

CONSULTATION QUESTIONS

Overall Approach

This consultation reflects a continuation and development of the Scottish Government's current approach for mental health. There is a general consensus that the broad direction is right but **we want to consult on:**

- The overall structure of the Strategy, which has been organised under 14 broad outcomes and whether these are the right outcomes;
- Whether there are any gaps in the key challenges identified;
- In addition to existing work, what further actions should be prioritised to help us to meet these challenges.

Comments

The Princess Royal Trust for Carers and The Scottish Young Carers Services Alliance, consulted with carers throughout Scotland. The feedback response will be emailed to mhstrategy@scotland.gsi.gov.uk

Improvement Challenge Type 1

We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes. An example of this is the implementation of the Dementia Strategy. There is a consensus that services for people with dementia are often not good enough and we already know about a range of actions that will improve outcomes. However some of these changes involve redesigning the way services are provided across organisational boundaries and there are significant challenges attached to doing this.

Question 1: In these situations, we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes

Comments

Improvement Challenge Type 2

We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes. Supporting services to improve care for people with developmental disorders or trauma are two areas where further work is needed to identify exactly what needs to happen to deliver improved outcomes.

Question 2: In these situations, we are keen to get your views on what needs to happen next to develop a better understanding of what changes would deliver better outcomes.

Comments

Outcome 1: People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.

Question 3: Are there other actions we should be taking nationally to reduce self harm and suicide rates?

Comments

Question 4: What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

Comments

Question 5: How do we build on the progress that see me has made in addressing stigma to address the challenges in engaging services to address discrimination?

Comments

Question 6: What other actions should we be taking to support promotion of mental wellbeing for individuals and within communities?

Comments

Outcome 2: Action is focused on early years and childhood to respond quickly and to improve both short and long term outcomes.

Question 7: What additional actions must we take to meet these challenges and improve access to CAMHS?

Comments

Question 8: What additional national support do NHS Boards need to support implementation of the HEAT target on access to specialist CAMHS?

Comments

Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.

Question 9: What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?

Comments

Question 10: What approaches do we need to encourage people to seek help when they need to?

Comments

Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.

Question 11: What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?

Comments

Outcome 5: Appropriate, evidence-based care and treatment for mental illness is available when required and treatments are delivered safely and efficiently.

Question 12: What support do NHS Boards and key partners need to apply service improvement approaches to reduce the amount of time spent on non-value adding activities?

Comments

Question 13: What support do NHS Boards and key partners need to put Integrated Care Pathways into practice?

Comments

Outcome 6: Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.

Question 14: How do we continue to develop service user involvement in service design and delivery and in the care provided?

Comments

Question 15: What tools are needed to support service users, families, carers and staff to achieve mutually beneficial partnerships?

Comments

Question 16: How do we further embed and demonstrate the outcomes of person-centred and values-based approaches to providing care in mental health settings?

Comments

Question 17: How do we encourage implementation of the new Scottish Recovery Indicator (SRI)?

Comments

Question 18: How can the Scottish Recovery Network develop its effectiveness to support embedding recovery approaches across different professional groups?

Comments

Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.

Question 19: How do we support families and carers to participate meaningfully in care and treatment?

Comments

Question 20: What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?

Comments

Outcome 8: The balance of community and inpatient services is appropriate to meet the needs of the population safely, efficiently and with good outcomes.

Question 21: How can we capitalise on the knowledge and experience developed in those areas that have redesigned services to build up a national picture of what works to deliver better outcomes?

Comments

Outcome 9: The reach of mental health services is improved to give better access to minority and high risk groups and those who might not otherwise access services.

Question 22: How do we ensure that information is used to monitor who is using services and to improve the accessibility of services?

Comments

Question 23: How do we disseminate learning about what is important to make services accessible?

Comments

Question 24: In addition to services for older people, developmental disorders and trauma, are there other significant gaps in service provision?

Comments

Outcome 10: Mental health services work well with other services such as learning disability and substance misuse and are integrated in other settings such as prisons, care homes and general medical settings.

Question 25: In addition to the work already in place to support the National Dementia Demonstrator sites and Learning Disability CAMHS, what else do you think we should be doing nationally to support NHS Boards and their key partners to work together to deliver person centred care?

Comments

Question 26: In addition to the proposed work in acute hospitals around people with dementia and the work identified above with female prisoners, are there any other actions that you think should be national priorities over the next 4 years to meet the challenge of providing an integrated approach to mental health service delivery?

Comments

Outcome 11: The health and social care workforce has the skills and knowledge to undertake its duties effectively and displays appropriate attitudes and behaviours in their work with service users and carers.

Question 27: How do we support implementation of *Promoting Excellence* across all health and social care settings?

Comments

Question 28: In addition to developing a survey to support NHS Boards' workforce planning around the psychological therapies HEAT target – are there any other surveys that would be helpful at a national level?

Comments

Question 29: What are the other priorities for workforce development and planning over the next 4 years? What is needed to support this?

