CONSULTATION RESPONSE
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Green Paper: Improving the mental health of the EU population

social care
institute for excellence
scie

Introduction

SCIE welcomes the formulation of a mental health strategy for the European Union (EU) and welcomes the opportunity to comment on the proposals set out in the Green Paper. Particularly given the increasing mobility of EU citizens between member states, the mental health and well-being of citizens should be a shared priority at EU-level, as well as at individual member level.

1. How relevant is the mental health of the population for the EU's strategic policy objectives, as detailed in section 1?

Prosperity

SCIE has well developed views about the relevance of mental health in the context of this first policy objective of putting Europe back on the path to long term prosperity. The high unemployment levels among people with long term mental health problems serves to highlight the significance of the relationship between mental health and prosperity. In the United Kingdom (UK) for example, among adults with long term mental health problems, fewer than a quarter are in employment – the lowest employment rate for any of the main groups of disabled people[i]. Therefore supporting people with mental health problems (where relevant) in to, or back in to, employment is crucial.

Currently in the United Kingdom, there *is* a drive to help people with mental health problems back into employment. This is associated with government proposals for welfare reform which include plans to reduce the number of people claiming the non means tested, 'Incapacity Benefit'. These proposals have huge implications for people facing mental health issues because, 40% of incapacity benefit recipients in the UK are claiming on the basis of poor mental health. The government's proposals could also potentially have a significant impact on mental health services.

As stated above, it is crucially important that appropriate support is available to help people with mental health problems in to employment. SCIE therefore broadly welcomes the UK government's proposals and suggests that a mental health strategy for the EU must also consider the provision of this kind of support. However, while we endorse this general strategic direction we are cautious about the detail of the UK government's proposals and would therefore present them as a warning to those charged with formulating the EU's mental health strategy.

For example, there are proposals for the use of so called 'action plans' which benefit claimants must adhere to or face reduction of their benefits in a series of 'slices'. While we welcome their use for rehabilitation and where suitable, eventual (re/) entry into work or work related activity, we are concerned about the arguably coercive function of action plans. This is particularly relevant for people facing mental health problems. SCIE warns that the *thought* of the conditionality of the action plans in relation to benefit levels, with the threat of having benefits slashed, could make many people extremely anxious and this may be counter productive to the successful fulfilment of the plans. This is where we believe the action plans could be particularly problematic for people

experiencing mental health difficulties. During our consultations[ii] with service users with experience of the benefits system, it was often pointed out that the threat of losing benefits has made people already suffering with depression and anxiety feel even worse. The action plans should support people back in to work or other activity, in a safe environment. People should not be scared to lose their benefits in the event of a fluctuation of their condition or where plans have not been thoughtfully constructed in the first place.

Although the proposed use of action plans is specific to the UK government's current proposals for welfare reform, we feel strongly that our concerns over them should help inform the development of a mental health strategy for the EU. While welfare provisions vary at member level, the principle is basically the same; returning to work or entering employment following or with mental health problems should not be about "gambling on stability" – the risk to the individual should be minimal.

In fact SCIE believes there are other means of ensuring people experiencing mental health problems can contribute to the long term prosperity of Europe and there are also other principles that should be incorporated into a strategy. As one suggestion, we would highlight the importance of working with employers to help them support employees with mental health problems to remain in work. In particular, there is a need to educate employers about aspects of working practices and job structures that create problems, especially for those with fluctuating disability and mental health conditions.

There should be recognition of the nature of many mental health problems. Although some people currently unable to work because of mental ill health might be quite capable of rehabilitation through, for example, individual work-type activities, they may not be able to sustain a job because they can only do these sorts of activities for limited periods in a day or may have some days when they cannot do anything. Any work done is sporadic and dependent upon the, often fluctuating, health status of the individual on any given day. Such individuals are therefore unlikely to be an attractive prospect for employers. This is why we maintain that any mental health strategy should seek to educate and support employers. In particular they should be encouraged to develop more opportunities for flexible working to take account of people with mental health problems and indeed other fluctuating conditions. Incentives should also be provided for employers, not least in the public sector, to improve their record on employing disabled people and those facing mental health difficulties.

