

# LTCAS Consultation Response



## **Towards a Mentally Flourishing Scotland: The Future of Mental Health Improvement in Scotland 2008-11**

**Submitted February 2008**

### **About LTCAS**

The Long Term Conditions Alliance Scotland (LTCAS) aims to bring together hundreds of voluntary and community organisations across Scotland to give a national voice to ensure the interests and needs of people living with long term conditions are addressed.

The long term conditions sector comprises a broad range of organisations including large national bodies as well as small volunteer-led community based groups. The sector contains a wealth of expertise, experience, information and services that work to support the estimated two million people who live with a long term condition in Scotland.

## **Key Recommendations**

These recommendations are discussed in detail in the body of LTCAS' response.

- Improve detection and care of mental health problems among those with long term physical conditions.
- Continue to use anticipatory approach to prevent people with mental health problems developing physical long term conditions and to diagnose/intervene early where this happens.
- Make appropriate links between the self management and recovery agendas.
- Undertake work to understand and address the relationship between having a long term condition, experiencing stigma and discrimination and the impact this has on mental health and wellbeing.
- Support partnership, voluntary sector led work to develop new approaches to address mental health and wellbeing of people with long term conditions.
- Recognise target groups within long term conditions who may experience multiple challenges to good mental health and wellbeing as well as barriers to accessing support.
- Engage with LTCAS to ensure linking between long term conditions policy and practice and that relating to mental health and wellbeing.

### **1. Broad comments**

LTCAS welcomes the opportunity to comment on the future of the mental health and wellbeing agenda in Scotland. LTCAS members consistently identify this as an area of considerable importance and one where policy and practice is not yet addressing the needs of people who live with long term physical conditions.

Paragraph 4.1 of the discussion document refers to a continuum at one end of which people are flourishing while at the other they are languishing. People with long term physical conditions are among those who tend towards the 'languishing' end of this spectrum. The next stage of work on mental health and wellbeing must help to redress this.

## 2. People with physical long term conditions and the risk of mental ill health

People who live with a long term physical condition are known to be at greater risk of mental health problems and conversely those with mental health problems are more likely to develop a physical long term condition.

### A Snapshot of the Evidence:

- People with limiting long term conditions are at significantly higher risk of 'mental distress and psychological disorder'. On the General Health Questionnaire (GHQ) rating system (which runs from zero to 12 with scores of 4 and above indicating potential mental ill health) 30 per cent of those with limiting long term conditions scored 4 or more, compared with only 9.4 per cent of other adults<sup>1</sup>.
- Depression and suicide are four or five times more common among people with epilepsy than in the general population<sup>2</sup>.
- A study in 2004 found higher rates of depression among people with epilepsy or asthma<sup>3</sup>.
- People with diabetes are three times more likely than others to experience depression and this is likely to be severe and recurring<sup>4</sup>.
- Depression and mania are known to be more common among people with dementia<sup>5</sup> and depression affects between 30 and 60 per cent of carers of people with dementia<sup>6</sup>.

LTCAS welcomes the discussion document's recognition of this inter-relationship between mental and physical ill health. In particular paragraph 5.3 which discusses the need for prevention work to address the 'interaction between mental illness and other

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<sup>1</sup> 'Characteristics of adults in Scotland with long term health conditions: An analysis of Scottish Household and Scottish Health Surveys' Wendy Loretto and Matt Taylor, University of Edinburgh, Scottish Executive Social Research 2007

<sup>2</sup> 'Epilepsy (Fast Facts)', M Brodie, S Schachter and P Kwan 2005

<sup>3</sup> 'Depression and comorbidity in community-based patients with epilepsy or asthma', Alan Ettinger MD, Michael Reed PhD and Joyce Cramer for the Epilepsy Impact Project Group <http://www.neurology.org/cgi/content/abstract/63/6/1008>

<sup>4</sup> 'Identification and treatment of depression in people with diabetes', Marie Clark in Diabetes and Primary Care Vol 5 2003

<sup>5</sup> 'Enduring increased risk of developing depression and mania in patients with dementia', Nilsson, Kessing, Sorensen, Andersen and Bolwig, University of Copenhagen 2002

<sup>6</sup> 'A follow up study of depression in the carers of dementia sufferers', C G Ballard, C Eastwood, M Gahir and G Wilcock BMJ 1996  
<http://www.bmj.com/cgi/content/full/312/7036/947>

health conditions, such as heart disease, cancer and diabetes and other long term physical conditions’.