Comments

Question 30: How do we ensure that we have sustainable training capacity to deliver better access to psychological therapies?

Outcome 12: We know how well the mental health system is functioning on the basis of national and local data on capacity, activity, outputs and outcomes.

Question 31: In addition to the current work to further develop national benchmarking resources, is there anything else we should be doing to enable us to meet this challenge?

Comments

Question 32: What would support services locally in their work to embed clinical outcomes reporting as a routine aspect of care delivery?

Comments

Outcome 13: The process of improvement is supported across all health and social care settings in the knowledge that change is complex and challenging and requires leadership, expertise and investment.

Question 33: Is there any other action that should be prioritised for attention in the next 4 years that would support services to meet this challenge?

Comments

Question 34: What specifically needs to happen nationally and locally to ensure we effectively integrate the range of improvement work in mental health?

Comments

Outcome 14: The legal framework promotes and supports a rights based model in respect of the treatment, care and protection of individuals with mental illness, learning disability and personality disorders.

Question 35: How do we ensure that staff are supported so that care and treatment is delivered in line with legislative requirements?

Comments



SCOTTISH
young carers
SERVICES ALLIANCE



The Princess Royal Trust
for Carers

Scotland Office
Charles Oakley House
125 West Regent Street
Glasgow
G2 4SA

Telephone: 0141 221 5066
Facsimile: 0141 221 4623
Email: infoscotland@carers.org

Websites:
www.carers.org
www.youngcarers.net

PRESIDENT
Her Royal Highness
The Princess Royal

VICE PRESIDENTS
The Rt Hon
The Lord Mackay of Clashfern
Pam Ferris
Trevor Hemmings
John Paterson
Lord Vallance of Tummel
Dame Gillian Wagner DBE
Sir Philip Wroughton

CHAIRMAN
Ian Robertson

Written Submission – Draft mental Health Strategy for Scotland

Mental Health Strategy for Scotland 2011-2015 – Public Consultation

The Princess Royal Trust for Carers and The Scottish Young Carers Services Alliance welcomes the opportunity to submit information to The Scottish Government as it considers the Mental Health Strategy for Scotland 2011-2015.

The Princess Royal Trust for Carers (The Trust) is the largest dedicated resource supporting unpaid carers and young carers in the UK, through a network of Carers' Centres and through young carers' projects. Further information on the network and The Scottish Young Carers Services Alliance is included in Appendix 1.

Many of the Carers' Centres within our network and young carer services within The Young Carers Services Alliance will offer support to carers who live with someone affected by mental health problems. The services include:

- Mental Health Awareness
- Emotional and practical support, including peer group support, relaxation and meditation techniques
- Helping carers maintain their own wellbeing – Steps to Wellbeing
- Training which could include, e.g., moving and handling, stress management, understanding medical conditions etc
- Identifying carers, e.g. through partnership work with GP's, primary care practitioners, the acute sector and other voluntary sector organisations.

Young carers projects, part of the Scottish Young Carers' Services Alliance, will offer specific support to children and young people who have a caring role because their parents and/or siblings have mental health problems.

The Scottish Government funded a dedicated Young Carers Mental Health Development Coordinator (more information about the role in Appendix 2). Currently an on-line toolkit has been developed for young carer workers. This toolkit will offer ideas and resources for workers to hold interactive workshops around mental health and promotion of wellbeing with young carers. This will be available from late February 2012.

The Princess Royal Trust for Carers
Registered Charity SCO 15975



Incorporated in Scotland as a non profit-making company limited by guarantee number 125046.

Registered Office:
7 West George Street
Glasgow G2 1BA
Charity Number SC015975

General Feedback

We welcome the early publication of this consultation and many of the points made within it.

Our feedback to this consultation covers:

- Child and adolescent mental health service provision and plans
- Recognition and involvement of carers and young carers
- Mental health improvement factors

We focus on the specific needs of unpaid carers and young carers and the contribution that specialist carers' and young carers services can make.

Overall Approach

- **Comments on overall structure of strategy and whether these are the right outcomes**
- **Whether there are any gaps in the key challenges identified**
- **What further actions should be prioritised to help us meet these challenges**

The outcomes stated appear to be well thought out and appropriate, however more emphasis could have been placed on prevention and promotion work. There is no specific outcome looking at forensic mental health services, service users and carers who can be particularly marginalised and isolated. They can feel excluded from discussions and decisions about care and treatment, and in particular decisions about discharge back to the community.

We would very much like to see an outcome focussing on maintaining the emotional and mental health of carers in the final mental health strategy given their critical role in delivery of health and social care in Scotland. The Scottish Government has acknowledged that "*carers are providers of services, not service users*".¹ This should place carers on an equal footing with other service providers in being recognised, listened to and involved.

Up to 70% of carers will hide the fact that their health is suffering; one in five give up work to care; 46% need to see a GP due to the impact of caring on their own health; where spouses or partners provide caring support to each other and where one person in the partnership falls ill or experiences an adverse event, this can result in both being admitted to hospital at much greater cost to health and social care budgets.² Providing timely support to carers can help carers' health, reducing their own need to use services. This is one of the outcomes within the Carers Strategy and one we would urge the Scottish Government to highlight and acknowledge this in the final mental health strategy.