We would also suggest that in supporting people in to employment, a strategy on mental health should recognise the importance of certain fundamental principles. SCIE is particularly concerned that if it is an appropriate one to take, the route back to employment should be planned with the individual according to the principles of *person centred planning*. Although person centred planning is normally understood to be the basis for a particular way of commissioning, providing and organising social care services, SCIE believes that the principles behind it can be applied to planning people's routes back to employment. In Valuing People[iii] the UK government outlined the principles behind person centred planning. We believe these principles are broadly relevant to the formulation of a strategy which ensures that people who have faced

mental health problems can contribute to the long term prosperity of Europe. For example, people should be supported in to employment in a way which reflects their capacities and what is important to them; in a way which shows a shared commitment to action that will uphold a person's rights and ultimately, the individual should be supported in getting what they want out of life and work.

It should be clear that SCIE believes mental health *is* relevant to the prosperity of Europe. We feel strongly that people facing mental health problems should, where suitable, be supported in to employment and that a mental health strategy for the EU should make provision for this. We do however have concerns about the means of achieving this. Although we have used the UK government's proposals for welfare reform as an illustrative example we maintain that the reservations we have outlined should serve as lessons in the formulation of a broad EU strategy.

There is a further point in relation to mental health and the prosperity of Europe that we would want to flag up. The objective places a clear emphasis on putting Europe back on the path to *long term* prosperity. This being the case, SCIE is keen to point out the importance of the mental health of children and young people on the basis that they are our future workforce and therefore relevant to long term prosperity. SCIE is committed to understanding and developing ways of meeting children's emotional and developmental needs and this is reflected in among others, a recently commissioned practice guide on the emotional needs of children in residential care.

Solidarity and social justice

SCIE believes that mental health is also relevant in relation to the second strategic policy objective of sustaining 'Europe's commitment to solidarity and social justice'.

SCIE seeks to ensure the social inclusion of people with mental health problems by ensuring their views are expressed, along with those of other service user groups. As one means of doing this, SCIE hosts a forum called, the Partner's Council. The Partners' Council was set up, following extensive consultation with stakeholders, by SCIE in March 2004 to advise SCIE on its priorities, programmes and performance. Its purpose is to ensure that SCIE's work reflects the needs of people in the social care sector, especially that of service users and carers. The council is made up of representatives from more than 40 organisations across the UK including employers and service providers in the private and voluntary sectors, professional bodies and trade unions, higher education and research institutions, local authorities, regulatory and standards bodies and health organisations. However, crucially, included on the membership are representatives of service user and care organisations. The service user organisations on the council include organisations for people who use mental health services, but also those for people with learning disabilities, children and young people, parents and families, disabled people and older people.

As stated, one of the main roles of the council is to ensure SCIE's work reflects the needs of users and carers in the social care sector. To this end, the council helps to develop SCIE's work programme. Members also assist and support SCIE staff and the

Board of Trustees in hearing from and communicating with stakeholder interests, identifying priorities and gaining feedback about SCIE's work programme and products. In sharing their knowledge and experience of best practice in the social care sector, service users and carers also, crucially, have the opportunity to contribute to SCIE's responses to Government proposals for policy reform. In this way, service users, including those using mental health services, are in a position to comment on and help influence developments in the social care sector. We maintain that through this process and the other activities the council performs, this is a means of promoting social inclusion and solidarity among people with mental health problems, and indeed other user groups.

In the same way that SCIE relies on service user and carer views and promotes their contribution to the development of UK policy, we firmly believe that user and carer views must be incorporated in the development of an EU mental health strategy. The strategy itself must also detail how service users and carers will be involved in its development and implementation. However we are concerned about the need for proper funding resources for a mental health user group at a European level. Such a group did once exist but has now lost all funding. SCIE is concerned that user groups should be better supported and funded to maintain their independence and critical function. Service user and care involvement is, after all, essential if the strategy is going to promote social solidarity through mental health policies that are relevant to service users.

