

## **CHAPTER 5**

### **SECONDARY MENTAL HEALTH SERVICES - PART II**

#### **INTRODUCTION**

- 5.1 A person-centred approach is core to the vision of the Strategic Framework and as noted in Chapter 4 services must reflect the multi-dimensional nature of user and carer needs. While the primary focus of the last Chapter was on health and social care services reform, we must now consider a range of other issues – Education, Occupation, Accommodation, Income, Advocacy, Personal Life, Family Life and Culture, Carer and Family Needs.

#### **EDUCATION, TRAINING, OCCUPTION**

- 5.2 Occupation can be defined as all purposeful human activity encompassing personal activities of daily living, leisure activities and work activity. Education and training relates to activities compatible with both vocational outcomes and personal development. Occupation is a basic human need, which is directly related to the meaning, and quality of ones life<sup>1</sup> and important for both physical and mental well-being. Everyday occupations play a significant part in maintaining structure, meaning, and social inclusion.
- 5.3 Serious mental illness often results in a disruption of occupational balance, with lack of meaningful occupation limiting social connections and increasing stress and isolation.<sup>2</sup> In quality of life studies, service users report lack of a job, loneliness, health problems, looking after self and lack of leisure activities as priority areas in relation to quality of life.<sup>3,4,5</sup> The Labour Force Survey of 2002 Great Britain found that only 21% of adults with mental illness are in employment.<sup>4</sup> Three issues are important for this review - assessment, barriers to employment and employment models.

### **Assessment**

- 5.4 Recent clinical guidelines emphasise the importance of holistic assessment including social functioning, occupational status and potential, with interventions beginning at the earliest opportunity. The importance of assistance to access employment, education and training opportunities has been acknowledged.<sup>7</sup> Supported employment programmes is but one aspect of work activity which should be made available. Interventions aimed at maintaining and improving social networks through appropriate day care programmes should be available to all service users.<sup>3</sup>
- 5.5 The Mental Health Policy Implementation Guidance advises that the availability of specialised employment, education and occupation services should be a priority for all those with severe mental health needs. Trained professionals with the skills to assess these areas should be available to all community mental health teams. With respect to early intervention for psychosis the guidance is that all users should have a vocational assessment within three months of referral to the service.<sup>9</sup>

### **Barriers to Return to Work**

- 5.6 Many severely mentally ill service users are financially better off if they remain unemployed and in receipt of Social Security benefits. Current rules and financial incentives to move from benefit to work are complex, fragmented and assume a move from no work to full-time work. For those on Incapacity Benefit, permitted work is allowed in specific circumstances. To be sufficiently up-to-date with the rules on benefit entitlement, requires a considerable knowledge of social security issues. Even with the support of Disablement Employment Advisors and professional staff the process can be complicated and daunting.<sup>10</sup> This significant obstacle on the pathway to gaining employment needs to be explored as part of this Review.
- 5.7 The Department for Work and Pensions has recognised these difficulties and produced a new set of proposals to address some of the issues. The proposals emphasise rehabilitation and job retention. Specialist help will only be effective provided there are closer working relationships between DHSSPS, Department of Enterprise, Trade and Investment (DETI), Department of Employment and Learning (DEL), Department of Education (DEs) Department of Social Development (DSD), healthcare providers, the voluntary sector and employers.<sup>11</sup>

## Employment Models

- 5.8 The following are models of employment, which encompass the range of provision from social support through to health care and to those concerned with productivity.<sup>12</sup> With the exception of Clubhouse, all of these options exist in Northern Ireland.

Vocational rehabilitation (Prevocational skills training)	PACT (Placement, Assessment and Counselling Team)
Sheltered employment	Transitional employment
Clubhouse	Supported employment
Voluntary work	Social firms/ businesses

- 5.9 The paucity of quality research in this area could lead to a narrow view of those services which represent ‘best practice’. While a Cochrane review concluded that “supported employment is more effective than prevocational training in helping severely mentally ill people to obtain employment.”<sup>13</sup>, it must be noted that there is a tendency to select more able individuals for supported work placements. Most of the studies reviewed were conducted in America, where the social security systems are less extensive than the UK. The primary outcome measure for studies included was the number of clients in competitive employment.

- 5.10 Two features of employment programmes that have most empirical support are: integration of mental health and vocational services within a single service team; and the avoidance of pre-placement training.<sup>14</sup> People with severe mental health problems should be offered choice in terms of occupational, education and training opportunities, facilitating service users to experience a meaningful day and consequently improving quality of life. Emphasis should be placed on user-focused initiatives that allow a progression towards paid employment where this is the most appropriate option for the client. A range of occupational services should be provided within each Trust area to allow professionals and service users to match the level of need with the service provided. The continuum should include:

services with a predominantly  
treatment function

high quality sheltered workshops

leisure and creative activities	links to learning and training opportunities and voluntary work
good quality vocational guidance	social enterprises
specialist day care	access to supported placements in competitive employment.

- 5.11 The use of mainstream community services, facilities and activities should promote social inclusion and help reduce the stigma that mental health service users face. Effective links to voluntary work and organisations such as Further Education Colleges, Educational Guidance Service for Adults and the various job brokers and training organisations will expand the opportunities for people with severe mental health needs.
- 5.12 Some service users will require considerable support in order to access mainstream services. Supported education initiatives for employment or leisure services have been shown to be effective in relation to health gains for people with more enduring mental health needs.<sup>15</sup> The key worker should maintain overall responsibility for the client<sup>16</sup> with the health services taking the lead in providing and promoting employment opportunities. Studies have emphasised that the positive effects of participating in college activity ie having structure to day, gaining strengths and skills, developing self identity and social inclusion need to be balanced with possible negative effects. Sensitive, needs-led, flexible support must be maintained to reduce anxiety and alleviate barriers to engagement.<sup>17</sup>
- 5.13 A similar caution must be stated with regard to volunteering. A recently - completed project reports on the significant benefits of volunteering for those with mental health problems.<sup>18</sup> For those service users with severe and enduring illnesses adequate support and careful tailoring of opportunities must be provided in order to maximise potential to benefit from volunteering.
- 5.14 The importance of engagement in leisure activities must be acknowledged. Leisure as an occupation contributes to social identity and is fundamental to physical, social and psychological well-being. For many service users successful engagement in leisure activities can be a catalyst towards employment. For others it can be the

predominant occupation that defines their identity and maintains social inclusion. At all levels leisure occupation should be valued and facilitated by mental health workers.