¹ Caring Together; The Carers Strategy for Scotland 2010-2015, pg22.

² Caring Together: The Carers Strategy for Scotland 2010-2015 pg 22.

The network of Carers Centres throughout Scotland, and the Scottish Young Carers Services Alliance, currently offer innovative and highly praised activities looking at prevention of mental health problems in carers. These include sessions around stress management; looking after your mental health; steps to wellbeing; relaxation techniques; pampering sessions and, one of the most important of all, someone to talk with and share experiences and ideas. Solution focussed approaches are at the heart of the work that Carers Centres and Young Carers Services carry out with a focus on the wellbeing and health of both carers and young carers.

For young carers a crucial element of the work carried out is peer support. Indeed feedback from Young Carers Festival 2011, noted that getting the chance to go to groups *'You got to meet other young carers like you. It makes you feel like you aren't the only one'*³. Similarly the Festival itself, supported by the Scottish Government, is another innovative service provided by The Scottish Young Carers Services Alliance and enables young carers to have their voices heard and get respite from their caring role. One attendee noted, *"Over the past few Festivals I have met some amazing people, and I am still in touch with at least 10 of them. My closest friends are people from the Festival and they have made the biggest impact on my life and I am so grateful to the Festival for that."*⁴

Within Carers Strategy and Young Carers Strategy emphasis is placed on the importance of identification of carers and this must be reflected in final mental health strategy. Funded by The Scottish Government, the work of The Trust developing a toolkit to identify and support younger young carers is an example of how we can assist professionals to identify carers, and of helping carers to have the confidence to come forward to ask for help when they need it.

Priority has to be given to working in partnership with other organisations working with children and young people to promote good mental health, in particular education services/higher education facilities, youth services, young carer services and further education facilities. There is very little mention of these partners in the Strategy. The national Young Carers Mental Health Development Coordinator, employed by The Princess Royal Trust for Carers and funded by the Scottish Government, has compiled a training toolkit around mental health and wellbeing which will be rolled out to Scottish Young Carer Services Alliance. This work could be replicated with adult carers, so reducing the impact of caring on mental health and promoting positive coping strategies for all carers.

³ Young Carers Festival Report, 2011

⁴ Young Carers Festival Report, 2011

Improvement Challenge Type 1

We know where we are trying to get to and what needs to happen to get us there, but there are significant challenges attached to implementing the changes.

Q. 1. In these situations we are keen to understand whether there is any additional action that could be taken at a national level to support local areas to implement the required changes

Building capacity within specialist carers' services such as Carers Centres could help to implement changes and the vision to be outlined in the final strategy. Providing dedicated staff who can work with carers and mental health service providers to coordinate information sharing would be one approach. Carer advocacy services would also be welcome to this group and would go a long way to improving Care Pathways approaches to involving carers and families. This could also assist those carers who become Named Persons under the 2003 Act, a role many of them are not prepared for and can find difficult and confusing.

Making more use of not-for-profit sector organisations when designing community discharge packages should be a priority. These are especially significant in out of hours care and can be more accepted by service user and carer as they are seen to be independent and not tied to statutory services which may be seen as an option of last resort.

The critical nature of the carers' role is one which is supported by the network of Carers Centres and The Scottish Young Carers Services Alliance in partnership with other not for profit organisations. This partnership approach enables carers and young carers the chance to access support that is appropriate to their caring situation and their own lives.

Mental health prevention work is routinely carried out within specialist carer services, including Carer Centres, and young carer services. It has been revealed that young carer projects save £6.72 for every £1 invested.⁵ This represents considerable value for money and, the prevention work helps to instil coping strategies with young carers that can see them cope more confidently with their caring role, increasing their self-esteem and resiliency to cope with the challenges of life as a young carer and a young person in modern Scotland.

⁵ At What Cost to Young Carers Report (2009)

Improvement Challenge Type 2

We know we need to improve service provision or that there is a gap in existing provision, but we do not yet know what changes would deliver better outcomes.

Q. 2. What needs to happen next to develop a better understanding of what changes would deliver better outcome.

The Strategy should highlight the importance, and success, of local partnerships in driving forward significant gains in mental health improvement. These have come about as a result of previous strategies, "Delivering for Mental Health," "Towards a Mentally Flourishing Scotland" and "With Inclusion in Mind". The new Mental Health Strategy must highlight that these integrated approaches have worked and make a difference to public mental health, and build on such success. The fear is that public mental health and population based mental health improvement will indeed suffer if not adequately supported and promoted.

Specialist carer services, including Carers Centres and Young Carer Services, play a vital role in the promotion of positive mental health and wellbeing. This is done in partnership with other organisations. More emphasis in the final mental health strategy around such partnership working with the not for profit sector has to be made clearer – cross organisational working within the not for profit sector but also statutory and non-statutory sectors working together and in equal partnership. This has to include specialist carer services.