SCIE also maintains that social inclusion could be promoted through recognition of the impact of mental health problems on families. After all, mental health problems do not just affect individuals but also their family and friends. Providing early support to families can help to prevent children's longer-term emotional and mental health problems, so not only is this relevant to social inclusion, but also to *long term* prosperity as discussed above.

However, in the specific context of social solidarity, SCIE is engaged with work on promoting mental health and social inclusion for parents with mental health problems and their children. Working in partnership with the National Institute of Mental Health in England (NIMHE), SCIE is helping to establish the 'Action 16 Group'. The group is being formed in response to the publication of the UK government's 27-point action plan to reduce social exclusion as a result of mental ill health[iv]. It was a cause for celebration that the recognition of the impact on families had been included in the government's plans and articulated in action 16, 'Better support for parents and their children'. Therefore, the partnership between NIMHE and SCIE formed the group of the same name, 'Action 16'. The group, comprising NIMHE, SCIE and other interested stakeholders will negotiate how to translate action 16 into a set of achievable objectives and will oversee implementation. SCIE would be happy to keep the Commission informed about the group's work and progress with implementing the Government's plan, which includes; ensuring that the common core of training for professionals working with children and families addresses mental health issues; encouraging emerging local structures for children and families' services to take explicit account of the needs of parents with mental health problems and their children; a review of the

quality and access to family visiting facilities within hospitals and improvement of access to family and parenting support.

SCIE's endorsement of promoting social solidarity through support for parents facing mental health problems and their families is also reflected in a systematic review currently underway. The Department of Health has commissioned SCIE to conduct a systematic review of evidence and existing practice by health and social care services in supporting parents with mental health problems with their parenting needs, including meeting the needs of ethnic minority parents. SCIE will ultimately publish new practice guidelines and again, we will be happy to share our findings with the Commission so that lessons can be incorporated into an EU mental health strategy that will promote the social inclusion of people with mental health problems.

In the context of the increasing mobility of EU citizens, the provision of support for 'minority' communities has become an EU wide issue. Therefore a strategy on mental health that seeks to promote the social inclusion of the whole population must incorporate the perspectives of minority ethnic groups and indeed, asylum seekers and refugees. To help achieve social solidarity, a strategy for the EU should also acknowledge the difficulty that minority ethnic communities and asylum seekers and refugees often face in accessing services. This issue is further highlighted by the disproportionately high numbers of Afro-Caribbean people who, in the UK for example, are grossly over represented in the mental health system.

SCIE has undertaken work in this area which includes a recently commissioned knowledge review of specialist mental health advocacy for African Caribbean men. This work is based on the high incidence of mental health problems among Afro-Caribbean people which is compounded for men, by the particular difficulties they have been found to experience in accessing appropriate mental health services and support. In particular, they are underrepresented as users of enabling services and over represented in the population of patients who are compulsorily treated by mental health services. SCIE has also carried out a series of consultations with black and minority ethnic groups, asylum seekers and refugees about their preferences for the way in which support should be delivered.

Although the feedback gathered in our consultations related to all people with social care needs, we believe the lessons learned are transferable for the formulation of a strategy to support people with mental health problems. If the EU strategy supported the development of mental health services that incorporated the principles outlined below we are confident it would help promote social inclusion for refugee and asylum seeking communities.

People with social care needs are some of the most vulnerable within refugee communities and their needs are frequently overlooked. As described above, SCIE's 'Stakeholder Participation' work recently explored the barriers faced by refugee and asylum seekers with social care needs and ultimately made recommendations for overcoming those barriers[v].

Barriers to access were found to include; frequent and high profile changes to legislation generating much confusion about entitlement; language and communication problems particularly for women; and agencies' lack of information about the numbers, characteristics and needs of local refugees.