*Good Practice Examples*

**Southwest London and St. George's Mental Health NHS Trust:** *In this service OT's act as clinical vocational leads, working with specialist services to increase access to employment and education for clients. There is a vocational support worker on each team.<sup>19</sup> Prior to intervention > 60% clients SMI group were not engaging in any work, education or structured activity. This reduced to 20% after 1 year's experience on the programme. 888 people have specific vocational input in the period from Nov. 01 – Nov. 02. After 1 year 469 were involved in open employment. This scheme is mainstreamed within the Trust, and is being piloted in six different sites across Europe over a three-year period. (Contact: 0208 682692.)*

**Avon & Wiltshire Mental Health Partnership NHS Trust, Work Development Team.** *The existing OT service was re-profiled and a model developed to assist people remain in work and re-enter the workforce after a period of mental illness through re-deployment or retraining. The team developed partnerships with local FE colleges, voluntary services and New Deal provisions. Standardised assessment tools are used. Since its inception in 2000, until Jan 2003 over 550 Occupational Action Plans have been completed. 250 people have returned to full-time employment. A job retention service has been developed. Primary evaluation confirms that the JRT is delivering considerable benefits to stakeholders who include, clients, employers and GPs. Key factors in the provision of an effective service were identified; early intervention, a focus on return to work, ongoing support, access and role of case manager. It is recommended that a national network of job retention services should be developed and a longitudinal evaluation conducted<sup>20</sup>. This is a NHS Beacon Service and is now being replicated in over 60 Healthcare Trusts in UK. (Contact: 01179633681.)*

**Pentreath Industries – Employment Project:** *Registered charity providing “gateways to employment for people with or recovering from mental ill health in Cornwall” 4 main areas of service delivery: training, employment placement advice, social, firm development and raising awareness of mental health issues. 76 staff provided long-term support for 598 service users in 2000, referred from community mental health teams. An average of 30 people per year move into full-*

*time waged employment. A wide range of opportunities and options are on offer, including 4 social firms. (Contact: The Sainsbury Centre 0207 403 8790.)*

*Local Examples of Good Practice.*

**Down & Lisburn Trust** have appointed a full-time Senior OT with a specific remit for vocational rehabilitation in the mental health team. They are the only Trust in N.I. to have a specialist vocational mental health post. The postholder works in partnership with Action Mental Health (ACCEPT) (Contact: 028 92665141 ext.2336.)

**Causeway Trust** has a full-time Senior I with a similar remit. This post is based at the Pavestone Centre, a recently established social enterprise. Although funded through the physical disability programme, the post holder also deals with clients with an SMI diagnosis. Plans have been proposed to develop a vocational assessment and supported employment service at Pavestone. No funding source as yet identified. (Contact: 028 70347875.)

**WELL Project:** - Well being, Education, Learning and Living Project

*This initiative aims to provide a sustainable support service, linking existing statutory and voluntary services, to enable people with enduring mental illness to access a wide range of learning activities, which will enhance quality of life, personal development, skills, opportunities for achievement, social inclusion and reduce stigma. (Contact: 44613311 ext. 3292.)*

- 5.15 Assessment of an individual's occupational performance, exploration of vocational goals and networking with local service providers is currently being performed by many CMHTs within Northern Ireland. However, many teams do not have access to OT expertise or when present in teams they are engaged in generic work due to high caseload numbers amongst multidisciplinary team members. The 'Avon' model could be replicated in Northern Ireland. The interventions required are core skills of occupational therapists and partnership working is already established in many Trusts.

## Recommendations

130. People with severe mental health needs should be offered an early opportunity to participate in a full occupational assessment. This should be reviewed on an annual basis as part of the service user's review.
131. Assessment should be conducted by an OT with the emphasis on quality of life, time management and occupational issues.
132. More straightforward and flexible social security benefits should be introduced to facilitate the transition from benefits to work.
133. A comprehensive range of occupational services must be provided within each Trust area and should include access to voluntary work, educational and leisure opportunities.
134. Day care services should provide a comprehensive range of activities and opportunities to support the different needs of service users.
135. Vocational specialists with mental health expertise should be commissioned to enhance the rehabilitative function of CMHTs.

## ACCOMMODATION

- 5.16 Having a home is a basic human right. The impact of poor housing on mental health has been well documented, as has the association between type of housing and prevalence of mental health problems. The Audit Commission 1994 found that:
- poor housing is particularly common among people with mental health problems;
  - mental illness is a frequent cause of tenancy problems and tenancy breakdowns; and
  - poor housing and inappropriate accommodation can lead to the development or exacerbation of mental health problems.
- 5.17 Suitable accommodation is a fundamental element of effective services to support people with mental health problems. A number of principles need to be considered in order to ensure an appropriate range of accommodation and support. These principles draw mainly on the recommendations of the Newby Inquiry.<sup>21</sup>
- as far as possible people with mental health problems should have a choice of the type of accommodation they wish to live in. This has to be balanced in relation to the degree of risk posed to themselves or others;

- assessment of accommodation needs should be a component of an overall assessment;
- support for people receiving mental health services should be available to people with mental health problems regardless of where they are accommodated; and
- providers of accommodation should receive training and should be supported regardless of whether the accommodation is statutory, voluntary or private.

5.18 Supporting individuals in suitable housing in ordinary settings will help them gain access to a wide range of mainstream services and resources. The challenge is to provide accommodation with support for the range of needs experienced by those with mental health problems without recreating institutions.

5.19 Homeless and rough sleepers present particular challenges. A recent study in Belfast identified some kind of mental health problems among 86% of single homeless people.<sup>22</sup>

5.20 The Northern Ireland Housing Executive, through joint planning arrangements with the Health and Personal Social Services, seeks to extend the supported housing option for various client groups in response to discharge from hospital and wider community needs. Each year 20% of the new build programme is targeted to meet supported housing needs.<sup>23</sup>

### **Accommodation Needs**

5.21 People with mental health needs have a range of accommodation requirements. The foundations of good provision include quality of care and management. Accommodation needs range from independent tenancies in mainstream housing to 24 hour intensively supported accommodation. A key objective of People First: Community Care in Northern Ireland for the 1990's was to promote the development of domiciliary day and respite services to enable people to live in their own homes whenever possible.