Outcome 1: People and communities act to protect and promote their mental health and reduce the likelihood that they will become unwell.

Q. 3. Are there other actions we should be taking nationally to reduce self-harm and suicide rates?

The Choose Life programme has been of benefit to those carers who have taken part. It has been expressed to us by young carers that they would like access to something like this but appropriate to their age. Young carers have expressed their increasing frustration over lack of help they receive when living with, or dealing with, someone with suicidal ideation. They point out that having a poster on a school wall with a help line phone number is not enough. Many young carers support their peers through episodes of self-harm or suicidal thought and they (the young carers) feel unsupported to do this. Within The Scottish Young Carers Services Alliance we are hoping to look at this issue with young carers and promote an awareness raising tool which could be used with young people.

The ASSIST programme of suicide prevention has been a welcome move by the Scottish Government through its Choose Life initiative. This could be further

strengthened by making this more age appropriate for younger people. Similarly continuing the programme of training facilitators in this valuable programme will ensure that more people are trained in suicide prevention and intervention work. Within the network of Carers Centres there are some staff members trained to deliver ASSIST and this is something which should continue to be replicated across a wide variety of organisations and communities.

Priority has to be given to remote and rural areas of Scotland, in particular island communities. Carers from these parts of the country report feeling frustrated at lack of out of hour CPN cover. The distance between islands, and between island and mainland, also presents particular problems, especially in getting emergency services to people.

Another major "ask" from carers and service users in these areas is for someone to actually listen to them and take into account the vital experience of these carers. In vast majority of cases of self-harm and suicidal ideation the carer can be the first to notice changes of behaviour in the cared for person. These changes often indicate the state of mind of the person. Carers, who live constantly with the person, can be best placed to spot these sometimes subtle changes. Carers have expressed to us that if they feel included and valued if they are listened to and their experiences are taken into account, and they feel it makes a difference to the eventual outcome of the psychiatric intervention. One carer noted that, as a result of the CPN listening to what she had noticed in her husband's behaviour, quick action was taken to implement a crisis plan and avoid admission to hospital.

Access to appropriate respite for mental health carers and those they support remains a challenge and gap in Scotland. It would be interesting to see how the additional respite investment directed through the voluntary sector is addressing this and whether this specific group of carers is benefiting from this welcome investment.

The emphasis on suicide prevention and reduction of self-harm must remain over the next few years, but more work needs to be done to develop these approaches in all organisations and communities. In particular certain high risk groups need to be targeted, for instance, prisoners, those living in deprived areas, newly unemployed, young people, and those living with addictions.

The Princess Royal Trust for Carers is beginning a new initiative in partnership with Breathing Space. This exciting new work will see a reciprocal approach to awareness raising amongst Breathing Space staff about role of carers and impact of caring, and awareness amongst carer support staff about the work of Breathing Space. The intention is to make the Breathing Space helpline more recognised and used by carers.

Q. 4, 5 and 6. What further action can we take to continue to reduce the stigma of mental illness and ill health and to reduce discrimination?

There was mention in the Strategy about the work done by *see me* but no mention of future development. Much has been achieved by this programme, but more could perhaps be done to tackle the stigma that mental health carers face in particular. An emphasis should be placed on working towards eradicating the discrimination experienced by service users and carers in accessing areas such as employment, education, benefits, bank loans etc. The work to date of *see me* has focussed mainly on language and terminology, but as one service user commented, "you can call me what you like, but when you turn me down for a job because of my illness, then it is serious."

Further development of *see me* could involve strengthening the work it does around discrimination and barriers to accessing mainstream services which still exist for many service users and carers. Educational programmes do go a long way to achieving this, but there is nothing more powerful than the collective experiences of service users and carers, and if utilised effectively they can contribute to reducing stigma and discrimination across a range of organisations and communities.

The new Mental Health Strategy needs to highlight that schools and further/higher education establishments have an important role to play in anti-stigma work. They should be encouraged to actively work in partnership with service users and carers to reduce discrimination and engage with service users and carers to establish what constitutes discrimination for this group of people (as much of the discrimination reported is discreet and hidden). Similarly for forensic carers there needs to be more work done on reducing the stigma attached to them. One area of contention is the use of the term "Forensic" which, for many people, implies association with the Criminal Justice system. For some service users this has not been the case. This association with Criminal Justice system is cited as being a reason for forensic carers not accessing specialist help and support earlier in their caring journey.

The impact of bullying on children and young people, both during childhood and in later life, can be substantial. This can lead to forms of discrimination and stigma experienced by young people, including young carers. Scotland is leading the way in anti-bullying work through the work of *respect me*. The Strategy needs to highlight the priority of supporting the work of *respect me* and should include a focus on anti-bullying.

Outcome 2: Action is focused on early years and childhood to respond quickly and to improve both short and long term outcomes.

