson Hospital

2 Homeland Drive,

Sutton,

Surrey, SM2 5LT

Henderson Outreach Services Team,

132 Wandsworth

Road, London SW8 2LD

020 8661 1611

020 8770 3676

Referrals from CMHTs, psychotherapists, psychiatrists, probation services, social workers

Inpatient Service: 24 hours, 7 days a week

Outpatient Service: Monday - Friday, 9:00 - 17:00

Therapeutic Community for treatment of PD. Residents are offered a treatment programme of up to one year.

The outreach service provides consultancy to referrers, assessment, preparation for admission and 6 months follow up outpatient services.

11. Personality Disorder Service Pilot Project

North Cumbria Mental Health and Learning Disability Trust

No further details

12 Oswin Ward, PD In Patient Service

St Nicholas Hospital
Gosforth
Newcastle upon Tyne

24 hours 7 days per week

13. Adult Forensic Community Personality Disorder Team

St Nicholas Hospital
Gosforth
Newcastle upon Tyne
0191 2232868

Police, Probation Service & Solicitors via a CMHT

Monday to Friday 9.00 am to 5.00 pm

The service provides assessments and treatments for people with personality disorders who are linked to the criminal justice service. The team works across the Northern Region.

14. Complex Case Service

Roch House Therapy Centre
Fairfield General Hospital
Rochdale Old Road
Jerico
Bury
BL9 7TD
0161 764 6081

Monday -Friday 9am -5pm; Service based on Psychological approach with an emphasis on psychological formulation and treatment

15. Cawley Centre - Maudsley

The Maudsley Hospital
Denmark Hill
SE5 8AZ
020 7919 2679
020 7919 2680

Monday to Friday; A therapeutic community based at the Maudsley Hospital which provides an environment wherein clients are actively involved in the maintenance and day to day running of the unit. Large groups, small groups and individual meetings provide opportunities for clients to

reflect upon and consequently alter their ways of relating to each other and to the outside world.

16. Personality Disorder Service (Number 63)

63 Headlands
Kettering
NN15 7EU
01536 526760
01536 526760

09.00-17.00 Mon to Fri

Training, consultation and therapy for major personality difficulties. Staff consultation in response to referral. Work with Service User's (NHT caseload) care co-ordinator. Very limited direct work.

17. Psychotherapy Day Programme

Holly Court
Summerlands
56 Preston Road
Yeovil
01935 431725 (8.30 -5.00 Mon- Fri)

Mon, Wed, Fri 10.00 - 3.30

The programme works with people with longstanding personality disorders to help them to value and desire personal change by a process of group therapy. The programme provides 6 therapeutic groups on 3 days for 40 weeks, mirroring school terms. The content of the group sessions reflects the programme's aims and includes cognitive analytic therapy, creative therapies (arts, dance and drama) educational and holistic therapies.

18. Buckinghamshire Complex Needs Service

01296 504349
maura.healy@bmh.nhs.uk
vuntary sector; housing
09.00-17.00 Mon - Fri

A tiered service for people with personality disorder or complex needs. Tier 1 is an active engagement level and incorporates a pre-therapy group, where the client will make a decision on future care pathways through the service. Tier 1 also incorporates supervision, training and teaching to professionals working with people with complex needs. Tier 2 incorporates psychological therapy provision including a twice weekly analytic group in both mid and south Bucks. It is envisaged that educational/cognitive groups for issues such as self harm will be available in the future. Tier 3 is an intensive 3 day a week Therapeutic Community programme. Members stay in this programme for 12-18 months. Tier 4 is a step down programme from the TC.

19. Personality Disorder Clinical Network

Unity Court
431 Meanwood Road
Leeds
LS7 2LD

Only via CMHTs Mon - Friday 9am-5pm
Community pilot project. multi agency, multi disciplinary working with clients with personality disorder.

20. Thames Valley National Initiative (Personality Disorder Service)

Oxfordshire Complex Needs service
Manzil Way
Cowley Road
Oxford
OX4 1XE
01865 455872 09:00-17:00 Monday to Friday

Police, ASW, CRHT, local authority, voluntary sector etc..
09:00-17:00 Monday to Friday

OMHT is participating in the Department of Health's National Personality Disorder Development Programme. The Personality Disorder Service provides countywide treatment for people diagnosable with a personality disorder, treatment includes pre-therapy work, therapy groups, intensive five day therapy program and step down groups. The service also provides consultation, training, supervision and advice to primary care, voluntary sector, mental health services and general hospitals on working with people with personality disorders.

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