## **Types of Supported Housing**

5.22 Supported housing involves providing integrated housing and support. The type of housing available covers a wide range including:

- temporary or homeless hostels: shared housing where board or access to cooking facilities are provided;
- rehabilitative supported housing: shared housing in group homes or hostels providing a rehabilitation service;
- shared supported housing accommodation in shared housing or flats providing a permanent home;
- self contained supported houses: housing provided in flats or houses, which is not shared with others but has targeted integrated support; and
- residential care homes: usually shared accommodation, which are registered under the Registered Homes (Northern Ireland) Order 1992 (since 1<sup>st</sup> April 2003 many of the registered care homes in Northern Ireland managed by the voluntary sector and the statutory sector with special provision for people with mental health needs have de-registered and now operate under Supporting People).

5.23 People who require support to stay in their own or rented accommodation may require essential support at a practical level to ensure the maintenance of the tenancy, e.g. floating support, home help, mental health support workers. Those who need respite on a short stay basis to prevent acute admission may require emergency or non-emergency respite. Non-emergency respite may be required to accommodate people whose mental health is deteriorating and who require input from experienced staff over a period. Examples of this provision is available mainly in statutory/non hospital facilities in Northern Ireland.

### *Good Practice Example*

***Clare House Enniskillen** has a six-bedded attached unit, where people with mental health crisis may come for unplanned respite. The unit is staffed by nursing and an Occupational Therapist with Consultant back up. Residents are encouraged to be as independent as possible and prepare their own food and attend to their personal needs with support from staff (Contact: 028 6632 6361).*

- 5.24 Crisis diversion/non-hospital accommodation may be provided as part of Crisis Response to prevent inappropriate admission to hospital.

*Good Practice Example*

**Homefirst Trust** in partnership with M.U.S.T. hostel in Cookstown provides one bed as an alternative to hospital admission to those to those who have been assessed suitable. This unit is staffed by Voluntary Sector staff on a 24-hour basis and receive support from the Crisis Team as appropriate (Contact: 028 9040 2038).

- 5.25 People who are returning to independent living as part of their rehabilitation require specialist accommodation with support. They should, as far as possible, have choice of location. Moving out of an institutional setting to independence can be daunting. Many will require phased independence combining suitable accommodation and daytime occupation. Being able to cope with a range of every day activities will increase independence and quality of life. Many people with mental health problems are socially isolated and have no friends outside of the mental health system. Staff in supported housing can provide valuable help to those who lack social skills. This can be enhanced by access to daytime occupation and leisure facilities. Confidence building is important and input is required from trained and experienced staff.

*Good Practice Example*

**First-Step Move-On Accommodation.** There are many examples of statutory hostels across Northern Ireland providing first step move-on accommodation with intensive rehabilitation as a stepping-stone to supported or independent accommodation. Staff come from Nursing, Social Work or NVQ trained background and are supported by Community Psychiatric Nurses, Mental Health Social Workers and Consultants or Senior Registrars. Examples are Norfolk Court Hostel, Rathenraw, Antrim (028 9442 8089); Kintyre Park Hostel, Ballykeel, Ballymena (028 2565 3755); and Ballymacoss Hostel, Lisburn, (028 6632 6362).

- 5.26 People with challenging behaviour require specialist facilities with high staffing levels (see 4.61). This accommodation may be provided by the Housing Executive or Housing Associations in conjunction with Trusts or voluntary sector. It may also be provided through therapeutic type communities. It is important that the layout of the accommodation provides adequate personal space and there is access to daytime

occupations and intensive staff support. Staff require specialist training in relation to dealing with challenging behaviour and potential violence. Risk assessment should be carried out to identify patterns of behaviour, which may lead to harm either to the resident or others. Thorough risk assessment and risk management are essential to allow an acceptable level of freedom and independence for personal development within a context of safety for both service users and staff.

*Good Practice Example*

**Stamford Avenue, Herts.** *A registered mental health nursing home providing client support for people with learning disabilities, mental health needs and/or challenging behaviour. The project is registered to take people detained under the Mental Health Act. It provides intensive support with nursing and project workers and is supported by a Registered Medical Officer and a multi-disciplinary team (Contact: 01763 236 167).*

- 5.27 People with mental health problems without accommodation pose a particular challenge. Homelessness may have been caused or exacerbated by their mental health problems. Some may have been rejected from accommodation as a result of their mental illness or degree of challenge posed to staff. Some may have become displaced because of their mental health problems. Many have dual diagnosis.
- 5.28 It is essential that homeless mentally ill people have access to mainstream services at primary and secondary care level. Accident and Emergency Services provide an important access point to care for homeless mentally ill people. Good communication between generic and mental health services is essential if effective interventions are to be made.

*Good Practice Examples*

**North and West Belfast** *under their Health Action Zone have set up a Care Co-ordinator Service for single homeless people in North and West Belfast. The service assists single homeless people and rough sleepers to enhance their health status (Contact: 02890 755434).*

**Health and Homeless Guidance (Scottish Executive)** *There are 15 health and homelessness action plans across Scotland covering each NHS Board area.*

*Discharge protocols have been agreed in many areas, which have ended the practice of people being discharged from hospital without accommodation. Innovative and effective interventions have been developed to encourage health screening for rough sleepers; an example of this is offering veterinary checks for dogs of rough sleepers. (Contact: 0131 2445132).*

- 5.29 Access to housing alone is not sufficient but requires to be complemented by the provision of appropriate treatment and support, for example using Assertive Community Treatment. “Housing Patterns of Homeless Mentally Ill Persons Receiving Assertive Treatment”.<sup>24</sup>

*Good Practice Example*

***Belfast Homeless Support Team** and hostel, has had a major impact on the homeless mentally ill in the Belfast area. (Contact: 02890 238091).*

- 5.30 The Homeless Strategy and Service Review Northern Ireland Housing Executive 2001 aims to reduce the levels of homelessness by the provision of a tenancy support service and by developing move on accommodation as part of their supported housing programme.
- 5.31 Discharge protocols in mental health services in Northern Ireland require further refinement to ensure that people leaving mental health facilities have appropriate accommodation on discharge. Close co-operation is required between Housing, Mental Health, Statutory and Voluntary Services.

