Chapter 8 A service framework for involuntary care

> I should say that we should not do any of this if we have not got a way of helping these people. There is no point in making a decision like this if we have not got places or environments where people can be cared for. I think that this is probably fundamental: Is society prepared to provide the support? It ought to, but is it able or prepared to provide an environment where people who are so vulnerable or harmed can get some support?[432]

In the previous chapter the Committee set out the elements of a new legislative framework for involuntary care aimed at protecting the health and safety of people with severe substance dependence. In this chapter we identify the key elements of the service framework that will necessarily underpin the legislation: evidence-based services and treatment guidelines, integrated service delivery, and investment in specific services. Before we discuss these elements, we explore the critical issues of the need to resource the new system of involuntary care, and where that care should be provided. The chapter concludes with the recognition that involuntary care should be conceptualised along a continuum of high quality, accessible, holistic and humane care. Underpinning the discussion is the principle stated earlier in the report: that when intervening without a person's consent we need to maximise the benefits to that person. Involuntary care must be used as an opportunity to do the most good.

A new service framework

8.1 In Chapter 6 we established the ethical basis for a system of short term involuntary care for people at risk of serious harm, for the purpose of protecting their health and safety. The care would necessarily entail evidence-based medical interventions, provided in a medical setting. While treatment, harm reduction and psychosocial measures would be tailored to a person's needs, several core interventions are envisaged: containment in a safe place; where necessary, medicalised withdrawal; comprehensive assessment, including neuropsychological assessment where required; the development of a post-discharge treatment plan; referral and support to engage people in the voluntary system and other services, including care and support under guardianship where necessary; and assertive follow-up. In Chapter 7 we noted that such intervention would necessarily involve detention. We also recommended that the period of care be 7 to 14 days, but that in exceptional circumstances, a further period of up to 14 days may be ordered.

8.2 In Chapter 6 we also documented the need for non-coercive mechanisms to assist people who have complex needs and challenging behaviours associated with their substance dependence. In doing so, we noted both the difficulties that this particular group create for families and communities, and also the multidimensional nature of their needs. The service system struggles to respond to this group because their needs traverse the boundaries of government agencies. We also noted that there is inadequate investment in the range of human services that are likely to assist them.

8.3 After exploring how a mechanism to assist people with complex needs and/or antisocial behaviour could be operationalised through legislation, in Chapter 7 we recommended the

[432] Emeritus Professor Ian Webster AO, NSW Expert Advisory Committee on Drugs, Evidence, 18 February 2004, p6

establishment of a cross-agency task force to determine a policy position on this issue. We also recommended that this task force consider providing within the proposed legislation elements of Victoria's *Human Services (Complex Needs) Act 2003*, to establish a localised decision making body that holistically assesses people and acts as a filter, channelling them towards involuntary care where this is required and/or non-coercive services, as appropriate to their needs.

8.4 We now turn to the service framework that must underpin the legislative mechanisms we have recommended. Our primary focus is on the system of short term involuntary care that we have recommended in previous chapters. At various points in the discussion we also discuss responses to people with complex needs.

8.5 The Committee has identified three key elements essential to an effective service framework for involuntary care:

- evidence-based services and treatment guidelines
- integrated service delivery
- investment in specific services.

8.6 Before the Committee explores and makes recommendations on each of these elements in turn, we explore two fundamental and related issues: the need to resource the new system of short term involuntary care, and where people in involuntary care should be placed.

Resourcing the system

8.7 Inquiry participants readily recognised that in order to work effectively, any new system of involuntary care must be adequately resourced. Having undertaken their review of the literature on compulsory treatment, Ms Amy Swan and Ms Sylvia Alberti of Turning Point Drug and Alcohol Centre told the Committee that this is borne out in research: benefits to those made subject to coercion are maximised through investment in appropriate services. They also stated, conversely, 'if you don't have the systemic support, that's where it doesn't work well.'[433] Likewise, Professor Hall warned that a well resourced system could be expected to achieve good outcomes, but that such programs are typically not well funded.[434]

8.8 Several witnesses, like Professor Webster at the start of this chapter, noted the moral imperative to provide high quality services when a person is detained. Others such as the Law Society of New South Wales suggested that sufficient services will not only ensure that needs are addressed, but also that people's rights are protected.[435]

8.9 In its submission, Illawarra Health observed the particular challenges associated with resourcing a system of short term intervention such as that recommended by the Committee.

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433 Ms Sylvia Alberti, Manager, Forensic and Clinical Services and Senior Research Fellow, Turning Point Alcohol and Drug Centre, Evidence, 28 April 2004, p32; Ms Amy Swan, Research Fellow, Turning Point Alcohol and Drug Centre, Evidence, 28 April 2004, p28

434 Professor Wayne Hall, Professorial Fellow and Director, Office of Public Policy and Ethics, Institute for Molecular Bioscience, University of Queensland, Evidence, 29 April 2004, p4

435 Submission 36, Law Society of New South Wales, p4

It identified acute care interventions to address harm as potentially the most difficult goal to implement, given the scarcity of resources in relation to detoxification beds, medical beds, emergency department activity, and police.[436]

8.10 A major message from participants, whether service providers, administrators, ethicists or clinicians, was that implementing a better system of involuntary care should not be at the expense of voluntary drug and alcohol patients, whether by diverting resources away from them or undermining the quality of care they receive. As Professor Hall put it:

> The bigger question is the availability of treatment for people seeking it voluntarily … We have to remind ourselves when we are proposing to pull people off the streets and treat them for their own good that there are plenty of people who want to be treated who we are not accommodating.[437]

The shortage of alcohol and other drug services

8.11 The shortage of alcohol and other drug services became clear to the Committee when we spoke with drug and alcohol service staff in metropolitan, regional and rural areas. Participants acknowledged the significant injection of funds that occurred after the Drug Summit, but pointed to their waiting lists for detoxification and rehabilitation services.[438] As Dr Stephen Jurd of the Herbert Street Clinic told us, 'Currently we are exploding at the seams with voluntary clientele'.[439]

8.12 The Committee was particularly concerned by the challenges faced by rural communities in providing timely and accessible drug and alcohol services. As Ms Didi Killen, Area Coordinator of Drug and Alcohol Services in the Mid West Area told the Committee, drug and alcohol services share the same challenges of service delivery in rural areas as other agencies, such as delivering services over large geographical areas, having to factor in transport, and attracting and retaining appropriately skilled staff.[440] Participants in the New England area also told us about a lack of general practitioners and reliance on outreach. When talking to participants in both these areas we were struck by the poor availability of detoxification services. As Ms Vi Hunt told the Committee:

> Through the New England Area Health Drug and Alcohol Service we have five drug and alcohol teams across the area, all of which provide outreach services. So we do try to provide some services to most towns. As far as other drug and alcohol services are concerned, there is no detoxification unit as such. If clients wish to undergo inpatient detoxification they do it through the public hospitals. We have two non government organisation [NGO] rehabilitation services - one in Armidale and one in Moree. Some NGO facilities provide limited drug and alcohol services, such as the Salvation Army.