Q. 7 & 8. What additional actions must we take to meet these challenges and improve access to CAMHS?

It is disappointing to see that the section dealing with child and adolescent mental health focused entirely on the CAMHS service (including both consultation questions). The notion of promotion of positive mental health and coping

strategies with our young people is not recognised but could have very positive outcomes. One in ten 5 – 15 year olds experiences a mental health problem. Investment in mental health of children and young people must go beyond CAMHS, incorporating health in early years education, early intervention programmes for parents and early years health visitors trained in mental health. There are bound to be a great many young people in the statistic above who struggle with their mental health but can be helped if intervention and education is provided as effective ways of living with the challenges of life.

Youth services need to have investment in them to promote and educate about mental health. The Young Carers Mental Health Development Coordinator has done much work around a dedicated on-line toolkit to promote positive well-being with young carers. More could be done to develop this approach further. For many young carers the stress and isolation of being a young carer, as well as coping with the demands of growing up, can lead to deteriorating mental health situations. These are not serious enough to warrant intervention by CAMHS, and indeed many young carers are told they cannot access CAMHS because they have no diagnosed illness. However these young carers are struggling with their mental health and if intervention is not timely they can become the adult mental health patients of the future.

The promotion of child and youth mental health requires greater investment and the strategy should highlight need for more planning and investment in preventative and early intervention approaches that would in turn reduce the pressure of referral to specialist services. There is a crucial role for the voluntary sector in promoting child mental health and this should be featured in the final version of the Strategy. The vital role played by Scottish Young Carers Services Alliance and specialist young carers services could be highlighted as an example of the innovative work which is carried out in promoting mental health, in particular the Scottish Government funded post of YC Mental Health Development Coordinator. Appendix 2 contains a summary of work achieved to date. This unique approach has allowed the Alliance to pilot and promote work with young carers to help them understand risk and protective factors affecting mental health and strategies for maintaining good mental health. This work needs further investment to extend its reach into adult carers and hard to reach and hidden young carers. The work of specialist adult carer support services has an important preventative focus which can help maintain the mental health and wellbeing of unpaid carers.

The Strategy is to be commended for making investment in CAMHS. However this investment must not come at a cost to preventative, complementary services which promote good mental health.

CAMHS provision across Scotland is still patchy. The stated target of 26 weeks from referral to treatment is too long and will leave many children and young people at the severe end of mental illness in great distress, placing further stress on families and carers. Carers tell us that they can wait for lengthy periods of

times for recognition and for diagnosis. Such waits can also have a detrimental impact on the education of these children and young people (and indeed any siblings) if their illness or behaviour causes them to miss, or be excluded, from school. This target should be reduced.

There must be more reference made in the Strategy to CAMHS joining up with other non-psychiatric services where appropriate, such as in eating disorders where some children are admitted into paediatric wards and addiction services where a young person has problems with alcohol or substance misuse.

Outcome 3: People have an understanding of their own mental health and if they are not well take appropriate action themselves or by seeking help.

Q. 9 & 10. What further action do we need to take to enable people to take actions themselves to maintain and improve their mental health?

According to the Scottish Executive,⁶ around a third of GP appointments are about mental health problems. Research however suggests that GPs don't feel confident in providing information on mental health. The Strategy should offer GPs regular continuing professional development opportunities in positive mental health and common mental health problems. This is especially the case when dealing with children and young people.

Carers need to be identified as carers and the impact of caring recognised by front line medical staff, employers and teachers. Cross referencing to The Carers Strategy in the new Mental Health Strategy is one way of emphasising this approach.

Early identification and recognition of carers is essential to ensure that they can gain access to specialist carer services such as Carer Centres and Young Carer Services. GPs are pivotal in this and much work has been going on with The Scottish Government, The Princess Royal Trust for Carers, other partner organisations and The Royal College of General Practitioners to promote role of carers and specialist carer organisations.

The earlier specialist carer services become involved with carers, the better the outcome for carers in terms of their own mental health and wellbeing. The work of Carers Centres and Young Carer Services in promoting coping strategies, managing stress levels, speaking in confidence with others in similar situations and getting more practical help with the everyday demands of caring role are an excellent example of what can be achieved to ease the impact of caring. In particular young carers' role needs to be recognised by health and social care staff. The impact of being a young carer can have far reaching consequences for the young person, often carrying on the caring role into adulthood.

⁶ Health In Scotland: Report to Chief Medical Officer, 2003,

Young carers need help and support to look after their own mental health and wellbeing. The Scottish Government has stated its *intention* "From 2010 onwards, the Scottish Government will work with NHS Boards to ensure that identifying and supporting young carers is included in workforce training."⁷ Part of this work has been noted in the draft Mental Health Strategy, that of the pilot authorisation card in partnership with The Scottish Young Carers Services Alliance.