## **Recommendations**

136. Trusts should ensure that a complete range of accommodation is available to meet the needs of people with mental health problems.
137. Supporting people partnership between Trusts, Boards, Northern Ireland Housing Executive and the voluntary sector should be sufficiently flexible to make timely responses to the accommodation needs of people with mental health problems.
138. Service users should have choice of accommodation appropriate to their needs.
139. Service users should be given maximum independence through appropriate levels of support.
140. Discharge protocols should ensure that people leaving mental health facilities have appropriate accommodation.
141. Staff working in residential settings should have adequate support and training.
142. Statutory services should provide support to residents and staff to optimise community living and prevent unnecessary hospital admission.
143. Appropriate support and services should be provided to reduce the risk of homelessness in people with mental health needs.
144. Service principles must underpin the development of standards and must focus on the needs and rights of individuals.
145. Monitoring and evaluation of services should be a continuous process and involve users and carers.
146. Care environments and practices should be designed to maximise personal autonomy and reduce the risks of institutionalisation.

## **SOCIAL SECURITY BENEFITS AND SUPPORT**

5.32 In the non-disabled population in the UK, 15% of people are economically inactive compared to around half of the disabled population. The figure for people with mental health difficulties is around 80%.<sup>25</sup> In Northern Ireland, more than a third of incapacity benefit claimants have a mental or behavioural disorder. In November 2002 over 37,000 people were in receipt of incapacity benefit as a result of mental and behavioural disorders and just under one in five people receiving disability living allowance cited mental health problems as their main disabling condition.<sup>26</sup>

- 5.33 The key issues facing people with mental health problems are:
- inadequate levels of benefit, for example, personal expenses payments for people in residential/institutional care, help with the cost of prescriptions, problems with the Social Fund;
  - assessment – the prevalence of medical examinations that are often seen as intimidating; many of those conducting assessments have limited experience of mental illness;
  - easing the transition to work; there is much of a gap between incapacity and getting back to work. The current rules and financial incentives to move from benefit to work are complex and fragmented and there is a need for simpler, more flexible and improved financial incentives to allow people to return to work without the fear of penalties if unsuccessful; and
  - delivery – there is a need to take greater account of mental health issues in the administration of social security benefits. Awareness training, increased user involvement in training and planning, improved claim forms and tailored independent advice and advocacy services are all needed.

#### **Levels of Benefit**

- 5.34 While considerable effort has been made to improve the level of financial assistance available to families (both in and out of work) and older people, Incapacity Benefit for a single person unable to work because of ill-health or disability is worth barely one sixth of average earnings. The weekly rate of Income Support based Jobseeker's Allowance for a single person is £55 if aged 25 or over and £44 if under 25.
- 5.35 Young single people's difficulties are compounded by private rented sector housing benefit rules which apply a 'single room rent' rule to entitlement. Many young single people with mental health problems fall foul of this rule and get into difficulties paying rent. Young people therefore find themselves pushed towards less self-contained, cheaper accommodation which may not be appropriate. An exemption to the single room rent should be made for people with mental health difficulties.
- 5.36 Social Fund rules make it difficult for single people to qualify for grants for essential items such as furniture or household equipment. Often, the only option is a loan

which compounds financial difficulties. The Social Fund should be reviewed so that loans do not continue to be the main form of discretionary support.

5.37 Income Support for people in residential care or other institutional settings entails paying a personal allowance of £17.50 a week to meet living expenses. This can lead to difficulties in managing the transition to independence.

5.38 Prescription charges can be a major cost to people with ongoing health problems. Often, people with long-term mental health problems on incapacity benefit alone do not qualify for help with prescriptions. Pre-payment certificates allowing multiple and long-term prescriptions to be paid in advance are helpful but are often beyond the means of people on low incomes. People with severe mental health problems should be exempt from such charges.

#### **Assessment**

5.39 The current strategy for Social Security is ‘work for those who can, security for those who cannot’. As a result, a considerable effort has been put into encouraging the long term sick and disabled back into work.<sup>27</sup> However, there is a need to recognise that not everyone is capable of open employment (going beyond those granted an automatic exemption from these arrangements). It is important that all frontline employment advisers receive mental health awareness training, part of which should involve interaction with people directly affected by mental ill health.

5.40 The current strategy also contains an element of compulsion. People on Incapacity Benefit who fail to attend interviews can be penalised by loss of benefit or incapacity status. This fails to acknowledge the pressure having to attend such interviews can cause for someone with a severe mental illness.

5.41 Medical assessment is a regular feature of establishing and retaining entitlement to key disability benefits (notably Incapacity Benefit and Disability Living Allowance) and the quality of such assessments has been subject to significant scrutiny.<sup>28</sup> Rushed assessments, lack of knowledge of mental ill-health, disbelief of claimants, a disregard of specialist evidence and cultural insensitivity are not uncommon experiences. A report on the Social Security Agency’s Medical Referee Service by

the Advice Services Alliance in 2002 was also critical of the quality of assessment and sensitivity of some doctors.<sup>29</sup> The Social Security Agency (Northern Ireland) has recently announced a review of the Medical Referee Service. This could usefully lead to greater use of occupational nurses and mental health specialists (medical and non-medical).

### **Easing the Transition to Work**

- 5.42 People with mental health problems who have been on benefit for long periods often need intensive support to get back to work. The current Social Security system does not allow for a continuum that would enable a person to move gradually through voluntary work to part time work and full time work or to stay at one level for a prolonged period if appropriate. The Government has improved flexibility within the Social Security system to encourage a return to work, but the current arrangements are complex, fragmented and not easily understood by claimants. An understanding of the arrangements requires extensive knowledge of social security and concerns have been raised that a move into training or work triggers a review on the assumption that a person's condition has improved. This is a disincentive to rehabilitation through work or training.
- 5.43 Improvements have been made to claim forms in recent years, but there is a considerable way to go. The claim form for disability living allowance remains complex and significantly oriented towards physical impairments. The claim form for incapacity benefit has an open question about mental health with no guidance as to the information required.
- 5.44 The Social Security Agency is moving towards providing greater support to assist with claims for disability benefits. It has also worked with the voluntary sector to look at ways of enhancing its customer service to particular groups (for example, physically disabled people and ethnic minorities). A similar exercise working with voluntary sector and other interested parties to examine customer service issues for people with mental health problems would be a welcome development.
- 5.45 There is a need to ensure that all those involved in frontline benefit administration and decision-making receive mental health awareness training that incorporates

interaction with people with mental health problems. This also applies to the Medical Referee Service personnel, as well as chairpersons and panel members hearing social security appeals. People with mental health problems should have access to an independent dedicated advice and advocacy service to deal with social security problems.