436 Submission 26, Illawarra Health, p2

437 Professor Hall, University of Queensland, Evidence, 29 April 2004, p11

438 Ms Diane Paul, Manager, Detoxification Unit, Herbert Street Clinic, Evidence, 4 March 2004, p27; Ms Toni Colby, MERIT Caseworker, Alcohol and Other Drugs Service, Tamworth, Evidence, 24 March 2004, p1

439 Dr Stephen Jurd, Area Medical Director, Drug and Alcohol Services and Addictions Psychiatrist, Northern Sydney Health, Evidence, 4 March 2004, p25

440 Ms Didi Killen, Coordinator, Alcohol and Other Drugs Program, Mid Western Area Health Service, Evidence, 25 March 2004, p24-25

> They tend to be in places like Tamworth and also in Armidale. Once you get out into the smaller towns it is very limited. There are not a lot of services around.[441]

8.13 While some hospitals provide detoxification, we were told that others do not, so people may have to travel some distance to access these services, possibly after lengthy negotiations between drug and alcohol workers and the hospital. On the other hand, we were told that in small communities, general practitioners often have admitting rights whereby they can arrange for someone to receive detoxification.[442] Some rural participants highlighted the need for specific detoxification services, while others sought greater provision of hospital beds specifically allocated for detoxification. They also noted that where hospital detoxification is provided, patients need to be appropriately linked to other drug and alcohol and primary care services to meet their psychosocial needs.[443] Some also noted that hospital based detoxification is less than ideal:

> The hospital experience of detoxification is very unsatisfactory for a lot of our clients because most people can handle the physical withdrawal, but what about the social-psychological factors? We can detoxify our clients from drugs and alcohol but the issue is keeping them off them. It is very unsatisfactory to be put on the general ward of a hospital with other patients with numerous physical complaints and with nursing staff who may or may not have limited experience and expertise in dealing with these clients, and we are looking at a whole range of clinical specialist expertise in dealing with their cravings, their withdrawal symptoms, coming to terms with their grief, loss, remorse and guilt for their lifestyle. There are many multifaceted issues and I find that unsatisfactory when we put our patients in a public hospital in a normal bed.[444]

8.14 Looking at the broader alcohol and drug system across New South Wales, the Committee was told that there is greater provision for illicit drug treatment as opposed to alcohol treatment, perhaps because of the political imperatives of addressing illicit substance misuse and the investment that has flowed through diversion programs targeting that group. Professor Mattick of the National Drug and Alcohol Research Centre, for example, told us that there has been a shift away from funding alcohol services to illicit drugs, despite the substantially greater prevalence of alcohol misuse. He also explained that many detoxification programs around the State were closed some years ago in the mistaken belief that people who were dependent on alcohol could have their needs met through less intensive measures.[445]

8.15 In light of the shortage of services, the Committee is, like several participants, concerned about the capacity of the existing drug and alcohol system to absorb involuntary clients. We are aware that pressure and displacement has already occurred in the voluntary system as a result of diversionary programs such as MERIT. Ms Val Dahlstrom, Area Manager of Aboriginal Health in New England, and other people from the Indigenous community in

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441 Ms Vi Hunt, Area Coordinator, Alcohol and Other Drug Services, New England Area Health Service, Evidence, 24 March 2004, p1

442 Dr Ian Kamerman, General Practitioner and NSW Director, Australian College of Rural and Remote Medicine, Evidence, 24 March 2004, p8

443 Dr Kamerman, Australian College of Rural and Remote Medicine and Ms Colby, Alcohol and Other Drugs Service, Tamworth, Evidence, 24 March 2004, pp8-9

444 Ms Colby, Alcohol and Other Drugs Service, Tamworth, Evidence, 24 March 2004, p8

445 Professor Richard Mattick, Director, National Drug and Alcohol Research Service, University of New South Wales, Evidence, 8 April 2004, p6

Moree spoke of how clients diverted from the court system into treatment took up much needed voluntary services and also had a negative impact on other clients.[446]

The Committee's view

8.16 In this environment of an existing shortage of services, the Committee is concerned that involuntary care might be seen as a prioritisation system, where involuntary clients are simply given higher priority, such that some voluntary clients lose access to the system. Like many inquiry participants, we consider that involuntary care should not be at the expense of voluntary clients, whether by diverting resources away from them or undermining the quality of care they receive. In addition, we believe that in order to operate effectively, to achieve optimal outcomes for those subject to care and to protect their rights, involuntary care needs to be well resourced in its own right.

Recommendation 30

That the Government provide additional resources to fund the proposed system of involuntary care for people with severe substance dependence.

Where should involuntary care be provided?

The absence of demand data

8.17 Unfortunately, there is very little information available on which to estimate the numbers of people who might be placed in care. While the Committee identified at least 45 people being placed under an inebriates order in the last three years, no participants were able to offer a sound estimate of demand that might arise under new legislation. Representatives of the Kirketon Road Centre indicated that they would use involuntary care in extremely rare circumstances: out of 150,000 attendances at their service (whose clientele is generally people with an illicit substance dependence) in the last three and a half years, there were only three people for whom they believed involuntary care would have been appropriate.[447] By contrast, Mr George Klein of the Centre for Drug and Alcohol Medicine at Nepean Hospital conservatively estimated that 3% of his service's caseload could be suitable.[448] Dr Stephen Jurd had a 'stab in the dark' at 100 to 200 people a year across the State.[449] Thus participants' estimates were rough and varied significantly.

446 Ms Val Dahlstrom, Area Manager, Aboriginal Health, New England Area Health Service and Mr Faulkner Munroe, Manager, Byamee Homeless Persons Service, Evidence, 24 March 2004, pp25-26

447 Dr Hester Wilce, Medical Practitioner, Kirketon Road Centre, Evidence, 7 April 2004, p5

448 Mr George Klein, Behavioural Scientist, Centre for Drug and Alcohol Medicine, Nepean Hospital, Evidence, p56

449 Dr Stephen Jurd, Northern Sydney Health, Evidence, 4 March 2004, p24

Which facilities?

8.18 Although the Committee sought the views of participants on the most appropriate environment in which to place people under an order, no obvious solution emerged. While many called for a system of involuntary care, few indicated they would be willing to be the ones to provide it.

8.19 In the NSW Government submission, NSW Health stated that, given the necessity for withdrawal of this client group to be managed by health professionals, there are four options for where care might occur: a specialist medicated detoxification facility; a general hospital bed; an outreach detoxification service to non government agencies funded through the Supported Accommodation Assistance Program (SAAP); or a designated purpose built facility.[450] Given the evidence presented in relation to the *Inebriates Act*, the Committee does not consider that mental health facilities are an appropriate option.

8.20 There was broad agreement that any facilities chosen would need to be locked and equipped to provide the medical care required during the period of withdrawal and stabilisation, and to meet other acute care needs. Similarly, the services would need to have the appropriate alcohol and other drugs skills base to assist the person to make the most of the opportunity to gain insight and engage in a process of change. In addition, the services would necessarily have the capacity for the critical steps of actively linking people to services, as well as providing follow-up, which are core activities in the Committee's model.

8.21 There was less agreement among participants as to whether involuntary patients should be integrated with voluntary clients, or if they should have their own service, perhaps in purpose built facilities. Participants from Moree argued strongly for stand-alone facilities, having seen the problems arising from placing diversion clients with voluntary clients in a rehabilitation service, with the former undermining the care and motivation of those who choose to be there.[451] A number spoke of involuntary clients sometimes having disruptive behaviours, challenging the motivation of voluntary clients, and sometimes leading them astray.[452] Associate Professor Paul Fanning pointed to the need to adequately provide for the 'disinhibition and antisocial behaviour during the acute and recovery stage' likely to characterise many of the people who might be placed under the proposed involuntary care legislation.[453]

8.22 When we asked people working under the system in Victoria, where people receive compulsory treatment in a regular detoxification service with other clients, participants noted the beneficial effect that voluntary clients can have on involuntary ones. They also argued that many voluntary clients are 'coerced' into being there, for example by family members, case managers and so on, so that the term 'voluntary' client was somewhat artificial.[454] When we

450 Submission 47, NSW Government, p25

451 Mr Bill Grose, Community member, Evidence, 24 March 2004, pp34-35; Ms Dahlstrom, New England Area Health Service, Evidence, 4 June 2004, p9

452 Ms Diane Paul, Herbert Street Clinic, Evidence, 4 March 2004, pp8-9

453 Email from Associate Professor Fanning, Area Director, Mid Western Area Mental Health Service, to Senior Project Officer, 1 June 2004, p1

454 Evidence, 28 April 20041

asked NSW Health representatives whether they thought co-location was appropriate, they indicated that they did not have a definitive view but that it would be possible do so.[455]

8.23 Participants also had views on whether detention and care should be provided locally. A number of participants such as the NSW Section of Addiction Psychiatry envisaged a system of 'two or three small specialised tertiary drug and alcohol treatment units' developed specifically for people under the new legislation.[456] On the other hand, one of the problems with the *Inebriates Act* was that people were necessarily sent a long way from home. Rural and regional participants argued strongly for a localised approach as far as possible, so that people did not have to leave their support base and cope with reintegration when they returned.[457]

8.24 The Network of Alcohol and Other Drugs Agencies (NADA) suggested that a new, specialised service model, with appropriate staffing, be established specifically to provide medical care in accordance with the Committee's proposed legislation:

> NADA proposes that the initial period of treatment should take place in a medical setting, in order to address the health needs of the person as they go through detoxification. To this end it is believed that the appropriate initial treatment setting could be an Intoxicated Persons Service, attached to a Hospital, that can conduct the initial assessment of the person's condition, and provide medical interventions if needed and ongoing treatment if required. This service should also have the power to detain people for compulsory treatment.[458]

8.25 In the NSW Government submission, NSW Health rightly states that the likely cost of any model will depend on the number of people within the ambit of any new legislation, and that a cost-benefit assessment of options will be required.