Good practice in ensuring proper provision for asylum seekers and refugees included; partnerships between the statutory and voluntary sectors and a holistic view of individual social situations taking into consideration practical and legal issues, as well as social care needs. Good practice is also based on partnership with refugee communities. In particular, refugee community organisations can play a valuable role in the planning, design and provision of social care services, yet their potential is largely untapped.

From the findings which arose out of the consultations, SCIE made the following recommendations for proper provision of social care and support for asylum seekers and refugees. We would emphasize that as principles for service provision, they should be applied to support for all user groups *including* people with mental health problems from refugee and asylum seeker communities;

- As part of planning and designing services, EU members should carry out local level mapping and consultation exercises to collect data and information about refugees and asylum seekers. As those with support needs are likely to be the hardest to reach, innovative methods should be used.

- The support needs of refugees and asylum seekers cannot and should not be met by generic 'asylum teams'. Instead, specialist teams and services should plan and deliver services that meet the needs of service users who are refugees or asylum seekers. Consultation and feedback with refugees and asylum seekers would be a good basis for doing this.

- The refugee community and voluntary sectors should play a far bigger role in the planning, design and delivery of support services.

SCIE does believe that mental health is relevant in the context of promoting social solidarity. Poor mental health is a problem which cuts across the boundaries of specific interest groups (for example, refugees, asylum seekers, parents, older people and adolescents), so the challenges they *each* face must be addressed by a strategy which seeks to promote social inclusion.

Quality of life

SCIE maintains that promoting mental health is inextricably linked with quality of life and that this could be addressed through the proposed EU strategy. SCIE's support for improving quality of life through addressing mental health problems is reflected in a number of our ongoing or recently completed projects.

Our work on Parental Mental Health and Child Welfare seeks to improve the quality of life of parents with mental health problems – it recognises that more than being users of mental health services, they have important roles as parents and they need support in those roles. The Parental Mental Health and Child Welfare network and related systematic review take a life course approach to mental health problems and a multi agency approach to dealing with them. Although this work is explained in more detail in relation to question 3, it is relevant to note that the work seeks to improve the quality of family life where the parents have mental health problems, and ultimately, for their children, the longer term quality of adolescent and adult life.

SCIE so recognises the importance of mental health and well-being in improving the quality of later life. SCIE recently completed a practice guide on assessing older people with mental health needs. In producing the guide, SCIE recognises that many things can be done to help older people with mental health needs, and their families, improve their quality of life. The guide aims to help professionals working with older people to maintain a positive outlook and gives practical suggestions for things they can do. It is also meant to be a valuable resource for older people themselves and their families and friends.

Indeed, the quality of life of the friends and family of older people with mental health problems represents a specific concern for SCIE and is addressed in a related research review[vi]. We would strongly endorse recognition in the EU mental health strategy of the impact that mental health has on the quality of the lives of informal carers. We maintain that the impact of caring responsibility on employment is a particular challenge and it highlights the need for a coordinated strategic approach. Indeed, although caring affects people's lives in many ways it is significant that large numbers of people give up work to care for family or friends. Particularly for people over fifty who may have left work to care for dependent parents, there is a real difficulty in gaining re entry to employment, so this is where a mental health strategy would have to work with wider welfare policy. We are keen to point out that this situation facing carers is already recognised at EU level.

Action for Carers and Employment, or 'ACE National', is led by Carers UK and funded by the European Social Fund's EQUAL Programme. SCIE supports this critical work as one of the ACE National 'policy partners'. ACE National undertakes groundbreaking work in supporting the inclusion of carers in training and work. From 2002 - 2005, ACE National has focused on the barriers facing individual carers who want to work, testing support such as pre-vocational training, tailored advice and guidance, targeted support services from mainstream employment services such as Jobcentre Plus, and the promotion of carer-friendly policies and practices in the workplace.

We are confident that the complex systems barriers facing carers who work or who want to work *are* recognised at EU level, as reflected by the Social Fund's crucial financial support. We would therefore strongly recommend that findings from ACE National and relevant activities from the wider EQUAL programme are incorporated as a priority in the development of the EU strategy on mental health. We maintain that an EU strategy would fall far short of its potential if it focused only on people experiencing mental health

problems at first hand. The strategy must support the critical role of family, friends and carers and tackle the barriers and challenges they face.