### **Recommendations**

The Social Security system should support and enable people with mental health problems to live independently with dignity and a good quality of life, both in and out of work. Therefore;

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|------|---|
| 147. | The Social Fund should be reviewed with a view to ending loans as the main form of discretionary financial support  |
| 148. | An exemption to the single room rent should be made for people with mental health difficulties  |
| 149. | People with severe mental health problems should be exempt from prescription charges  |
| 150. | Trusts must ensure that people with mental health problems have access to independent dedicated advice and advocacy services to provide assistance in dealing with social security problems   |
| 151. | People with mental health problems wishing to work and who have been on benefit for long periods should be provided as necessary with intensive support.  |
| 152. | Rules encouraging a return to work should be made more flexible and easier to understand  |
| 153. | All frontline benefit advisers, social security decision-makers, medical referee service staff and appeal tribunal members should receive mental health awareness training, part of which should involve interaction with people directly affected by mental ill health |
| 154. | Medical assessors must have appropriate skills in assessing the mental health needs of applicants. Consideration should be given to greater use of mental health specialists (medical and non-medical).   |

## **PERSONAL LIFE, FAMILY LIFE AND CULTURE**

5.46 Mental well-being has been defined as the emotional and spiritual resilience which enables us to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own and other dignity and worth.<sup>30</sup>

### **Social Self**

5.47 A person's social connectedness – activities, relationships, interests, networks – has a significant impact on mental well-being and self-esteem. The reactions of others are often influenced in our social life, our activities, interactions, our social self.

Becoming mentally unwell can profoundly affect both our own social interactions and the reactions of others. It is in such situations that the experience of ignorance, fear and stigma can bring a new dimension of distress to the sufferer.

5.48 Mental ill-health and the accompanying distress can affect all aspects of one's social life and relationships - within the family, with friends, with work colleagues. The sense of feeling isolated and stigmatised is a very real experience of many sufferers. There is also a sense of disempowerment and the distress arising from this – “my life will never be the same again”. Acknowledgement of these issues and concerns can be of particular importance in promotion of recovery and needs to be recognised by professionals.

### **Relationship between Service User and Professionals**

5.49 The relationship between service providers and service users is of considerable importance in building and maintaining self-esteem, hope and self-worth for individuals with severe episodes of mental illness, experiencing loss of insight, loss of control, in addition to the painful experience of the symptoms of mental illness. This relationship can also provide a role model for family members who themselves may be bewildered and distressed through the experience of an illness episode. The engagement and empowerment of family members can greatly assist in the recovery and re-engagement of the service user in their social life and relationships.

### **Sharing of Information**

- 5.50 From a service user perspective, knowing that the professional you are relating to is trustworthy, will listen in a non-judgemental way and respects user views and requests, is essential to a partnership of trust, respect and empowerment. Confidentiality is an important part of this relationship. However if a service user asks a family member or friend to request information on his/her behalf this request should be respected by professional staff. Once a delegated person has been named and the request confirmed by the user of the service requested information should be given to the nominated person. This need not include personal information.
- 5.51 Access to information has generally been experienced as a problem for service users in mental health services. It is often difficult to get clear information and this lack of clarity is a problem for users, family and friends. The failure to convey relevant information clearly and in simple terms can cause distress to the user and their families. Information is required about services, choice of services, specific interventions including, for example, medication side-effects and crisis arrangements.
- 5.52 In the situation of involuntary admission clarity takes on even greater importance. The sufferer in such situations often experiences a significant intrusion into their personal and family privacy. Involuntary admission procedures should be clearly explained and all involved should identify themselves to the sufferer, family and friends. Difficulties for the user in understanding information at such times requires professionals to pay even greater attention to communication and information sharing.

### **Spirituality**

- 5.53 Within a multi-cultural society, the service user's specific cultural, spiritual and religious needs need to be recognised and acknowledged. With the emphasis on community based care and treatment, the religious and spiritual dimension of an individual's life should be considered as part of holistic assessment.
- 5.54 From a user perspective, spirituality can be an important part of one's personal life and in times of crisis a major source of sustenance. This can be of particular

importance in situations where admission to hospital is required with the inevitable separation from family, friends and one's local community. It is a common user experience when in hospital, that religious and spiritual needs are not adequately met. Service providers need to be sensitive to the spiritual needs of service users at such times.

### **Culture**

- 5.55 Culture shapes many aspects of mental health and people from ethnic minority communities have needs and concerns related to their cultural uniqueness, their minority position and often issues related to recent immigrant status. Culture shapes both perception and expression of mental distress and disorder. It also influences attitudes and coping mechanisms for the person, the family and for the specific cultural group. Ethnic minorities are especially vulnerable to stigmatisation, discrimination, racial stereotyping and social isolation. Many of these issues have been highlighted in the recent user survey of ethnic minorities in Northern Ireland.<sup>31</sup>
- 5.56 Mental health services must be sensitive to these issues and to the particular needs of ethnic minorities. The Department of Health report "Inside Outside"<sup>32</sup> emphasises three key objectives:
- to reduce and eliminate ethnic inequalities in mental health service experience and outcome;
  - to develop cultural capability of mental health services; and
  - to engage the community and build capacity through community development workers.
- 5.57 Important factors are personal attitude, professional skills and competencies, and awareness and appraisal of specific cultural norms. These point to important aspects of professional development among mental health professionals. Priority must also be given to the provision of better information, better communication including the appropriate use of interpreters and translators.