8.26 While the Committee expects that the use of new legislation will be significantly higher than for the *Inebriates Act* in recent years, we have no reliable estimate of demand. We consider that gaining a reasonable estimate will be an essential first step in planning the implementation of our recommended model.

8.27 While acknowledging the difficulties arising from co-locating voluntary and involuntary clients, the Committee considers that this is probably the only feasible option at this stage. In the absence of demand data to justify the establishment of a specific service, and in light of the very reasonable concern that people be treated close to home, the Committee favours a localised model. We believe that it is alienating and disempowering enough to be put into care, but to be sent a long way from home would make it more so.

8.28 Given the agreed need for medical care and specialised drug and alcohol expertise, we consider that detoxification services are the only real option for where people might be placed. While as we have already indicated, detoxification units do not exist in many rural areas, they at least have reasonable coverage across the State, and we do not consider that hospital-based

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455 Mr David McGrath, Acting Deputy Director, Centre for Drug and Alcohol, NSW Health, Evidence, 29 April 2004, p18

456 Submission 50, NSW Section of Addiction Psychiatry, p2

457 Ms Vi Hunt, Area Director, Drug and Alcohol Services, New England Area Health Service, Evidence, 24 March 2004, p10; Mr Lloyd Duncan, Byamee Homeless Persons Service, Evidence, 24 March 2004, p40

458 Submission 29, Network of Alcohol and Other Drugs Agencies, p12

detoxification would be appropriate for the purpose of involuntary care. In order to ensure reasonably local access, it may be appropriate for perhaps two detoxification services per area health service (with their new boundaries as at August 2004) to be designated for the purpose of receiving people into involuntary care, while also providing for their voluntary clientele. Keeping rural communities in mind, and given their historically greater demand under the *Inebriates Act*, the number of facilities receiving people in rural areas may need to be greater.

8.29 The Committee acknowledges the challenges of using already existing detoxification services and co-locating involuntary and voluntary clients. In the first instance, provision would need to be made for locked environments, with consideration given to the logistics of how to physically co-locate both detained and voluntary patients. Providing secure facilities would necessarily require capital funding. Such a system would also require careful consideration of occupational health and safety issues, staff training, and achieving cultural change among providers of voluntary services. Provision would also need to be made to ensure that key elements of linking clients to services, supporting them to access guardianship, and providing assertive follow-up, could all be provided. This will be made more complicated as some detoxification services are non government agencies and some are funded by the Commonwealth.

8.30 While she did not disagree with using existing detoxification services, Dr Ferguson, who works in such a service at Rozelle and Concord Hospitals, warned of the practical challenges of integrating an involuntary system into existing drug and alcohol services:

> How do we do this in the current withdrawal services … ? Within the government sector, the hospitals where we run withdrawal services, we would not have the facilities to contain anybody. We don't and haven't for 40 years operated on that sort of an approach. Staffing would have to change; functionally it would have to change, it would have to be contained and there would have to be police back-up to bring people back, so in fact you are talking about a major upgrade of facilities to contain what could be anything from a few people a year to many people, so in fact the practical application of a locked model is very hard and the costs are quite high.[459]

8.31 A number of other participants such as Dr Jurd emphasised that in order to achieve the necessary cultural change in 'vigorously voluntary' drug and alcohol services, both resources and leadership at all levels will be required.[460] Dr Patfield warned of the occupational health and safety issues, the high costs associated with running a contained unit, and the difficulties of attracting staff to undertake such work.[461]

8.32 Other participants such as Dr Mark Doverty of Southern Area Health Service and the North Coast Regional Coordination Management Group pointed to the need for further consultation to occur in relation to demand for involuntary treatment and the best services to respond. Dr Doverty stated in his submission:

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459 Dr Joanne Ferguson, Staff Specialist Psychiatrist, Drug Health Services, Rozelle and Concord Hospitals, Evidence, 4 June 2004, p24

460 Dr Jurd, Northern Sydney Health, Evidence, 4 June 2004, p14

461 Dr Martyn Patfield, Consultant Psychiatrist, Medical Superintendent and Director of Acute Services, Bloomfield Hospital, Evidence, 4 June 2004, p25

> … modern alcohol and drug detoxification units across the state are not designed for the involuntary treatment of such patients. This is an issue that requires debate, research and deliberation. There does not appear to be a ready made answer or solution to this problem, the scale of which is not accurately known. It would be valuable to conduct a statewide review/consultation process to determine the possible levels of and likely use of involuntary treatment centres, and the most appropriate deployment of such centres and associated resources. This is indeed a very complex matter.[462]

8.33 We are also mindful that the model of care we are recommending is more holistic and less clinical than might ordinarily be provided in a detoxification service. In particular, we envisage a need for 'welfare' functions associated with referral to other services such as housing and supported accommodation and strong follow-up. As we have stated, these will require resourcing: for example, we understand that there is little capacity for assertive follow-up in drug and alcohol services at present.[463]

8.34 Given these considerations, the Committee believes that further work needs to be done before the most appropriate service arrangements can be determined, and we consider that this would best be done by the Centre for Drug and Alcohol in NSW Health. First, a reasonable estimate of demand for involuntary care, using the essential criteria we have stipulated, is required. In addition, a scoping study of all detoxification services in the State would be necessary to inform the decision as to where people should be detained and treated. Such a study should also identify the necessary capital work to be done to provide for locked environments. This work should then form the basis for a decision as to the most appropriate service arrangements for the provision of involuntary care. The Committee understands that a statewide review of current levels of alcohol related harm and the need for treatment is underway and will form the basis for the *NSW Drug Treatment Services Development Plan 2006-2015*.[464] It may be appropriate and valuable for the proposed survey and scoping study to be linked to this review.

8.35 The Committee also considers that, subject to a better estimate of demand, there may be some merit in NADA's proposal for a purpose built unit, perhaps located in the inner city where it might offer a range of other medical services to intoxicated people who would otherwise be sent to hospital emergency departments, which we understand to be quite problematic. We anticipate that there may be greater demand for involuntary care in the inner city, given the relatively high concentration of homeless people in that area. This service could also detain a person immediately where necessary, as is discussed in the following section. Given our strong preference for a localised approach, we do not, however, consider that such a unit should offer a statewide service. We encourage NSW Health to consider this option as an inner-Sydney service.

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462 Submission 34, Southern Area Health Service, p3

463 Ms Andrea Taylor, past Deputy Director, Ryde Community Mental Health Service and present Manager, Quality and Risk Management, Royal North Shore and Ryde Health Services, Evidence, 7 April 2004, p22; Mr Larry Pierce, Director, Network of Alcohol and Other Drugs Agencies, Evidence, 4 June 2004, p9

464 NSW Government, *Outcomes of the NSW Summit on Alcohol Abuse 2003: Changing the Culture of Alcohol Use in New South Wales*, May 2004, p55

Recommendation 31

That NSW Health immediately undertake:

- a detailed survey of all drug and alcohol services in New South Wales, and facilities where people are currently detained under the *Inebriates Act*, to estimate the likely annual demand for involuntary care
- a scoping study of all detoxification services in New South Wales to determine where people could be detained and treated, and identify the work necessary to provide for locked environments.

This information should then be used to determine the most appropriate service arrangements for the provision of involuntary care.

Recommendation 32

That involuntary care be provided according to a localised model making use of existing medical detoxification facilities.

Recommendation 33

That in light of the information gathered through Recommendation 31, NSW Health should consider the potential for a purpose built facility in the inner city.

Aboriginal communities

8.36 The Committee recognises the need to develop an appropriate service model for Aboriginal communities, as we did in the previous chapter when discussing the decision making process in relation to involuntary care. The unique and complex problems associated with substance use in many Indigenous communities, and the sensitivities associated with detention of Indigenous people, are broadly understood.