2. Would the development of a comprehensive EU-strategy on mental health add value to the existing and envisaged actions and does section 5 propose adequate priorities?

The answer to the first part of this question depends on whether the strategy would be effective in rationalising the current range of piecemeal policies or whether it will just represent another, separate strand. If the former is to be the case then we would firmly support the development of a comprehensive EU strategy and maintain that this would add value by consolidating the existing policies and envisaged actions.

In relation to section 5, we suggest that tackling the problems of drugs and alcohol misuse should be made an explicit priority. We note that section 6 highlights work that has been done at community level in an effort to reduce substance use disorders. However we maintain that tackling drugs and alcohol should comprise a specific priority of a new EU mental health strategy.

We endorse the creation of a priority on drugs and alcohol partly because of the increasing proportions of people with mental health problems who also have drug and alcohol problems. We are concerned that existing services for mental health and treatment services for people with addictions are incapable of adequately supporting people with both mental health and substance misuse problems. As noted above, increasingly people in psychiatric hospitals for treatment of mental illness also have alcohol or drug problems. People in alcohol and drug treatment programmes often have mental health problems. We would point out that this dual diagnosis presents problems for treatment services and people run the risk of not being able to access either service.

Although SCIE is keen to see a specific priority made of tackling drug and alcohol abuse, we do not feel that it should be an alternative to any of the four already proposed. We support those set out in section 5. In particular, priority 3 which seeks to improve the quality of life of people with mental ill health or disability through social inclusion and the protection of their rights and dignity. Our interest in this and related issues is reflected in the work we have carried out on direct payments as a means of ensuring people have control over their own lives[vii]. SCIE endorses the use of Direct Payments as a method of arranging care because they offer service users greater independence and flexibility in support arrangements. For example, for people from minority ethnic groups this can mean improved access to culturally sensitive support.

It is also relevant to emphasize the lessons learnt from our work on person centred planning[viii], which we refer to under question 1, above. Person centred planning is concerned with protecting people's rights in the planning and provision of their care. We are convinced that the principles associated with person centred planning should be incorporated in the EU strategy as a means of meeting this third priority. Although the principles apply to planning services for all user groups, we are determined that they should be incorporated in this specific strategy on mental health.

The concept of person centred planning was introduced in the White Paper, *Valuing People*[ix], in which it is defined as 'the process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends'. SCIE's practice guide 4 provided the following examples of models for achieving truly person centred planning in the provision of support and SCIE suggests that lessons could be transferred to the provisions of the mental health strategy.

- **Essential lifestyle planning (ELP)**: essential lifestyle planning is a tool that lets you know how someone wants to live and shows you how they would like it to happen through an extremely detailed action plan. ELP lets you discover what is important to service users, what support they need (from their perspective) to remain healthy and safe. A good plan reflects the perceptions of the service user and those who love and care for that person. Essential lifestyle plans look at:

  What people like and admire about service users

  What is important to service users

  Communication

  How to provide support

  Identification of successful methods

  How to solve problems

  ELP is a good way of starting to get to know someone, and work out what is needed on a day-to-day basis. It does not focus on 'dreams' unlike some of the other methods.

- **Personal futures planning**: this is similar to essential lifestyle planning, and includes access to community resources. It is a way of describing life now and looking at what the person wants in the future. It provides more of an overview than the detail of some of the other approaches.

- **MAPS:** this is similar to PATH, below, in that it focuses on desirable futures or dreams, and how service users might try to achieve these. It covers people's history and identifies their gifts.

- **PATH**: PATH stands for Planning Alternate Tomorrows with Hope. This is a fast - moving tool that can be quite graphic and powerful. It pays most attention to the process of change, and helps a group of people who are committed to the service user to understand the plan and how it will progress. This is not so much about gathering information, but planning action. It focuses on the 'dream' and works its way back from there, mapping actions required along the way.