Better understanding of caring for patients with mental health problems within the world of physical medicine is essential but not referred to in the Strategy. Carers very often report that in non-psychiatric settings, such as medical or surgical wards or outpatient departments, the mental health of the patient is not always taken into account. For some this means having to take time to make sure staff are aware of the cared for person's mental health problem and treatments which need to be carried out. If the person is unable to communicate then again it is up to a family member/carers to do this, but if the carer is not involved in admission (which often happens in case of young carers) then this vital information is missed. Staff training and continuing development is required with non-psychiatric NHS staff to ensure they are aware of mental health problems and their impact.

Similarly the admission of children with eating disorders into general paediatric wards must be stopped. Paediatric nurses often do not have the training to deal with such patients and their families. This is an area where joined up work with CAMHS and specialist eating disorder services needs to be promoted. This is not mentioned in the Strategy. The new eating disorder unit in Livingston is a welcome development in the care and treatment of people with eating disorders.

Outcome 4: First contact services work well for people seeking help, whether in crisis or otherwise, and people move on to assessment and treatment services quickly.

Q. 11, 12 & 13. What changes are needed to the way in which we design services so we can identify mental illness and disorder as early as possible and ensure quick access to treatment?

Mental health and allied services should be challenged to ensure that they are providing services which are proactive in providing equitable access. The Strategy should link its focus to the various policy areas for action around the Equality agenda.

Of some concern is the lack of mention of equality of access to services for people with communication and sensory difficulties, including people with learning disabilities. Again the burden falls to carers to ensure that the cared for can access appropriate services, but very often that also involves signing for someone, or using other communication techniques and can take time. Appointment times do not always allow for this resulting in clinician speaking to carer instead of cared

⁷ Getting It Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015

for and carer together. Use of family members to interpret, e.g., BSL or other languages can be inappropriate and the use of independent communicators is beneficial.

Involving young carers in first contact with services is not recognised in the proposals for the Mental Health Strategy. It would be important here to link in with The Young Carers Strategy. Very often young carers are ignored by services, especially at times of crisis and for many young carers that increases their sense of isolation and frustration. Recognising that young carers are also partners in care across all services, including first response services, will help patients get appropriate access to assessment and treatment. The Young Carer Authorisation Card is an example of one way this can be achieved.

Involving carers and young carers in assessment and treatment decisions is crucial. Staff must be familiar with policies around confidentiality and sharing of information with carers. Carers must be viewed as equal partners in care. The carer becomes an expert on the illness/condition of the cared for person and develops an awareness of behavioural changes, and how the person is responding to treatment. It is essential therefore that they are listened to and involved at all points of care and treatment decisions as carers are the people with knowledge that can assist health care staff work more effectively with the patient and so help on the road to recovery.

At times of crisis carers are often best placed to make the emergency call or reach out for help. If staff do not respond appropriately, or take time to listen to the carer/young carer, then vital information can be lost. This information can be essential in making the difference between a lengthy stay in hospital (possibly using legal measures) and a more satisfactory shorter term outcome for both patient and carer. In these situations it is also important to ensure that there is no added stress on the carer, and that is where specialist carer services can play a major role in assisting the carer to cope.

More emphasis on working with specialist carer services such as Carers Centres and Young Carer Services should be reflected in the Strategy as one way of achieving this knowledge. Carer support staff can take a lot of the burden away from over-stretched nursing staff by working with the carer and providing information in a manner easily understood.

Making it easier for carers to inform crisis teams, community mental health teams, GPs and others that the person they care for is becoming ill is also needed. The crucial role of carers here is not reflected in the Strategy. Encouraging the use of Advanced Statements, which has a place for consenting to appropriate information being shared with carer and young carer, should be highlighted in Strategy and promoted to all organisations working with service user and carer.

Education is crucial to helping people understand when their mental health is being compromised and they themselves need help. Availability of support and

information services people in local communities can turn to is essential. There is no mention of this in the Strategy. Instead it relies on people seeking help from NHS. A great many people would benefit from speaking to someone not from the NHS, such as their carer support worker, and the Strategy should reflect the need for more of this kind of approach. This can ensure that precious GP appointments are not used up by people seeking help with problems that are not medical but which do impact on their mental health, such as debt advice; the impact of caring; reduction of income and lack of opportunities for work outside the caring situation.

Continuous training and development of staff within services such as Job Centre Plus and other non-medical services should be encouraged. They can play a part in prompting people to seek appropriate help at quite vulnerable times.

Generally the role of wider partners (local authorities, education, employers, voluntary sector and communities) is not covered. There is no mention of the education sector, yet with Curriculum for Excellence and GIRFEC there are major opportunities to promote mental health for children and young people.

Greater involvement with service users and carers in shaping Integrated Pathways needs to be encouraged, as well as greater involvement from voluntary sector providers.

Outcome 6: Care and treatment is focused on the whole person and their capability for growth, self-management and recovery.

Q. 14 – 18

There needs to be continued and sustained work done by the Scottish Recovery Network and partners to ensure that recovery values and messages are reinforced within psychiatric services, in particular within forensic services.