8.37 All the Aboriginal community representatives we spoke with, including the peak body for Aboriginal Medical Services, the Aboriginal Health and Medical Research Council (AHMRC), called for more community controlled drug and alcohol services.[465] For example, Ms Val Dahlstrom, Area Manager of Aboriginal Health in New England called for an enhancement to existing residential rehabilitation programs, and the establishment of a 'half way house' to support the transition back to community living. She also called for better access to detoxification.[466]

8.38 A number of participants also noted that unless an initiative is owned by the Aboriginal community it will not succeed. Taking a broader perspective on the problem than short term harm reduction, Ms Dahlstrom told the Committee about a strategy she was hoping to establish in a small community:

465 Tabled Document No 7, p5

466 Ms Dahlstrom, New England Area Health Service, Evidence, 24 March 2004, p24

> [We are] trying to develop a community response, so that we have got a built in support system in the community for those people who consistently indulge, for want of a better word, in domestic violence, drug and alcohol abuse and child abuse, and I guess that is the reason why we are actually looking at it as a community, expecting the community to look at these issues to try and do something about it because … no government agency can get in and the people who make a difference are the people who are actually in there. Police cannot make a difference, doctors cannot make a difference, we cannot make a difference … we need to … get community members there to take responsibility for what is happening in their towns.[467]

8.39 Participants said that ideally, Aboriginal people are catered for through community-controlled services. As Mr John Williams of the AHMRC stated, 'The most efficient, cost effective, outcome oriented and appropriate manner is through the community itself, properly resourced and trained.'[468] However, there was a recognition that Aboriginal-specific services for involuntary care are not feasible, both because of the relatively small size of the target group, and the shortage of appropriately trained Aboriginal staff. Mr Williams told the Committee that area health services and mainstream services are better resourced to carry out many health services:

> We feel strongly that the Aboriginal community should take responsibility and we think the best way to do that would be through community-controlled health services associated with [Aboriginal Medical Services]. But every Aboriginal person has the right to go to mainstream services, and many choose to do so. I do not think the duplication of processes is a good idea; I think they should be complementary … People feel much more at home with an Aboriginal Medical Service. I think the analogy would be extended to these sorts of centres, not acting in a vacuum but working closely in partnership. Access is the next stage. We must work with the area health service, which has the expertise and the professional workers whom we can tap into and refer issues to.[469]

8.40 Dr Matthews of NSW Health also emphasised a partnership approach, with agreements between area health services and other agencies and community-controlled organisations. He saw Aboriginal Medical Services (AMS) and Land Council involvement as essential.[470]

8.41 The Committee was told that if Aboriginal people are to receive care in mainstream services, a culturally appropriate approach to care is essential. For example a greater emphasis on family involvement would be required.[471] Along with the creation of partnerships, other strategies that were identified as enabling cultural appropriateness included the employment of Aboriginal staff, cultural awareness training for non-Aboriginal staff, monitoring, links to supportive networks of AMSs and community organisations, and ensuring that services are 'hinged within an Aboriginal health context'.[472] Participants also suggested that the use of

467 Ms Dahlstrom, New England Area Health Service, Evidence, 4 June 2004, p21

468 Mr John Williams, Senior Policy Officer, Aboriginal Health and Medical Research Council, Evidence, 27 November 2003, p14

469 Mr Williams, Aboriginal Health and Medical Research Council, Evidence, 27 November 2003, p14

470 Dr Richard Matthews, Acting Deputy Director General, Strategic Development, NSW Health, Evidence, 11 December 2003, p25

471 Ms Louise Peckham, Aboriginal Health Education Officer, Alcohol and Other Drugs Services, New England Area Health Service, Evidence, 24 March 2004, p20

472 Tabled Document No7, p6

Elders to watch over people while in care,[473] and liaison with workers from the Aboriginal community would be important strategies. In addition, family and community members will need support and liaison to understand the purpose and process of involuntary care.[474]

8.42 The Committee considers that in implementing the model of involuntary care, NSW Health will need to recognise and incorporate the needs of Indigenous people, in consultation with Indigenous communities.

Recommendation 34

That in implementing the Committee's proposed model of involuntary care, NSW Health recognise and incorporate the needs of Indigenous people, in consultation with Indigenous communities.

Culturally and linguistically diverse communities

8.43 Thought also needs to be given to implementation of the proposed model in non-English speaking communities. The Community Relations Commission's submission indicates that there are some communities, for example in the Maori and other Islander communities, 'where alcohol problems are considered to be endemic and a significant anti-social issue affecting community harmony and family relationships'. It also notes that use of alcohol is taboo in some cultures, such that significant substance use problems may be denied by communities.[475] The Committee also understands that detention and involuntary care may be highly traumatic for people who have been subject to state-sanctioned torture or trauma. In any case, it is vitally important that anyone subject to involuntary care and their family fully understand what will happen.

8.44 The Community Relations Commission indicated that it will be important to ensure that support is available to family members when a person is placed in involuntary care, and that they are adequately informed about what will happen to the person while detained. They suggested that provisions should be made to 'ensure that the person has access to culturally appropriate community support services and bilingual medical services.'[476]

8.45 The Committee considers that the needs of culturally and linguistically diverse communities will also need to be addressed during implementation.

473 Ms Leonie Jefferson, Senior Aboriginal Drug and Alcohol Counsellor, Northern Rivers Area Health Service, Evidence, 27 November 2003, p12

474 Ms Hunt and Ms Peckham, New England Area Health Service, Evidence, 24 March 2004, p20

475 Submission 12, Community Relations Commission, p2

476 Submission 12, Community Relations Commission, p2

Recommendation 35

That in implementing the Committee's proposed model of involuntary care, NSW Health recognise and incorporate the needs of culturally and linguistically diverse communities, in consultation with them.

Where should people be placed in the short term?

8.46 According to the decision making process we have recommended, a person may be detained on the certificate of a medical practitioner, but this may only continue subject to a further medical examination and a decision as to whether the person is to be subject to involuntary care. As established in the previous chapter, this medical examination must only take place once a person is no longer intoxicated. We envisage that once a person is examined and determined by a medical practitioner to meet the four criteria for involuntary care, the person is to be immediately taken to a medical detoxification facility. The Committee was advised that specialist detoxification units generally do not admit people while they are intoxicated because they can have a significant impact on other clients.[477]

8.47 Representatives of NSW Health emphasised the need for the Committee to consider where a person is to be placed during this window period. Understandably, there was a concern that hospital beds already in demand not be used for 'holding' someone while they sober up.[478]

8.48 Given the tight targeting of the proposed legislation, which requires the presence or threat of serious harm, many people for whom an order is sought will require acute care, and where this is the case, a hospital is an appropriate environment. We have also suggested that where people do not require urgent detention, they should not be immediately detained. However, some people for whom an order is sought may require detention in order to prevent them from further consuming alcohol or drugs, so that they can be examined. In addition, people generally require monitoring by someone with appropriate medical knowledge (although not necessarily a doctor) as they sober up and enter withdrawal. Ms Leonie Jefferson, an Aboriginal drug and alcohol counsellor, explained to the Committee:

> Hospitals are not really a suitable place unless they are extremely ill. A more appropriate place is one that is designed for people to sober up and that has a staff of qualified people to oversee how they are going. Sometimes they might be ill and you are not sure, so you need to monitor that. If they are going to fit, you have to get them to the appropriate care. You have to be able to do all that sort of stuff. You cannot just put them in a place with unskilled or unqualified people and leave them there.[479]

8.49 As established in the previous chapter's section on the *Intoxicated Persons Act*, there are few options as to where person may be placed for this purpose, not all of which currently enable detention. The first is police cells, which would require the provision of medical or nursing assessment during the period of detention. Other alternatives include SAAP funded intoxicated persons services, mental health facilities, detoxification facilities and other services

477 Submission 47, NSW Government, p24

478 Ms Noort and Mr McGrath, NSW Health, Evidence, 29 April 2004, pp21-22

479 Ms Jefferson, Northern Rivers Area Health Service, Evidence, 27 November 2003, p5

with drug and alcohol expertise such as residential rehabilitation services. In rural areas, the absence of appropriate facilities becomes even more problematic, and may also require transport to be arranged.