### **3. Early detection, prevention and promotion**

At present people are frequently viewed in relation to their primary condition and their broader needs can be overlooked as a consequence. Health professionals dealing with long term physical conditions do not routinely consider mental health issues and may not view this as within their remit. This often means problems are not picked up and people do not access support, services or treatment. For example among people with diabetes who have depression less than a third are diagnosed and given treatment<sup>7</sup>.

LTCAS welcomes the proposed action of ‘taking account of, and addressing, the mental health /mental illness components and consequences of physical illnesses and long term conditions’ (paragraph 9.2). However, further activity is required if this is to become a reality. LTCAS recommends building on paragraph 8.3.3 of the discussion document so that people involved in supporting those with long term conditions consider mental health and wellbeing and this becomes embedded in their practice. This is likely to require new training, tools and practice development work.

In addition LTCAS supports continued focus on improving the physical health of people experiencing mental ill health, for example through the type of screening and anticipatory care referred to in commitment 5 of Delivering for Mental Health.

### **4. Supporting people with long term conditions to flourish**

#### **Self management and recovery**

LTCAS welcomes the links made in paragraph 9.4 of the document between self management and recovery. LTCAS has recently developed a national Self Management Strategy for Scotland at the behest of the Scottish Government Health Department. The aims and ethos of self management and recovery are closely aligned and given the co-existence of physical long term conditions with mental health problems the target groups for these approaches will overlap significantly. It is important for policy and practice to increasingly connect these agendas.

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<sup>7</sup> ‘Identification and treatment of depression in people with diabetes’, Marie Clark in Diabetes and Primary Care Vol 5 2003

Self management will contribute considerably to the aim in paragraph 8.3 of promoting and embedding the 'skills, attributes, belief, values and circumstances that increase resilience, self-efficacy, a sense of mastery, coherence and control, individually and collectively'.

## **Discrimination**

The discussion document (paragraph 6) refers to the damaging impact of discrimination on people's mental health and wellbeing. People living with long term conditions identify discrimination as one of the biggest challenges to self management, recovery and good mental health and wellbeing. At a recent consultation event people described being discriminated against in employment and experiencing stigma caused by ignorance on the part of the general public, employers and the media<sup>8</sup>.

While Scotland has begun to make significant, and vital, progress in addressing discrimination and stigma relating to disability or mental health, little attention has yet been given to attitudes towards long term ill health more broadly. There is a pressing need to understand and address the relationship between having a long term condition, experiencing stigma and discrimination and the impact this has on mental health and wellbeing.

LTCAS recommends existing work be extended to encompass long term physical conditions. In addition the Alliance suggests further research aimed at better understanding the nature and extent of this type of discrimination and its effects. The research should be focussed towards identifying key actions and developing effective responses.

## **Developing new approaches**

While work already underway should be built upon, there is also a need to develop new approaches and provision. LTCAS therefore welcomes the suggestion (paragraph 8.4.2) that efforts to prevent mental health problems or illness among those at higher risk (including because of long term physical conditions) should be re-focussed and raised.

The key question is what form this activity will take.

LTCAS recommends a partnership approach driven by the voluntary sector. By bringing together successful approaches from the mental

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<sup>8</sup> 'Living Well with Long Term Conditions, Report of Open Space Events in Glasgow and Aberdeen' NHSScotland, Scottish Executive and LTCAS 2006

health sector with those from the long term conditions sector the benefit to people living with long term physical conditions could be maximised. For example condition specific organisations could work with mental health bodies to extend successful programmes such as 'Mindfulness' to their own constituent groups. This type of work has already begun to develop, for example through use of Mindfulness-based techniques within self management courses.

Other means of addressing long term conditions and mental health and wellbeing together could include the development of 'wellbeing centres'. This Thistle Foundation<sup>9</sup> in Craigmillar, Edinburgh is one example of where this model is proving successful.