## Recommendations

155. The distress accompanying mental illness and its impact on an individual's personal life, including a sense of stigma, needs to be recognised and acknowledged by mental health professionals.
156. The importance of the relationship between service providers and service users in the maintenance of self-esteem, hope and self-worth needs to be recognised and valued by providers.
157. Service users and where appropriate carers, family and friends should be provided with relevant information in clear and simple terms.
158. The information and communication needs of service users in situations of non-voluntary admission require special attention.
159. Within a multi-cultural society, the service user's specific communication, cultural, spiritual and religious needs must be recognised and acknowledged.
160. Services must be sensitive to the cultural needs of people from ethnic minority communities.
161. Priority must be given to improved methods of communication and information for people from ethnic minorities, including the use of interpreters and translators.
162. Staff training should be provided appropriate for the needs of local ethnic minority communities.
163. Advocacy services should be sensitive and appropriate for the needs of people from ethnic minority communities.

## ADVOCACY

5.58 In 1996 Building Bridges<sup>33</sup> identified service user involvement as a fundamental principle in mental health care and user advocacy as an important support of this process. The Mental Health Patient's Charter<sup>34</sup> states that service users should be informed of and have access to local advocacy service. The purpose of advocacy is to ensure maximum preservation of each service user's personal autonomy and self determination.<sup>35</sup> Advocacy assists service users in expressing their views and taking an active part in decision making affecting their situation. The United Kingdom Advocacy Network (UKAN) stresses that a key objective of advocacy is to enable people to advocate for themselves. Nevertheless, there are occasions when people are unable to represent their own views and interests.

- 5.59 The advocate’s role is to provide the service user with information and the opportunity to discuss concerns and options. The independence of the advocate therefore, is of fundamental importance in order to effectively represent the service user’s views.
- 5.60 The Review considers advocacy as an essential part of mental health services.

*Good Practice Example*

***NI Association for Mental Health Advocacy Service.*** *The key features of this model are:*

- *Independence with appropriate funding*
- *Training and relevant experience*
- *Good communication skills*
- *Good understanding of mental health services and legislation*
- *Ability to empower patients to speak for themselves*
- *Acceptance and support by professional staff*
- *Advocacy at the macro level in relation to policy and planning of services*
- *Advocacy with individual service users*
- *Access to appropriate administrative information*
- *Accountability and evaluation*
- *Education of patients and staff on the nature of the advocacy process.*

*(Contact: 028 9032 8474).*

### **Recommendations**

164. Independent Advocacy services ensuring maximum preservation of each service users personal autonomy and self determination must be established in all Trusts providing mental health services.
165. Advocates should be involved in service planning and development
166. Advocates should be given access to appropriate service information
167. Advocates should receive support as necessary from Trust staff

### **CARER AND FAMILY NEEDS**

- 5.61 The UK Government’s National Strategy report ‘Caring about Carers’<sup>36</sup> states that

- Northern Ireland has 250,000 carers, 7% (17,500) of whom are caring for a person with mental health needs and a further 15% (37,500) for someone with both a mental and physical disability;
- carers need support and information, especially when caring for someone with a mental health problem;
- nearly 60% of carers receive no regular support from service providers;
- stress related health problems are most acute among carers of people with a chronic mental health condition such as schizophrenia; and
- helping carers is one way of helping those they care for.

5.62 In the past, mental health systems around the world tended to focus on the individual without considering the system in which they lived, often overlooking their roles within families and communities.<sup>37</sup> Yet the family usually has primary responsibility for care, with approximately 50% of those with severe mental illness living with family or friends, and many who do not, still receiving substantial support from them.<sup>38</sup> The cost of this care in Northern Ireland, if provided by the state, is estimated by the Sainsbury Centre for Mental Health to be £122 million.

5.63 The inter-relationships among service user, carer and other family members is crucial everyone's well-being. The carer who is a spouse, may have to assume roles and responsibilities not envisaged at the outset of the relationship. The carer who is a mother, may concentrate on the ill family member to the neglect of others. A child whose parent is unwell may become a 'young carer' or worse, may suffer adverse consequences. Service users not living with their families may nevertheless have a close relationship with them or with a carer.

5.64 Mental illness can be demanding and stressful for a family. It can be intermittent, adding uncertainty to family life and an inability to plan in the short and long term. Social Security benefits are a constant source of concern for many and affect the financial survival of all family members. Children may experience difficulties at home but not speak about them at school because of stigma. Carers and families commonly experience fear of the unknown arising from lack of knowledge of the

illness and its consequences, and grieving for the loss of future potential in their own lives and that of their family member.

- 5.65 Individuals within a family whose lives are intertwined with that of the service user and who are affected by the circumstances, must be identified and offered support in their own right in order to avoid adverse consequences to their health and well being.

### **Carers**

- 5.66 **Current Policy and Legislation.** Service providers have traditionally shown a reluctance to comprehensively address the needs of carers. However, the needs of those caring for others with severe and enduring mental illness are especially high and cannot be ignored. Valuing Carers<sup>39</sup> (2002), Northern Ireland's carers' strategy, recognises that carers' health needs must be met, that they must be provided with adequate information and be involved in the planning and provision of services.

- 5.67 Its key elements relating to carers of those with serious mental illness are:

#### Recognition

- all organisations must begin to recognise carers and be prepared and able to direct them to sources of support;
- older carers should be sought out and supported; and
- young carers should be identified and supported in their education and development.

#### Assessment

- carers should be informed of their right to a separate assessment, separately recorded.

#### Information and Support

- clinicians should seek their patient's consent to provide relevant information to the carer;
- carers should be fully involved in the timing of hospital discharge and given the information they require for the aftercare of the patient. The carer's name should be included in the discharge letter to the GP;
- the training needs of carers must be assessed and training provided;
- handbooks of local services are required, as is information on the Internet; and

- locality-based and disability-specific self-help groups should be encouraged.

#### Services for Carers

- carer services should be reviewed with carers;
- reviews must be made of respite opportunities. Carers and service users must be involved in the reviews;
- a carer liaison or co-ordinator position should be created in each Health and Social Services Trust.
- carer advocates should be developed and trained; and
- front line staff should deal sympathetically with complaints.