8.50 The Committee agrees that this issue will need to be resolved in order for the proposed legislation to work effectively, not least to ensure the safety of those for whom involuntary care is considered. We agree that hospital beds should, as far as possible, not be used for any purpose other than acute care. We suggest that the most appropriate way to resolve this issue would be through the development of area protocols, such as those for the management of intoxicated persons. In many cases those already existing agreements could address this need with minimal adjustment.

Recommendation 36

That NSW Health lead a process of developing interagency protocols at the area health service level about the management of persons for whom involuntary care is being determined, during the intoxication phase.

Transport

8.51 Earlier in this chapter we stated our strong preference for a localised model of involuntary care, given the concern of rural participants that people should be treated close to home. Nevertheless, given the absence of appropriate facilities in many geographical areas, we acknowledge that the proposed model is likely to entail significant travel for some. In Chapter 3 we noted that current arrangements under the *Inebriates Act* create substantial practical problems for service providers and police, who are often required to transport the person to hospitals a significant distance away. If a person has acute care needs we envisage that they will need to be transported by ambulance.

8.52 Assistant Commissioner Bob Waites of NSW Police told the Committee that transport is a major issue for police, in relation to people who are in custody and particularly people who are subject to the *Mental Health Act*. He feared that under a new Act the problem would expand, and explained why transport creates such difficulties for police:

> The great difficulty is that most country towns have virtually one vehicle working at any one time. Obviously, when somebody has to be transferred to a larger centre an immense distance away, you cannot use that vehicle because you would then have no police resources to look after the general issues of concern to the community. So what has to occur is that, when that vehicle is finishing its shift and the next crew start, they dispatch that vehicle on an overtime basis. So we are then paying time and a half and double time to convey people immense distances, sometimes up to six and twelve hours … So obviously there is a reluctance at the local level - whether it be by the sergeant who is running the local station, or the local inspector - to be involved in that if they can avoid it, because of the budgetary cost of it, because of the likelihood of injury to officers and damage to resources, and in some cases the fear of the futility of

> it because in some cases where people are transported to a centre they are assessed and released and are back in the community two or three days later.[480]

8.53 The Committee is aware that the role of police in transporting patients is currently under discussion as part of NSW Health's review of the *Mental Health Act*.[481]

8.54 Likewise, participants such as the North Coast Regional Coordination Management Group and Mr Owen Atkins highlighted similar issues around resourcing, staff time and occupational health and safety when drug and alcohol or other workers escort patients in rural areas.[482]

8.55 In light of these important concerns, the Committee does not take for granted the capacity for the police or other services to transport people subject to involuntary care. We believe it important that NSW Health and NSW Police come to a formal agreement regarding this issue. It may also be helpful for specific budgetary provision to be made for transport for this purpose.

Recommendation 37

That the interagency agreement on respective roles and responsibilities under the proposed legislation referred to in Recommendation 6 address transport of people under an involuntary care order. In determining this responsibility, consideration should be given to establishing a budget specifically for the purpose of funding such transport.

Evidence-based services and treatment guidelines

8.56 At the beginning of this chapter the Committee identified three key elements essential to an effective service framework for involuntary care. The first of these is evidence-based services and treatment guidelines.

8.57 In previous chapters the Committee established the consensus among inquiry participants for an evidence-based approach to involuntary care. Participants felt very strongly that when a person is subject to coercion they have the right to high quality services tailored to their individual needs. Involuntary care is to be used as an opportunity to do the most good for the person. This position was reflected in the Government's submission to the inquiry, which noted the evidence-based policy underpinning drug and alcohol initiatives, and suggested as a key principle to be built into the proposed legislation:

> A right to treatment and quality treatment should be ensured, and there should be an evidence base to support the treatment provided.[483]

480 Assistant Commissioner Bob Waites, Commander, Greater Metropolitan Region and Corporate Spokesperson, Alcohol related Crime, NSW Police, Evidence, 27 November 2003, p22

481 NSW Health, *Review of the Mental Health Act 1990 – Discussion Paper 2: The Mental Health Act 1990*, July 2004, pp13-14

482 Submission 16, North Coast Regional Coordination Management Group, p3; Submission 2, Mr Owen Atkins, Homeless Persons Support Team, Narrabri District Community Aid Services, p3

483 Submission 47, NSW Government, p23

8.58 The Committee ruled out the possibility of a compulsory treatment system aimed at rehabilitation, on the basis of the absence of evidence to indicate that this would be effective. By contrast, our rationale for involuntary intervention for the purpose of protecting health and safety was that when harm is present, the capacity to benefit the person through medical care is self-evident. We have stipulated that involuntary care is to be provided in an appropriate setting where medical care can be delivered. Such care will necessarily make use of evidence-based, high quality withdrawal, drug and alcohol and other medical care.

8.59 In keeping with this framework, a number of participants suggested that the legislation should be complemented by guidelines to ensure the quality of care provided when people are subject to the Act. The NSW Government submission stated:

> NSW Health has suggested that implementation would benefit from guidelines concerning the nature of treatment provided under compulsory treatment orders.[484]

8.60 The Committee understands that guidelines are used in many clinical areas to ensure the uniform implementation of best practice and thereby to maximise positive outcomes for patients. Guidelines, such as those for the management of people with substance dependence, are necessarily evidence-based. The Committee proposes that guidelines taking a more holistic and multidisciplinary approach and setting out the pathway of care for involuntary clients will be very important to implementing the legislation. The guidelines should operationalise, amongst other things, the key elements of involuntary care that we have established, that is, comprehensive assessment and the development of a treatment plan, referral to appropriate services, and assertive follow-up. Ms Tonina Harvey of Northern Sydney Health also noted how important it was to engage families and carers in the process of treatment, both in order to support them in their own right, and to empower them in caring for their loved ones:

> … guidelines need to be established for the care and management of people under Inebriates orders and their families and carers because I believe they get left out of the equation a lot. They certainly need to be supported through this process if the aim is to make these patients voluntary and to have them supported within a home environment, I think we need to address those issues.[485]

8.61 The guidelines would also articulate the rights and responsibilities of staff in relation to detention of clients and providing treatments without consent.

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484 Submission 47, NSW Government, p17

485 Ms Tonina Harvey, Area Director, Drug and Alcohol Services, Northern Sydney Health, Evidence, 4 March 2004, p27

Recommendation 38

- That in order to ensure quality of care and optimal outcomes for those subject to the proposed legislation, NSW Health develop and publish guidelines for the treatment of people in involuntary care. The guidelines should address:
- the key elements of involuntary care, that is, comprehensive assessment and the development of a treatment plan, referral to appropriate services, and assertive follow-up
- how families and carers are to be engaged in the process of involuntary care
- the rights and responsibilities of staff.

Integrated service delivery

8.62 The second element of the proposed service framework is a strategy to ensure integrated service delivery or coordinated care.

8.63 Many participants identified the need for coordination and integration in relation to those placed in involuntary care. In previous chapters the Committee discussed this imperative in relation to people with complex needs and antisocial behaviour. The same principle applies to those who require short term involuntary care. Professor Webster warned of the danger of too much focus on detoxification services and acute care, arguing that the whole system needs to respond to the client group of people with severe substance dependence. He also noted that the success of the Committee's proposed model will rest on providing coordinated, joined up services and ensuring a 'chain of care'.[486] Similarly, participants such as Dr Victor Storm highlighted the multidimensional nature of people's needs, such that they might have other physical and mental health problems and require housing and other support services:

> There is not much future if you have nowhere to live, even if you deal with all your addiction problems. There are other elements that are part of the social infrastructure that are required to assist people who have already had a pretty disastrous period in their life and we need to integrate all those in the recovery.[487]

8.64 Echoing the Committee's concern that involuntary care be used as an opportunity to do the most good for a person, Ms Frances Rush, a Regional Manager with the Office of the Public Guardian put it well when she stated:

> In that sense it is about a web of care. It is not just a case of containing someone and then releasing them. It is trying to provide an integrated service across where they live, their communities and families … [488]

8.65 Participants also noted that follow-up and after care are important aspect of service coordination and integration. In particular, they emphasised the importance of linking clients

[486] Professor Webster, NSW Expert Advisory Committee on Drugs, Evidence, 4 June 2004, p8

[487] Dr Victor Storm, Clinical Director, Central Sydney Area Mental Health Service, Evidence, 27 November 2003, pp46-47

[488] Ms Frances Rush, Regional Manager, Office of the Public Guardian, Evidence, 7 April 2004, p50

to general practitioners and case managers. Professor Webster also pointed to the potential in the idea of a 'nominated person' or mentor to support, watch over and advocate for the person over time:

> That idea was having a nominated person who could take some special relationship with the person or become, in a sense, the person's "parent" … someone who would ensure that the person would get access or be followed up or get proper nourishment.[489]

8.66 The nominated person would not so much be a professional as a community member, for example an Elder in the Aboriginal community. He or she and the person with the substance dependence would mutually agree on this supportive relationship, so that in a sense, each would be accountable to the other.

