



## **Consultation Response: A New Mental Health and Wellbeing Strategy**

We spoke to members of the New Routes Home partnership to find out what their thoughts were on the new Mental Health and Wellbeing Strategy. We spoke to parents of autistic children detained in psychiatric hospital; parents of autistic children living in the community; support providers; advocates; and other people working in the field of inclusion.

### **The Vision for the Mental Health and Wellbeing Strategy**

The Scottish Government's draft vision for the strategy is:

*"Better mental health and wellbeing for all"*

We support this vision, but the key word is 'all', which must truly mean *all* of our citizens. If we were successful in achieving this mission, it would mean eradication of inappropriate out of area and psychiatric in-patient placements for autistic people and those with learning disabilities. In-patient assessments which promptly assess and discharge people into communities with bespoke support in place; compassionate communities that are equipped with a variety of housing options, with skilled and valued support services. Finally a mechanism of support that focusses on choice, control, dignity and freedom, as stated through the self-directed support legislation.

The vision needs to focus on "what would it take?" rather than "these are the resources available". If people are engaged in working with the person on this basis, the person won't feel left behind by gaps in the system, and there will be greater trust that flexible supports will be there when needed. Actions will be based on this, with a clear accountability link to the individual and those closest to them for both the actions taken, and any inaction. Each action should be measured against Human Rights legislation and the PANEL principles to support proactive and positive practice.



## The Proposed Outcomes

The draft outcomes proposed are:

- Promoting and supporting the conditions for good mental health and mental wellbeing at a population level
- Providing accessible signposting to help, advice and support
- Providing a rapid and easily accessible response to those in distress
- Ensuring safe, effective treatment and care of people living with mental illness

We agree with these outcomes, with some proposed amendments.

There needs to be a clear statement of intent towards early and effective interventions that take place before points of crisis. We suggest amending the second outcome to:

*'Providing accessible signposting to help, advice, and support, at the earliest possible point in time.'*

There should be a commitment to ensuring that there are early and effective supports available that build on strengths rather than make people's lives more limited and which are accessible to all to avoid crisis or deterioration, not simply a clinical focus. All interventions should be the least restrictive and lightest touch, as it is simply not good enough to continue with damaging regimes involving excessive control and restraint (physical and chemical). We suggest amending the fourth outcome to:

*'Ensuring person-centred, safe, and effective treatment, care and support of people living with mental illness, designed in partnership with them and delivered in their own communities.'*



## **Positive Impacts on Mental Health and Wellbeing**

The consultation asked about what the main things in day-to-day life are that have the biggest positive impact on mental health and wellbeing.

Our respondents told us that the biggest positive impacts included:

- Feeling listened to
- Being able to do things that matter to the person
- Having family and friends near by
- Feeling hope for the future
- Support that is flexible and person-centred

When we discussed this question, it was striking how much of an impact could be had from seemingly minor and ordinary things.

One parent, whose autistic child is locked in a psychiatric hospital, told us that they had been carrying out visits from outside the hospital, through the window of their child's room, on the hospital's instruction for several months. Recently, this had been changed to visits in the garden. This small change brings significant benefit to the person's wellbeing, relationships with their family, and ultimately to their dignity at being treated as normal human beings.

Another parent, whose autistic child is also locked in a psychiatric hospital, told us that they were excited to be able to have lunch together to celebrate mum's birthday, for the first time in six years. While they had wanted to have a day trip out to enjoy a meal together, with family supporting, this was deemed impossible by the hospital, but an agreement was made to bring a takeaway meal into a private room in the hospital so that they could celebrate together.

These small acts of humanity have far-reaching impacts.



## **Negative Impacts on Mental Health and Wellbeing**

We also fed back our thoughts on what actions had a negative impact on mental health and wellbeing.

The clear message from our group is that the biggest negative impact for autistic people and those with learning disabilities is caused when there is forced separation from family, loved ones, safe spaces and familiar routines. Families of people that are held in inappropriate out of area placements for several years have been severely traumatized, by a system they put their trust in. Earlier, effective interventions in the community for this group would have significantly reduced the likelihood that they would be held in hospital.

When the COVID lockdowns commenced, one family told us that their son – who had already been in hospital for several years – was not supported to understand the restrictions people faced. His advocate wrote to Scottish Government to understand whether or not there were exceptions that could be made to lockdown restrictions for those who had identified support needs that required them to not be isolated. This was confirmed as possible but the hospital would not entertain the idea, even when the family and external support staff offered to help and to follow all necessary COVID protocols.