The promotion of Wellness, Recovery and Action Planning (WRAP) as one tool should be encouraged, but how it is used and with whom needs greater consideration. A similar tool could be used with carers and young carers. Many carers do not understand the concept of recovery when applied to themselves as they don't feel they are recovering from anything, but the principles underlying mental health recovery and WRAP apply equally to unpaid carers and what they want for their own mental health and wellbeing.

Within The Princess Royal Trust for Carers we are looking at developing a carer specific wellness tool. However this needs continued funding to develop and maintain throughout the Network of Carers Centres and then beyond into The Scottish Young Carers Service Alliance. By bringing carers up to speed with concept of their own wellbeing, they can come to terms with the concept of recovery for the person they care for.

It is essential that recovery is a holistic approach and takes account of all areas of a person's life, their past, present and future wishes. Family and carer involvement must be reflected in recovery work. Staff need to acknowledge the commitment and experience of carers and young carers and see them as equal partners in care. This has to be reflected in this area of the Strategy.

The Scottish Recovery Network needs to widen its work with other agencies to ensure recovery message and values get out there. Continuing their WRAP training and promotion is one way of doing this, but also engaging with condition specific organisations (and not just mental health ones) and the range of carer and young carer organisations is essential in getting that job done.

Outcome 7: The role of family and carers as part of a system of care is understood and supported by professional staff.

Q. 19 & 20 How do we support families and carers to participate meaningfully in care and treatment?

What support do staff need to help them provide information for families and carers to enable families and carers to be involved in their relative's care?

The acknowledgement within the Mental Health Strategy of the role and contribution of carers and young carers is to be welcomed.

The MH Strategy needs to reflect the themes running through both the Carer and Young Carers' Strategies, in particular the identification and recognition of carers, especially young carers, in relation to the lives of people with mental health problems. Very often young carers report that they are routinely ignored, not out of ignorance but because professionals are not confident in interacting with them. Young carers tell us that medical staff do not discuss conditions or treatments with them. Very often, confidentiality is used as a way of avoiding this, but this can be dealt with without breaching patient confidentiality. Staff need to be aware of the principles behind confidentiality and sharing of information. The Strategy could link into work done by The Princess Royal Trust for Carers and The Royal College of Psychiatrists called "Partners in Care" this gives guidance to staff and carers about confidentiality and sharing of information.

Similarly adult carers of young people with mental health problems face difficulties in being involved in care and treatment decisions when their child becomes part of adult mental health services. Although no carer wants to interfere with the patient - doctor relationship, and carers accept their child's right to confidentiality, especially when over 16, many carers want, and need, to share information with medical staff. This information could be of great importance and staff need to know how to work with parents and carers to ensure it is handled in as sensitive a manner as possible and with full knowledge of the patient.

Staff within mental health teams and services should work with specialist carer services, such as The Princess Royal Trust for Carers network of Carers Centres and The Scottish Young Carer Services Alliance, to look at ways in which information can be given to carers and discussed with them. Please consider how best to utilise the expertise of these organisations in working with families and carers. The Strategy should identify these networks and encourage local services to work in partnership with them. Increased investment needs to be made to ensure these specialist carer services are fit for purpose and continue to be so.

Access to carer advocacy should be highlighted within the Strategy. This can be a means for many carers to challenge decisions, get their views across, manoeuvre their way through the health and social care system.

Forensic carers often highlight the very complex legal nature of MH Tribunals and Care Pathway meetings. Working with the forensic network of carers could help reduce the anxieties felt by this group of carers. Having access to people who can explain the formal, legal processes and what the carer's role and rights are is essential in helping these carers to be as meaningfully involved as possible in the treatment and care of a loved one.

Involving carers in emergency planning, alongside the cared for, is essential if services are to be proactive at times of crisis. Currently this is done in a very ad hoc fashion, often at the behest of the carer. More awareness of the role played by the family and carers in looking after the cared for is required. This would then allow services to carry out their work in a way which is more meaningful for patient and possibly speed up recovery.

Better discharge planning is required. This must involve the carer and family from the outset. Young carers routinely feel excluded from discharge discussions and this should not be the case. The strategy should reflect the importance of properly planning for discharge and the crucial role of the carer (and young carer) needs to be stated. Discharge planning must also seek to offer, where appropriate, training and information for the carer/young carer. This need not always be provided by medical staff; but staff can signpost to relevant (voluntary sector) organisations such as Carers' Centres to ensure that the carer's own health and wellbeing are protected.

Conclusion

Overall the Strategy builds strongly on achievements over the last few years to ensure that Scotland as a country protects and promotes mental health. However there are some gaps in the document, especially concerning carers, young carers and mental health improvement.

A key outcome we would welcome in the final Strategy would be a carer focused outcome; recognising the impact caring can have on the mental health and

wellbeing of carers and young carers, and the importance of promoting positive mental health with carers and young carers.

The final Strategy also needs to reflect the difficult financial situation currently experienced by the vast majority of people in Scotland. We know that unemployment, limited financial income, poor opportunities, poor housing, challenges such as anti-social behaviour and general feelings of despondency can all lead to increases in mental health problems and addictions. The Strategy, in this draft format, makes little mention of these difficult economic times.