5.68 The recent Carers and Direct Payments Order (Northern Ireland)<sup>40</sup> 2003 entitles those who provide regular and substantial care to an assessment of their own needs and enables Trusts to provide services directly to carers after assessment. Assessments should be undertaken annually and a written care-plan produced and implemented in consultation with the carer. In looking at the circumstances of both service user and carer consideration must be given to the degree of support a carer can, or is willing to provide, so that there are no adverse effects on her/his own health and well-being.

5.69 **Identifying the Carer.** Mental health professionals should know who is providing care and support. General Practitioners, other clinicians and mental health professionals should actively seek the consent of their patients to provide the key carer with information about the diagnosed condition and prescribed medication. This should be done on the basis of clear protocols for the identification of key carers.

5.70 Service users should be encouraged to nominate a key carer, who may not of course be a family member. This information should be reviewed regularly, keeping in mind that many carers would not identify with the term ‘carer’ or describe themselves as such, seeing their role simply as a family responsibility. The Review recommends the concept of a User-Key Carer partnership

5.71 **Partnership with the Carer.** Agencies and care providers should recognise and value carers and accord them equal status with other providers of care.<sup>39</sup> Working

with service users and carers in partnership is conducive to the creation of holistic support networks, which are important in bringing relief from isolation and loneliness. A culture in which families are considered to be responsible for their relative's condition is not constructive. A new culture of creating and encouraging support systems for the whole family should be developed.

- 5.72 Many carers' needs can be met relatively easily by individual mental health professionals who are prepared to work in partnership with carers. Carers and families need information about the mental health condition affecting their loved-ones, including medication and its side-effects, treatment regimes, what choices are available regarding treatment, prognosis, how to get help, what to do in a crisis, how to deal with certain situations and symptoms. Carers must be provided with names and telephone numbers of who to contact in a crisis. Carers need to be listened to when they report that a crisis is pending.
- 5.73 The carer should be involved in the drawing up of care plans, consulted about hospital discharge and periods of leave from hospital. Hospital admission and discharge are particularly difficult as they are often unplanned, with little or no involvement of patient or carer.<sup>41</sup>
- 5.74 **Information for the Carer.** Carers and families need a wide range of information to manage their day-to-day circumstances and alleviate the helplessness many experience. This would include information on social security benefits, the law, their own rights and entitlements and those of the service user. Social Security benefits can create urgent problems around the times of hospital admission and discharge. Carers are generally not familiar with mental health legislation and the associated processes and structures. Carers need information about the structure of health and social services so that they can effectively deal with them.
- 5.75 On occasion the needs of carers and families for information may conflict with the wishes of the service user. While the fundamental right to confidentiality for the service user must be respected, a way forward should be negotiated to ensure that the needs of the carer and family are also met. A person-centred approach to the delivery of care will both highlight and moderate these conflicting rights, with measures which

can be put into effect at times when the service user may not well enough to make informed decisions, such as advance directives, identifying and working in partnership with the carer, providing carers and families with information about the illness.

- 5.76 **Support for the Carer.** Stigma, guilt and shame can bring about a breakdown in natural, supportive social networks causing carers and families to experience a deep sense of isolation. Self help groups provide an effective counteracting measure where people can speak about their circumstances, receive and give support and make sense of their experiences. A variety of flexible and responsive support mechanisms should be on offer to assist families in dealing with the myriad issues they face including help-lines available during and after business hours, dedicated carer and family workers and opportunities for respite breaks.
- 5.77 **Carer and family workers.** Carers of people with mental illness, find this kind of support of value. It should be sensitive to ethnic diversity in Northern Ireland, often overlooked when considering the needs of the wider community.
- 5.78 **Respite.** A range of opportunities for long and short breaks, is required for users and carers and partnerships involving the voluntary sector are often an effective way of providing this service.
- 5.79 Support services for carers provided by the voluntary sector, and involving carers have particular advantages.<sup>38</sup>

*Good Practice Examples*

*C.A.U.S.E., a Northern Ireland carers' and families' organisation, provides a broad model of support for carers which includes a helpline, self-help groups, carer advocates, training and education programmes and the representation of carers' views. (Contact: 028 9023 8284).*

*RETHINK is a national organisation providing support for both service users and carers. Its programme includes self-help groups, training and education, carer*

*advocacy, and the representation of carers' views. It has an informative and useful web-site. (Contact: 028 90402323).*

- 5.80 **Empowerment of the Carer through Training.** There are well-researched training programmes designed to empower carers to deal with the challenges arising from the illnesses, increase their knowledge, help them to develop coping skills and deal with grief and isolation. These should be made widely available. The anticipated developments in Home Treatment and Crisis Resolution make it imperative that carers receive appropriate training to carry out the tasks required of them. They need to know about risk management and be advised about vulnerable periods such as the one immediately following hospital discharge.

*Good Practice Examples*

**CESP (Carer Education Support Programme.** *A collaboration between Rethink and the Sainsbury Centre. Held over 3 months, this course is co-led by trained carers and mental health professionals. It gives information about schizophrenia and skills training in problem solving, assertiveness, communication and managing symptoms. (Contact: 028 90402323).*

**PREP (Programme for Relatives: Education and Partnership),** *developed by Dr. Carole Castles from C.A.U.S.E. with funding from the Mental Health Foundation. The programme aims to alleviate feelings of subjective burden in relatives, to increase their knowledge of serious mental illness and to enable them to improve their quality of life. It is facilitated by trained, experienced carers and has input from mental health professionals. (Contact: 028 9023 8284).*

- 5.81 Family interventions can have considerable benefits for relatives' psychological distress, family functioning and the carer's relationship with the service user.<sup>42,43</sup> Despite its successes, few carers and families have access to this form of support, which also enhances understanding and cohesion in their relationships.