The young man responds well to routines and predictability, none of which were in place in hospital, with no time taken to think of alternative ways of supporting him to understand or plan differently with him. All of this resulted in a rapid deterioration of the young man's condition, where he expressed how frustrated he felt in the only way he could without verbal language, resulting in him classed as a higher risk than before.

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The example given earlier of the family who could only maintain contact through the external window of the young man's room reinforces this inhumane treatment. Rain, hail or snow they came every day for their allotted 30 minutes to talk to their son through the glass, and it is only recently that they have been able to see him face to face, outside in the gardens.

Parents of children who are locked in psychiatric hospital told us that the lack of person-centred approaches in hospitals meant their sons had lost skills that they had spent many years developing, around communication, social behaviour, and self-care. There is significant over-medication of undesirable behaviours, instead of encouragement, de-escalation, or taking time to communicate in a way that has meaning. When they are discharged, there will be a significant period of re-ablement required, which is a tragic waste of resources that could have easily been avoided.

### **Ways to actively look after mental health and wellbeing**

A list of day-to-day activities, such as exercise, sleep, time in nature, time with family and friends, is listed in the consultation as ways we can look after our mental health and wellbeing, many of which are not available to people in hospital or out of area placements. Our respondents had some ideas for other positive ways:

- Support organisation – create the space to connect and problem solve with others, as well as simply share experiences.
- Individuals and families – most of the above, but with the right support to make it work. People who take the time and care to communicate with me in a way that is meaningful and that I can understand. Access to routines and coping mechanisms, which will be different and unique to each person, but which must be respected.
- Planning next positive steps even if overwhelmed in the moment. Having a safe space with a trusted person to vent frustrations, almost as a safety valve so that fears and frustration with support staff don't impact on those relationships.



There are some significant barriers to people being able to take part in these activities which are important to note:

- Time
- Staff or service availability
- Headspace to prioritise over other practical concerns
- Perceptions of risk
- Clinical governance putting up barriers to external supports
- Physical location (travel)

Scotland has known for 40 years that institutions do not result in good outcomes for people, but the assumption prevails that when an autistic person or someone with an intellectual disability is deemed a risk to themselves or others, that the only option is to be held in a locked ward away from everything that could facilitate good wellbeing. We grew out of this mindset many years ago for the majority of the population; it cannot continue.

### **Financial worries**

Worries about money are a significant concern to many of our group. They told us:

- Support Organisation: Many people are adversely affected when a loved one is moved away from home, and their priorities often have to rapidly shift. The social care recruitment crisis is another key concern, with poor wages and conditions causing many to leave.
- Training/development organisation: out of area placements can be hundreds of miles away from the family home, resulting in significant financial pressures as families spend their often-limited resources on travel to either visit or take part in meetings. In addition, much of the expectation is that visits and meetings take place during the day, resulting in a loss of income potential for families as they limit their work and prioritise the essential contact with their loved ones.



Our members felt that support could be offered to families as well as to organisations working to support this community:

- Much higher minimum wage for direct support staff and those that manage them, and guaranteed uplift for income for individuals similar to the “triple lock” for pensions. The level of panic for some individuals around both ability to pay basic bills and retain support staff is a significant contributor to anxiety levels.
- Support to avoid fuel poverty.
- Availability of access to adaptations to the family home, or availability of suitable (ordinary but adapted) accommodation in the community.
- Universal basic income which offers a good standard of living to all regardless of their needs or situation.

### **Specific suggestions of how to improve the types and availability of mental health and wellbeing support in the future**

Our group had lots of ideas on how to improve the support available to autistic people and people with learning disabilities:

#### *Earlier and effective interventions*

All of the families we have spoken to have told us that they allowed their child to be held voluntarily for a period of assessment, because they were in crisis and felt they had no other option. For these families, voluntary assessment led to compulsory treatment orders, as their children’s conditions deteriorated in the alien clinical setting in which they found themselves, away from their routines and the people who understood them. Having flexible interventions in the community to avoid reaching crisis point is noted as either being poor – not specialized to the needs of autistic people - or absent entirely. There must be investment in this area, from practitioners who are skilled in the needs and aspirations of autistic people, to prevent crisis.



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### *Availability – and access to – independent advocacy:*

The barriers that hospitals put in place to people having external support make it feel like the hospitals have something to hide. Clinical governance is often cited as a reason to prevent advocates attending meetings. There must be clear mechanisms in place to allow independent advocates to be able to support patients, and they – and their families – must be informed about their availability, and the support they can offer.