It is at times such as these that more pressure is put on families and carers in particular. This is why it is vital that continued investment is needed in providing support, information and advice, and respite for carers. It is now time for an emphasis to be put on the mental health of carers. As a nation we are going to have to rely on them more and more, therefore we need to invest in them now to prevent the break-down of families and increasing pressure on mental health resources.

We would be happy to provide further information as needed and to discuss the role of unpaid carers and young carers within the wider context of the infrastructure and support in place for people with autism in Scotland.

Kind regards

Karen Martin

Karen Martin
Young Carers Mental Health Development Coordinator

Appendix 1

The Princess Royal Trust for Carers and The Scottish Young Carers Services Alliance - Additional Information

In Scotland, the Princess Royal Trust for Carers (the Trust) and The Scottish Young Carers Services Alliance currently helps over 53,000 carers and young carers cope by giving them information, support and advice through our work with the unique network of Carers' Centres, young carers' services and interactive websites, www.carers.org and www.youngcarers.net

Each of the centres in The Princess Royal Trust for Carers' network provides specific expertise for their particular area. The centres belong to the local carers and the services include:

- finding hidden carers through outreach in GP surgeries, hospital wards and schools
- finding the right information to provide personalised services
- fighting for carers' rights and entitlements and giving them a voice
- supporting carers emotionally
- helping to make caring a positive experience, by ensuring access to breaks, education or employment and the opportunity to share experiences with other carers
- Delivery of carer training, which enables carers to cope with their caring role, understand the condition/illness of the person they are caring for and deal more confidently with health and social care professionals.

The Scottish Young Carers Services Alliance support young carers – children and young people under the age of 18 who take on caring roles and responsibilities that are inappropriate for someone of their age.

Support for young carers includes:

- help to find other sources of support so that fewer families rely on a child for vitally required care
- running clubs, activities and holidays that give young carers a break and time to be children
- giving one-to-one support and mentoring, together with raising awareness in schools
- educating and training teachers, doctors, youth worker and social workers to recognise the signs of a hidden caring role, offer a carer-friendly response and access to specialist help.

Appendix 2

National Young Carers Mental Health Development Coordinator

The Scottish Young Carers Festival, 2009, asked attending young carers what further help they required as young carers in Scotland. A majority response was for help around mental health. The help requested was for greater understanding from the people who support them, help in maintaining their own mental health and help with understanding the demands and needs of people with mental health problems.

The Scottish Government funded a one year post initially to start to address these issues. Following a successful first year, The Scottish Government kindly extended the funding for another year to allow for work to be completed.

Outcomes of the post are:

- Young carers would experience improved mental health
- Young carers feel empowered as a result of having more information
- Young carers would feel happier as a result of receiving services tailored to their needs
- Mental health services and organisations recognised young carers and are aware of their needs
- Stronger links exist between the national mental health agencies and the Trust, and the Scottish Young Carers Services Alliance and Carers Centres. This will ensure better multi agency working and improved outcomes for young carers

Achievements of Post

- Conducted a training needs analysis of all young carer workers with The Scottish Young Carers Services Alliance. Training was developed in response to the needs of workers. This training covered topics such as, What is Mental Health; What Affects our Mental Health; Specific Conditions and Impact on Health; Supporting Mental Health Young Carers.
- Attended Young Carers Festivals in 2010 and 2011 to help with YC Zone consultation.
- Developed on-line information sheets for young carers called "Looking After Your Mental Health". These are currently available on www.youngcarers.net

- Working in partnership with NHS Ayrshire and Arran Health Improvement Department to produce a "Manage your Wellbeing" toolkit for use with school pupils and young carers in health board area.
- Developed an on-line "Young Carers: Your Mental Health" toolkit for young carer workers to use with groups. This will be available on www.youngcarers.net in late February.
- Promoted awareness of young carer issues and ways of supporting young carers to variety of organisations, including NHS and local authority agencies, national and local mental health organisations, community groups and other condition specific organisations.
- Involved with the Community Panel from the School of Life Sciences Department of Glasgow Caledonian University to represent the interests of young carers.
- Conducted presentations to student nurses, social workers, OTs and other allied health professionals at Glasgow Caledonian University.
- Provided support as required to workers and young carers.
- Met with a Norwegian Government Civil Service to promote Young Carers Strategy, Scottish Young Carers Services Alliance and the Festival. From this initial meeting a follow up visit has been arranged for this year by people wishing to set up Norway's first dedicated young carer service for children living with parents with addiction issues.
- Working in partnership with the Scottish Drugs Forum to provide an awareness raising session with young carer workers on the use of Naloxone, and the support needed for young carers who may be living in households affected by substance misuse.
- Co-developed Steps to Wellness programme in partnership with colleague from Renfrewshire Carers Centre. This is a recovery tool for carers to help promote positive coping strategies and wellbeing. This will be developed for young carers.
- Involved with University of Strathclyde post graduate Mental Health Officer training raising awareness of identifying and supporting young carers.