*Good Practice Example*

*Professionals trained in the multidisciplinary **Thorn programme** are greatly valued by carers and families. **The Meriden Project** in the West Midlands has expanded this model of support to a very favourable response from carers. (see Chapter 4.144).*

### **Children and Young People**

- 5.82 It is estimated that 30% of adults with mental health needs have dependent children. Rates of psychiatric diagnosis in these children range from 30% to 50% compared to 20% in the general population.<sup>44</sup> The presence of alcohol or drug misuse among parents can add significantly to the mental health difficulties of children. Service users may also be reluctant to seek help because of fear that children may be taken into care.
- 5.83 In the UK, it has been shown that children who become involved in the child protection system often have significant experience of parental mental illness, parental substance misuse and/or domestic violence.<sup>45</sup> Locally, a survey conducted in 2000 in the Northern Health and Social Services Board area found that 72% of the 467 children placed on the child protection register had a history of parental mental illness or substance misuse while, in the same period, 78.5% of the 703 children who received services under the Children (N.I.) Order 1995 had a history of parental mental illness or substance misuse.<sup>46</sup>
- 5.84 The potential effects of parental mental illness on the health and well-being of children in the same household has been recognised for some time. These children are more likely to experience financial hardship, marital discord and social isolation than children in a household without a parent with mental illness.<sup>47</sup> They may experience anxiety, extended periods of separation, disruption in schooling and, in a relatively small number of cases, neglect and/or abuse.<sup>48</sup> Other risks include:
- between 25% and 50% of children of parents affected by severe mental illness will experience psychological disturbance during childhood or adolescence with up to 14% of such children developing a psychotic disorder in adult life;
  - risk may double for children where both principal caregivers are affected;
  - risks to children increase during the acute phase of an illness and are exacerbated by marital breakdown, social isolation and stigma; and
  - some children may become involved in parental symptomatology.<sup>49</sup>

- 5.85 The mode of delivery of services can sometimes reveal tensions in a system that has been primarily created to help adults, sometimes at the expense of their children. For example:
- patient confidentiality can sometimes be an obstacle to the sharing of crucial information;
  - understanding of roles and responsibilities in multi-disciplinary teams can be highly variable; and
  - in-patient facilities are often not best suited to the needs of parents, babies, small children and/or adolescents.
- 5.86 Routine good practice among child protection workers is to consider the special needs of children in these circumstances. However, there is no certainty that these needs are routinely taken into account during the course of assessments carried out by mental health workers. Although there is a wider recognition of child protection issues among all professions, the recognition of these issues by hospital-based multidisciplinary teams varies. It is essential that the assessment process for parents with a diagnosis of severe mental illness includes an assessment of the needs of children within the household.
- 5.87 Support for the family must become an integral component of a comprehensive service which encourages a ‘family wrap-around’ approach.<sup>45</sup> Appropriate support must be provided for the children of those with mental illness so that they benefit from the same life chances as other children.<sup>38</sup> Their needs must be identified in the course of drawing up a care plan for the service user and they should be fully included and addressed in any subsequent care planning process.
- 5.88 Very young children may put additional pressure on the coping capacity of both service users and carers requiring measures to be taken to prevent extra stress within the home. These issues should be recognised as early as possible in the assessment process. In the longer term, children will need advice and help to ‘navigate’ their way through their education and transition to adulthood.
- 5.89 Children and parents value a range of supportive measures including:

- a contingency plan drawn up for times of crisis;
- maximum continuity and minimum disruption for children when their parent is admitted to hospital;
- an age-appropriate explanation for children of events surrounding an admission;
- the availability of a confidante for children during a crisis;
- facilitated access to other children in similar circumstances;
- continuity of family support workers;
- suitable visiting arrangements in hospital; and
- parental support groups.<sup>50</sup>

5.90 An agreed, formal protocol between Children's and Mental Health services should be established for those responsible for delivering health and social care to families where children may require protection. This would govern the sharing of information, the management of cases and the identification of lead agency and key worker status and roles.

5.91 **Young Carers.** Some children may be undertaking levels of care that are considered inappropriate for their age. As a result 'Young Carers' have been highlighted as a priority group by government policy in recent years. These children and young people assume levels of responsibility for caring which impacts on their health, education and development.

5.92 Valuing Carers<sup>39</sup> makes specific reference to young carers and recommends that they are identified and that services are put in place to ensure that their development and education do not suffer as a result of their caring duties. The Internet should be considered as a means of making information available to them.

5.93 The key messages in guidance from the Department of Health are that joint assessment of parent and children is necessary and that services should be comprehensive, flexible and timely.<sup>36</sup> Assessments can be seen as a means of supporting the family and of considering both their strengths and the areas in which they need support. Service users should be supported in their parenting and caring roles.

*Good Practice Examples*

***FACE**, a Northern Ireland organisation, has developed a local programme of support for young carers in the area of mental illness. (Contact: 028 3833 2261)*

***Barnardos Young Carers Project in the Northern Health and Social Services Board** area, deals with families with a parent with a disability, including those with mental health problems. They offer the young person counselling, group support, peer support and recreational opportunities, and take a holistic family approach. (Contact: 028 2564 8809)*

**Resources**

- 5.94 While much of the support that carers need to continue in their caring role is relatively inexpensive additional resources are necessary. In England and Wales the Government made available £140 million over two years, to facilitate the creation of a wider range of services to allow carers to take a break from their caring responsibilities. In resourcing changes to the mental health services in Northern Ireland, funding must be similarly earmarked and ring-fenced for carer and family support. The voluntary sector should continue to play a significant role in the provision of this support.

**Recommendations**

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| <p>168. Boards and Trusts must fully implement existing policy and legislative obligations relating to carers.</p> <p>169. The needs of carers, children and other relevant family members, should be identified at assessment.</p> <p>170. Key carers should be provided with appropriate support, education and information to carry out their role, as partners with the service user.</p> <p>171. Agencies should accord carers equal status with other providers of care.</p> <p>172. Key carers should be offered an annual assessment and a written care plan.</p> <p>173. Family interventions should become an integral part of mental health practice.</p> <p>174. Training programmes for dealing with mental health problems should be made available to all carers.</p> <p>175. Trusts should make available dedicated carer and family workers.</p> <p>176. Trusts should ensure that a range of support services in the form of helplines, self-help groups, directories of services, help with social security benefits and respite</p> |
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opportunities, is provided for carers and families.

177. Service users who are parents should be supported in their parenting role.
178. Children of people with mental health problems should be provided with appropriate support in their day-to-day lives and measures taken to support them in times of crisis, including the availability of a confidante.
179. Hospitals must ensure there are suitable visiting arrangements for families
180. Agreed protocols must be established between Child and adolescent services and Mental Health services where children may require protection.
181. The services of appropriately trained professionals should be made available for key carers.
182. Staff training must include engagement with carers and the assessment and management of their needs as carers.