The Strategy for Self Management<sup>10</sup> recommends consideration of 'Independent Health and Wellness Accounts' which would build on the person-centred, empowering approach of direct payments and work in a similar way to the existing 'Independent Learning Accounts (ILA)'. These would enable people on lower incomes to access supports (e.g. exercise, relaxation or sport) that could have a significant positive impact on their mental health and wellbeing but which are currently only available to those on higher incomes.

## **5. Targeting Key Groups**

People living with long term conditions are themselves a key target group. However within this there are some who may be at greater risk of poor mental health and who experience multiple risk factors.

### **Black and Minority Ethnic groups**

People from BME communities experience higher prevalence of some long term conditions. In some instances they are also more susceptible to mental health problems than others with long term conditions (for example in diabetes<sup>11</sup>). BME groups may also experience multiple challenges caused by discrimination, cultural issues, language barriers and difficulties accessing information.

### **Children and young people**

LTCAS recognises that significant attention has been given to improving the mental health and wellbeing of children and young

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<sup>9</sup> [www.thistle.org.uk](http://www.thistle.org.uk)

<sup>10</sup> 'Gaun Yersel, Being Human: The Self Management Strategy for Long Term Conditions in Scotland' LTCAS / Scottish Government (draft published 2007, final version not yet published)

<sup>11</sup> 'Highs and lows' Brian Burns in Diabetes Update Winter 2001

people. However they tend to be overlooked within the long term conditions agenda and work on long term conditions and mental health and wellbeing must also address their needs.

Children and young people with long term conditions face distinct challenges and these relate strongly to mental health and wellbeing. These include for example: anxiety and depression; shortened life expectancy; and stigma and lack of understanding from peers, teachers and families. Children with asthma have been found to experience anxiety (e.g. living in fear that their next attack will kill them), sleep deprivation (caused by symptoms) and associated depression and poor cognitive development<sup>12</sup>. In addition children and young people face dilemmas between balancing management of their condition and priorities such as having a job, participating in social activities and normal adolescent risk taking behaviour<sup>13</sup>.

### **Older people**

Older people form the largest group of those living with long term conditions and are more likely to have multiple conditions. Older people often face a range of challenges, for example greater risk of: age discrimination; poverty; social isolation; and difficulties in accessing information and services.

### **Men**

Men experience poor health outcomes and are less likely to access information, support or services. Indeed Men's Health Week 2007 focused on men and long term conditions<sup>14</sup>. Links should be made between long term physical conditions and mental health and wellbeing work aimed towards men.

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<sup>12</sup> Asthma UK Scotland

<sup>13</sup> 'Quality of Life Right Now!', Young Person's summit' Diabetes UK Scotland 2006

<sup>14</sup> [http://www.menshealthforum.org.uk/userpage1.cfm?item\\_id=2092#2006](http://www.menshealthforum.org.uk/userpage1.cfm?item_id=2092#2006)

## **6. Linking with activities targeted at long term conditions**

LTCAS welcomes the discussion document's recognition of the need for Community Health (and Social Care) Partnerships to link with activities targeted at long term physical conditions, anticipating where the greatest needs are and where activity should be targeted.

At a national level LTCAS would welcome the opportunity to engage with the Mental Health Division of the Scottish Government. The Alliance is playing a lead role in development and implementation of long term conditions policy and would value a discussion about the links between this and the mental health and wellbeing agenda. In addition LTCAS would wish to explore how the welcome recognition of people with long term conditions as a key 'at risk' group can be turned into effective actions.

## **Conclusion**

LTCAS welcomes the broad direction of 'Towards a Mentally Flourishing Scotland: The Future of Mental Health Improvement in Scotland 2008-11'.

The document makes reference throughout to the inter-relationship between long term physical conditions and poorer mental health and this recognition is vitally important. Mental health and wellbeing among people with long term physical conditions has not received sufficient attention to date despite this being a group at far greater risk of mental ill health.

LTCAS hopes the actions prioritised following the discussion document will redress this and provide the opportunity for people with long term conditions to move towards enjoying flourishing mental health.

### **For clarification or further discussion of the issues raised in this response please contact:**

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