8.67 Larry Pierce of NADA told the Committee that the building blocks for integrated service delivery in relation to drug and alcohol treatment already exist, but that the Government's framework has not yet changed the way agencies actually work together. As we noted elsewhere in our report, the importance of overcoming service boundaries and providing a 'joined up' service response is increasingly recognised by government, but achieving it is no easy task:

> If you look at what has been happening in New South Wales since the 1999 Drug Summit you will see that a framework is very much in place. The overall policy deems that alcohol and drug problems are a whole of government issue that affects not only the police or the Attorney General's Department but also housing, social welfare, education, family services and so on. There is already a clear framework for the way forward … What has not happened and what needs to happen is the implementation of an integrated planning process between NSW Health, DOCS, DADHC, Juvenile Justice, the Police and the Attorney General's Department, just to name the major players. In many ways, particularly from a non government point of view looking in, those agencies are still silos that have their turf, and within that there is turf within turf - for example, the alcohol and drug system and the mental health system. In reality, practice and organisational changes are not up with this very good government policy and framework. The framework is there and we know what the policy and plans should look like … But the reality is that departments and program areas are still too siloed.[490]

8.68 In the previous chapter we recommended that the Government develop an interagency agreement setting out the respective roles and responsibilities of relevant agencies under the proposed legislation. The Committee considers that agreement at the policy level will be fundamental to the success of the new legislation, but that measures must also be taken at the local level to ensure cross-agency coordination and collaboration. We suggest that local protocols at the area health service level be developed for this purpose. These will be based on the statewide agreement, but will allow for local variations and also establish the role of non government agencies. We also consider that the treatment guidelines recommended in the previous section, which are necessarily focused on the care that people receive, should reflect the need for interagency collaboration around individual clients.

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489 Professor Webster, NSW Expert Advisory Committee on Drugs, Evidence, 4 June 2004, p18

490 Mr Pierce, Network of Alcohol and Other Drugs Agencies, Evidence, 27 November 2003, p60

Recommendation 39

That interagency protocols be developed in each area health service setting out the roles and responsibilities of government and non government agencies in relation to involuntary care.

Recommendation 40

That the treatment guidelines to be developed by NSW Health in Recommendation 38 also reflect the need for interagency collaboration.

Investment in specific services

8.69 The third and final essential element in a new service framework for involuntary care is investment in specific services. Earlier in this chapter we highlighted the need for greater investment in detoxification services, especially if they are to be the facilities where involuntary clients are placed. Participants identified a number of other service areas where investment is critical if the proposed framework of involuntary care is to be effective. Significantly, several of these focused on people with alcohol related brain damage.

Neuropsychological testing

8.70 At various points in this report the Committee has stipulated that while in involuntary care, people must undergo a comprehensive assessment, including, where appropriate, neuropsychological assessment of their cognitive ability. The Committee was advised that a proper assessment is necessary to establish the grounds for guardianship for those who require it. In addition, as Ms Harvey told us, for people with less severe impairment, a diagnosis of brain damage can actually assist a person's recovery:

> There are degrees of damage … If you can measure the degree of damage and work with a person's deficit it gives them something tangible to work with. I have seen significant life changes made by people who have been diagnosed with a brain injury who can say, "It is not just me; maybe there is something I can do." That is a big relief for the person and his or her family because often they blame the individual. That gives them something is hang to on and the ability to go forward.[491]

8.71 Dr Jurd explained that a diagnosis also enables treatment to be tailored to the person's needs. While a person without brain injury can be given lots of information and use therapies focused on cognitive skills, people with cognitive disability will need to be steered down a 'slower stream' using modified psycho-social and other treatment tools.[492]

8.72 Despite the benefits of neuropsychological testing, Dr Jurd and Ms Harvey indicated that it is very difficult to access, and that there is a resistance to using it routinely because it is expensive and arduous for both the person doing the testing and the person being tested. Associate Professor Fanning in the Mid Western Area Health Services noted that there are

491 Ms Harvey, Northern Sydney Health, Evidence, 4 March 2004, p14

492 Dr Jurd, Northern Sydney Health, Evidence, 4 March 2004, p14

particular problems in accessing these skills in rural areas, and forewarned the Committee of difficulties in ensuring these assessments within the statutory time limits we have proposed.[493]

8.73 The Committee considers that given the important place we are envisaging for neuropsychological testing in the provision of involuntary care, it will be vitally important that these services are available. We recommend that NSW Health develop a strategy to enhance the availability of these services across the State. It may be appropriate that practitioners with neuropsychological skills are 'flown in' to rural areas when required. We understand that in Victoria, a non government agency, ARBIAS Acquired Brain Injury Services, is contracted to provide preliminary neurological examinations and full neuropsychological assessments for people with brain injury on a consultancy basis.[494]

Recommendation 41

That NSW Health develop a strategy to ensure the availability of neuropsychological testing services for people subject to involuntary care.

Programs for people with alcohol related brain injury

8.74 A number of participants called for the reinstatement of drug and alcohol treatment models specifically designed for people with alcohol related brain injury, such as the one that formerly operated at Rozelle Hospital. Ms Harvey, who used to work in that program, explained that it was staffed by a multidisciplinary team comprising psychiatrists, nurses, nurses' assistants, welfare officers and occupational therapists.[495] The model responded to the poor insight, motivation and learning skills that are typical of those with alcohol related brain damage, providing not just drug and alcohol treatment but also living skills development and intensive support. Ms Harvey told the Committee:

> We had two alcohol related brain damage units dealing with people with mild to moderate damage. A high percentage of people going through the program were subject to inebriates orders. Often they were on an order for the first three months of treatment. Some left after three months of treatment and some stayed longer because they felt they needed to … It was a highly effective program because there were options available for people to be managed according to their needs. They came into detoxification on an inebriates order, and if they were chaotic and absconding they would go to the acute admission ward for a short period and be dealt with by drug and alcohol liaison people. When they settled down in their withdrawal they had a mental state examination and it was determined whether they had any alcohol related brain damage. A recovery program was then developed for them.[496]

8.75 The Committee was told that while the Rozelle program achieved reasonable outcomes, it was expensive to run, and was wound down in the context of a broad shift of funding away from

493 Email from Associate Professor Fanning, Area Director, Mid Western Area Mental Health Service, to Senior Project Officer, 1 June 2004, p1

494 What is ABI and ARBIAS, *http://www.arbias.org.au/arbias.htm*

495 Ms Harvey, Northern Sydney Health, Evidence, 4 March 2004, p24

496 Ms Harvey, Northern Sydney Health, Evidence, 4 March 2004, p12

alcohol and towards illicit drugs. Alluding to the 'moral' dimension that can affect policy in this area, or perhaps just the lack of priority afforded to chronic alcoholism, Dr Jurd told the Committee, 'we do not spend that kind of money on alcohol dependent people'. Given that this treatment model is 'rehabilitative' in nature, we believe it would be appropriately resourced by NSW Health. We note the significant resources channelled towards rehabilitation of people with traumatic brain injury, which stand in stark contrast to those directed towards this group.