- **Individual service design**: this aims to gain a greater understanding of service users by seeing the past through their eyes. From this it is possible to identify how services need to be designed.

- **Circles of support:** a circle of support is a group of people who meet to help someone along the path to their hopes and dreams: a support network. The focus person asks the support group to help them to leap over barriers that they might come across. The support group also helps the person by opening new doors to opportunities and experiences.

SCIE also has a particular interest in priority 4 which is concerned with developing a mental health information, research and knowledge system for the EU. This is inextricably linked with SCIE's remit which is concerned with improving the experience of people who use social care by developing and promoting knowledge about good practice in the sector. In particular SCIE works with people and organisations throughout the social care sector to identify useful information, research and examples of good practice. Using this information, we produce resources which evaluate practice in a particular area of social care, draw out key messages for good practice and identify areas where more research is needed to inform good practice. We also run an extensive, free on-line resource called *Social Care Online*. Practitioners, researchers, service users and policy makers rely on SCIE's resources as a central and trusted point for evidence-based good practice guidance.

On the basis of our extensive experience and lessons learnt, SCIE would be delighted to cooperate with the EC to help with the development of the planned mental health information, research and knowledge system.

3. Are the initiatives proposed in sections 6 and 7 appropriate to support the coordination between Member States, to promote the integration of mental health into the health and non-health policies and stakeholder action, and to better liaise research and policy on mental health aspects?

SCIE broadly supports the initiatives set out in sections 6 and 7.

SCIE particularly welcomes the emphasis on a preventative approach to improving mental health. SCIE shares the EC's belief in the value of preventative approaches and this is reflected in our work on parental mental health as cited above, in answer to question 1. Our recently commissioned systematic review on parental mental health is based on our concern that parental mental illness has an adverse effect on child mental health and development. Furthermore, the mental health of children is known to be a strong predictor of their mental health in adulthood[x]. Therefore we firmly endorse the EC's emphasis on prevention.

As a general comment, we are pleased to find the first initiative broadly relates to policies on regeneration and community approaches to improving mental health. The promotion of mental health from childhood, through the working population and into old age would help tackle the stigma surrounding mental health problems. SCIE supports efforts to tackle stigma relating to mental health including media stereotyping because we recognise that stigma and the discrimination that results from stigma is one of the most important social factors negatively affecting peoples' mental well-being.

Specifically in relation to the consultation question, we would endorse dialogue between member states. In particular we support exchange of information between members based on research and piloting of policy initiatives in order for lessons to be shared from other EU countries. We promote the importance of research on mental health aspects that is *user led* although, as described above, we are concerned with the lack of financial support for user led organisations. We would reiterate that service user and carer contributions are essential if the strategy is going to develop mental health policies that are relevant to service users.

References

[i] Office for National Statistics, *Labour Force Survey (LFS)*, August 2003, figures for England only. The LFS provides employment data on people with the following health conditions: problems with the arms or hands; legs or feet; back or neck; difficulty in seeing; difficulty in hearing; speech impediment; skin conditions or allergies; chest or breathing problems; heart/blood pressure/circulation disorders; stomach/liver/kidney/digestion problems; diabetes; depression or bad nerves; epilepsy; learning difficulties; mental illness, phobia or panics; progressive illnesses; and other problems or disabilities.

[ii] Turner, M. and Beresford, P. (2005) *Contributing on equal terms: service user involvement and the benefits system,* London: Social Care Institute for Excellence

[iii] Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st century* London: TSO

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[vi] Moriarty, J. (2005) *Research Review 5: Update for SCIE best practice guide on assessing the mental health needs of older people,* London: Social Care Workforce Research Unit

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[viii] Social Care Institute for Excellence (2005) Practice guide 4: Adult placements and person centred approaches London: SCIE

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[x] Falkov, A. (1998) (ed) Crossing Bridges – training resources for working with mentally ill parents and their children – Reader. London: Department of Health