8.76 In terms of provision of such services, one mechanism is the use of a consultancy service providing specialist support to mainstream treatment and other service providers who have clients with acquired brain injury. This model is operating in Victoria through the non government agency ARBIAS. The service enhances the capacity of mainstream service providers by educating them on how to tailor their services to people with brain injury, for example, by providing a structured environment, reducing demands on cognitive functioning and dealing with challenging behaviour. When we visited Victoria we heard more about this approach from Ms Robin Fisher, Manager of Drug Treatment Service Operations with the Department of Human Services:

> … it is about what is appropriate within the alcohol and drug service; what sorts of skill sets our alcohol and drug clinicians need to have in order to be sensitive to the different sorts of presentations and how we need to modify our services to ensure that we are embracing those clients and they are not being rejected simply because they are seen as being too difficult. I think we have made a real breakthrough in that area in the past two or three years.[497]

8.77 The Committee sees strong potential in a model of this nature as it would be much more cost effective than a purpose built facility, and would potentially benefit a greater number of people across the State. The consultants would resource and train detoxification and treatment teams and a broad range of other service providers. They would also prove an important resource for family members and carers. If this consultancy service were to target drug and alcohol treatment and other health services, we believe it would be appropriately funded by NSW Health. If it also served as a resource to agencies providing longer term care and support to people as a result of their disability we consider it appropriate that the service be jointly funded by NSW Health and the Department of Ageing, Disability and Home Care (DADHC).

Recommendation 42

That NSW Health re-establish specific treatment and living skills development services for people with significant cognitive impairment arising from their substance use.

[497] Ms Robin Fisher, Manager of Drug Treatment Service Operations, Department of Human Services, Evidence, 28 April 2004, p23

Recommendation 43

That NSW Health and the Department of Ageing, Disability and Home Care establish a consultancy service providing specialist support to mainstream treatment and other service providers to enable them to work more effectively with people with alcohol related brain injury.

Supported accommodation for people with alcohol related brain injury

8.78 The case studies of Esther on page 57 and Margaret on page 94 highlight the gap into which people with alcohol related brain injury fall, especially in relation to accommodation. Very often their behaviour is such that they require containment and supervision.

8.79 When they appeared before the Committee, representatives of the Office of the Public Guardian stressed the need for long term care and support for people with alcohol related brain damage, telling us that the absence of these services affects the Office of the Public Guardian's ability to fulfil its duty of care. As Mr Graeme Smith stated:

> I think the area of greatest concern for the Public Guardian is access to appropriate supported accommodation services for people who have acquired a disability as a result of long-term dependence on alcohol or drugs … They are a group of people who typically fall between the gaps, so to speak. They are people for whom health services generally have nothing to offer. They are not long-term providers of supported accommodation. The State disability agencies do not provide direct services for people with brain injury. They do fund non government agencies in some circumstances to provide services for people with a brain injury, but, historically, people with a brain injury associated with long-term alcohol abuse have fallen into the area of responsibility of the State health authorities, and therefore the State disability agencies are reluctant to provide designated funds for that group of people. So it is an area of what might be termed dispute between the two agencies.[498]

8.80 Mr Smith explained to the Committee that in the absence of more appropriate accommodation options, people requiring high levels of care and/or supervision are typically placed in aged care facilities. While there are a small number of nursing homes that have specialised in providing for the client group of people with a brain injury, the demand for their services is much greater than the supply.[499] Ms Beth Burton, who presented the case study of Margaret, explained that nursing homes with a 'confused and disturbed elderly unit' have proved useful, but they are not widely available, and are often reluctant to take people with brain injury because of their agitation and volatility.[500] These environments are also much less than ideal for people who are not frail aged. As the Public Guardian's submission states, these facilities:

> … are not designed to support residents who are physically able, younger than the average resident and requiring a high level of supervision. Staff are typically unskilled

498 Mr Graeme Smith, Director, Office of the Public Guardian, Evidence, 7 April 2004, p34

499 Mr Smith, Office of the Public Guardian, Evidence, 7 April 2004, p34

500 Ms Beth Burton, Clinical Nurse Consultant, Alcohol and Other Drug Services, New England Area Health Service, Evidence, 24 March 2004, p12

> in the management of people with acute and chronic substance dependency and the range of appropriate diversionary activities is limited.[501]

8.81 When a person is placed in an inappropriate facility, there is often a breakdown in their care arrangements. The case study of Eddie below highlights the absence of appropriate accommodation options for this group.

Eddie

Eddie is a 58 year old man with alcohol related brain damage arising from a 20 year dependence on alcohol. He also had a mental illness and problems with his physical health. He has a long history of homelessness and frequent short term admissions to hospitals and rehabilitation centres.

Eddie was brought before the Guardianship Tribunal because people were extremely concerned that he would die on the street. He was being beaten up regularly and was having trouble fending for himself. His health had deteriorated to the point that he needed to have a number of operations, including being provided with an ileostomy bag. The Office of the Public Guardian arranged, with his agreement, for Eddie to be admitted to a secure nursing home for three months or so, while he underwent his operations. He needed a stable placement long enough to have his health problems addressed.

Because of his behaviour he was placed in a secure dementia-specific unit in the nursing home. Once he was detoxified he found it very distressing to be held there with patients who had dementia. The staff did everything they could to try to contain him but they could not. He would scale the wall of the secure unit every day, but would voluntarily return at night. Because he could not be effectively contained and continued drinking, his health continued to be at risk.

Ideally, he would have been placed in a secure facility where he could gain appropriate care, and be in an environment where he was reasonably happy.

The Public Guardian looked for other alternatives, but in the absence of any, it sought to have him placed under the *Inebriates Act*. Representatives of the gazetted hospital advised against this as they felt he would be more at risk there, because of his acute health needs, than he would be in a general hospital.

Not long afterwards, Eddie was hit by a car and both his legs were fractured. Ironically, because he was no longer able to run away, he was able to get the treatment he required.

8.82 Professor Webster was also very concerned that there be adequate provision for a 'place' for people with alcohol related brain injury. While society has developed systematic responses for people with similar conditions and resulting behaviours, such as people with dementia and severe mental illness, he observes that for people with 'chronic inebriation and brain impairment' 'there is neglect and deliberate exclusion.'[502] He saw the provision of humane shelter, health care and nutrition as fundamental needs in relation to this group:

> And it is in shelter, a place where the person has some security – for at least the medium term – where the basic necessities of life are available – that is the critical issue.[503]
>
> The greatest deficiency in our social systems is the availability of living and housing environments for people affected by these problems.[504]

501 Submission 49, Office of the Public Guardian, p4

502 Supplementary Submission 43, Professor Ian Webster, NSW Expert Advisory Committee on Drugs, p5

503 Submission 43, Professor Ian Webster, NSW Expert Advisory Committee on Drugs, p5

8.83 Our Committee recognised the need for action in this area when we undertook our inquiry into residential and support services for people with a disability. In our Final Report, released in November 2002, we recommended that DADHC acknowledge people with brain injury as part of the target group for the Disability Services Program, under which supported accommodation and a range of other programs are funded. We also recommended that DADHC, in collaboration with NSW Health, Treasury and a number of other agencies, develop a funding and policy framework to strategically address the needs of people with brain injury, in order to improve their access to the range of disability and mainstream support services, and to brain injury specific services. We noted that the framework should consider, in particular, living skills and behaviour/social skills development services and accommodation, respite, case management and other services.[505]

8.84 Ms Rush of the Office of the Public Guardian called for the development of different models of care and accommodation according to the range of people's individual needs. While some people will need confinement for a relatively short period in order to get well, others will need long term accommodation, supervision and support in a safe place. She stated:

> It is looking at different models that still meet their needs and looking at the dignity of the person still being maintained.[506]

8.85 The Committee is very concerned that people with brain injury continue to be excluded from eligibility for disability programs in this State. We understand that 'drug or alcohol related brain injury' is a specific exclusion criterion for emergency access to DADHC services through the Service Access System.[507] However, the Department has a clear statutory responsibility for this group under section 5 of the *Disability Services Act 1993*, which states that the target group for that Act is people with a disability however that disability arises.[508] We also note that people with acquired brain injury are eligible for Commonwealth provisions such as the Disability Support Pension.

8.86 We consider that DADHC should acknowledge its responsibility towards people with disability, no matter how that disability was acquired. In doing so, it should enable people with alcohol related brain injury to access supported accommodation.

8.87 Case studies such as that of Esther on page 57 also show the need for behaviour support for people with alcohol related brain injury. While Esther eventually gained accommodation through the Department of Housing, her initial placement broke down because of the impact her disruptive behaviour had on those around her. She was very unhappy in her second placement, with people with similar needs, because she found other residents' behaviour difficult, and they did hers. The Committee understands that DADHC operates a Behaviour Intervention Service for people with an intellectual disability who are at risk of moving to a more restricted environment because of challenging or offending behaviours. The Committee

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504 Submission 43, Professor Ian Webster, NSW Expert Advisory Committee on Drugs, p9

505 Standing Committee on Social Issues, *Making it Happen: Final Report on Disability Services*, Report 28, November 2002, p45

506 Ms Rush, Office of the Public Guardian, Evidence, 7 April 2004, p42

507 Department of Ageing, Disability and Home Care, *Service Access System Decision Rules – Requests for Support*, Document Number 2004/PM/8, November 2003.

508 s 5, *Disability Services Act 1993*

considers it appropriate that people with acquired brain injury should also have access to this service.

8.88 We reiterate our recommendations from our *Final Report on Disability Services.*

Recommendation 44

That the Department of Ageing, Disability and Home Care acknowledge its responsibility towards people with acquired brain injury, including those with alcohol related brain injury, as part of the target group for the Disability Services Program.

Recommendation 45

That the Department of Ageing, Disability and Home Care, in collaboration with NSW Health, Treasury and other relevant agencies, develop a funding and policy framework for strategically addressing the needs of people with brain injury, in order to improve their access to the range of disability and mainstream support services, and to brain injury specific services. In particular, this framework should consider:

- Living skills and behaviour/social skills development services
- Accommodation, respite, case management and other services.

Support for families and carers

8.89 Many participants called for greater provision of support for families and carers. At various points throughout this report we have noted the profound impact that a person's substance dependence can have on their family, as was highlighted at the Alcohol Summit. Earlier in this chapter we recommended that guidelines for the treatment of people in involuntary care should address how families and carers are to be engaged in the process.

8.90 Ms Diane Paul of the Herbert Street Clinic told us that most of the calls to their service are made by family members concerned about their loved one being 'out of control'. She reported:

> They stress that there is no support for them out there and they do not know where to turn because the drug and alcohol services are busy enough dealing with the actual client. There are not a lot of services for the families, and I think that needs to be addressed.[509]

8.91 Participants such as Mr Pierce of NADA and Dr Jurd indicated that while significant progress has been made in this area, more work is yet to be done.[510] As Mr Pierce stated:

> Anybody who knows the drug and alcohol field will know that the inclusion of families and family-oriented programs is a pretty recent arrival to drug and alcohol

509 Ms Diane Paul, Herbert Street Clinic, Evidence, 4 March 2004, p27

510 Mr Pierce, Network of Alcohol and Other Drugs Agencies, Evidence, 27 November 2003, p53; Dr Jurd, Northern Sydney Health, Evidence, 4 June 2004, p32

> treatment. After the 1999 [Drug] Summit – it was reaffirmed at the Alcohol Summit – government made a very clear statement of priority, saying, "Families are a target group; families are important to support. Drug and alcohol services ought to be made more family-friendly, they ought to interact and engage with families and offer family support." More work must be done to reorient drug and alcohol services to be family friendly, and probably more dedicated resources are needed for specific family support interventions.[511]

8.92 The Government response to the Alcohol Summit indicates that the new statewide *Drug and Alcohol Treatment Services Development Plan 2006-2015* will address recommendations of the Summit in relation to:

- Strengthening and increasing funding for family-based approaches
- Introducing a 'visitors program' allowing families a role in developing responsive services
- Supporting telephone and other linking services that can provide information, peer-support, advice and referral to parents and family members.

8.93 The Committee considers it vitally important that this commitment to families be fulfilled.

Recommendation 46

That the *Drug and Alcohol Treatment Services Development Plan 2006-2015* provide for greater engagement of families in treatment, and enhance provisions specifically aimed at supporting families and carers.

8.94 In light of the discussion at several points throughout this chapter we consider the evaluation of the proposed legislation, which we recommended in Chapter 7, should also address a number of issues related to service provision. These include service coordination and integration, identification of service gaps, and the experience of families and carers.

Recommendation 47

That the evaluation of the proposed legislation in Recommendation 26 also consider:

- service coordination and integration
- service gaps
- the experience of families and carers.

A continuum of services

8.95 As a final comment on the service framework to underpin the proposed legislation, we note that participants were eager to ensure that provision for involuntary care be seen as part of a

[511] Mr Pierce, Network of Alcohol and Other Drugs Agencies, Evidence, 27 November 2003, p53

continuum of services, covering prevention, early intervention and harm management, with an emphasis on ensuring access to treatment well before a person reaches the point of needing involuntary intervention. As Professor Matthews stated:

> I think coercive treatment is required for the few who need it and better treatment access is required for the many who do not fit into a coercive framework to stop them from progressing to more serious stages. Part of the discussion I had before coming here was whether the direction of focusing on coercive treatment is necessary but misses the other part of the discussion - which is if you intervene earlier and catch people earlier perhaps they will not need coercive treatment later because they will not progress to having severe problems. In considering that there is a need to look across a range of interventions throughout people's lives, not just at the end.[512]

8.96 Professor Hall emphasised the range of measures needed to provide humane protection to those with significant dependence:

> The conclusion we ought not jump to is that civil commitment is the only one to achieve this goal. I think there are a lot of other ways, eg proclaimed places and other forms of intervention that give time out for people who are heavy drinkers that attempt to reduce the harm are a good idea. I would be very supportive of them. It is a question of whether they have to be accompanied by coercion or whether they ought to be services that are more readily available in areas where heavy drinkers congregate and where they are to be found. I think we need to look at a range of options rather than simply either coercing treatment or leaving people to the mercies of the street.[513]

8.97 The Committee agrees with inquiry participants that the proposed legislation must be seen as one measure within a much broader spectrum of services and provisions in relation to drug and alcohol problems. Government policy needs to ensure that services are provided along the continuum of substance misuse. We need to be working hard on prevention, while ensuring timely access to services when treatment is required, and humane and compassionate care when this is needed. As we have noted throughout this report, an holistic approach that seeks to address the totality of people's needs is essential.

8.98 We strongly believe that there needs to be enough community-based services, for example accommodation, case management, mental health services and general welfare services, to ensure that people who require support get the assistance they need to live with dignity. It is no longer acceptable to control people with drug and alcohol problems by institutionalising them for a time. However, history has shown that initiatives to remove people from institutions have not been accompanied by sufficient investment in community based supports. As Professor Carney told the Committee:

> [The de-institutionalisation process] has left the responsibility with civil society. It has largely abnegated responsibility to provide assistance to the vulnerable population. That was never the intention of de-institutionalisation. The intention was to allow people to operate in the community and for governments to continue to invest the

512 Professor Mattick, National Drug and Alcohol Research Centre, Evidence, 8 April 2004, p11

513 Professor Hall, University of Queensland, Evidence, 29 April 2004, p4

> same number of dollars that used to be invested in institutional care in the more effective community-based care. I am speaking internationally …[514]

8.99 We think it very likely that many people with complex needs and antisocial behaviour would not be such thorns in the sides of their family and community were they to have access to supports that meet their needs. Similarly, we suspect that many of the people for whom involuntary care is sought would not reach that point were they adequately supported in the community. Each of the case studies presented in this report highlights the vulnerability and multidimensional needs of people with severe substance dependence. A humane and compassionate response to them will recognise and respond to these needs. It is vitally important that the government comes to grips with this issue, especially in relation to housing and shelter, one of the most basic of human needs.

8.100 Our final comments are focused on provisions for people with alcohol dependence. We note our concern that there has been a shift away from alcohol towards illicit drugs treatment, especially given the prevalence of alcohol related problems and harms in the community. It is vitally important that adequate provision is made for all substance dependencies. There may be political pressure to address illicit substance dependence, but there are also social and moral imperatives to address alcohol dependence.

8.101 Relative to many other client groups, people with alcoholism have been given little priority. This is borne out in comparison with services for people with other addictions, people with other chronic conditions, and people with disabilities acquired through other means. As the comments of Professor Webster and Dr Jurd earlier in this chapter indicate, value judgements about people with alcohol dependence appear to have influenced both drug and alcohol and disability policy in this State. Whether these value judgements have been explicit or implicit, attitudes about 'deservingness' of support still seem to be with us. While these value judgements were characteristic of the *Inebriates Act 1912*, they have no place in policy in the early 21st century.

[514] Professor Carney, University of Sydney, Evidence, 7 April 2004, p29