### *Good quality support planning and service design*

One parent told us that she had no idea that bespoke services in the community even existed; there is a real lack of information available about what is possible for people coming out of psychiatric hospitals. Service providers and independent advocates are happy to carry out high quality person-centred planning and service design early in the planning process, but again are often blocked by clinical staff from having access to families to do this. One advocate gave the example that it had been agreed by the hospital that a young man could have a person-centred planning session in the hospital, but this took over a year to get in place.

### *Effective ‘project management’ of discharge*

Families and advocates told us of their perception of a ‘house of cards’ for planning discharge, whereby many systems and processes need to be lined up at the same time – clinical, housing, community support, the person etc – and if one element falls down then the whole structure collapses. There is a feeling that nobody takes real ownership over this to successfully manage discharge and coordinate all the communication across the stakeholders. Accountability seems lacking, and often it is unclear who is making the decisions between health, social work, and the family.

### *Honesty and availability of support providers*

There is a recruitment crisis in the social care sector, which presents real risks to those on delayed discharge being able to have a home in their community in the immediate future. While we recognize this is a real issue; there is also a poor standard of training and understanding of the needs of this community within the current workforce. The workforce as a whole





requires more development in this area to be able to appropriately support people discharged from hospitals, with a recognition of the skills of these practitioners and pay and conditions to suit.

The balance of having providers that are willing, able, equipped, and available to deliver these supports is critical to strike correctly. Services for people leaving hospital cannot be procured through 'bog' standard framework agreements which emphasise cost over quality, and should be arranged via self-directed support prioritizing the values of choice, control, dignity and freedom. There needs to be the ability to bespoke services, meeting individual needs that will flex and change as the person's circumstances change.

### **Connections between health and social care services**

Members of our group come from a wide geographical spread of Scotland, and their perception is that interaction is hugely variable depending on the area and the people involved, as well as the level of proactive planning. Often there is not sufficient correlation between the level of effort to create positive change and the engagement from some groups to be able to implement those changes, and decision making is resource-led rather than person-centred. There were experiences shared whereby someone had asked for support, and they were given whatever happened to be available to them at the time (in many cases this was nothing, but also often unsuitable interventions), which has led to tragic outcomes.

Challenging decision making can be exhausting and challenging. When an issue arises, families and practitioners alike struggle to feel informed and supported to challenge, as information can feel deliberately vague.

The strongest outcomes have been felt where there is a shared set of values and commitments across services, and where these are applied across whole services (including for example hospitals, social work, police, communities etc) and result in true inter-agency working. A 'no wrong door' approach to getting help earlier is effective.



There is still too much focus for those in hospital on finding the perfect specialist resource, which often is not as effective as promised. The impact of out of area placement and the loss of family contact is often not written down and factored in sufficiently to decisions. This often results in a circular discussion of what is not possible, and waiting an excessive amount of time for a perfect solution, rather than building something possible, with positive informed risk taking and sustainability in conjunction with support providers.

Hospital can result in a vicious cycle of risk and public protection concerns for many: the person doesn't cope in hospital (for all the reasons we have already described) and so it is assumed that the risk will be the same in the community. Many times, decisions are made in the interests of 'public protection' which are based on this fallacy, and result in further institutionalization and a continuing cycle of behaviour-restraint-deterioration.

### **How funding for mental health and wellbeing supports and services could be better used**

When we spoke to our members they told us strongly that there is a huge amount of resource in this area, but it is not being used effectively. The many thousands of pounds spent each week to keep people in hospital was coined 'misery money', that could be used far more effectively through providing person-centred support in the community.

An advocate told us that they don't really see where the money goes, there has been a decimation of community teams as resources are moved to hospitals, with a lack of allied health professionals. They highlighted the benefits of hospital link workers, which was seen as good investment.

The availability of information and advice, in formats that are meaningful to people, would be a good area for investment, and this was supported by everyone we consulted. Currently, self-referral processes can be daunting and off-putting for autistic people or those with learning disabilities, and



their families, and investment should be considered here, including easy read information and peer support. One parent of an autistic child in psychiatric hospital told us again that availability of information on what is possible in the community is sorely lacking. Providing this in a way that everyone can understand benefits us all.

### **About New Routes Home**

New Routes Home is a partnership of people and organisations in Scotland who campaign for the right of all people with disabilities to have their own home and to have meaningful choices around where they live, and who (if anyone) lives with them. This includes having choices around how support is organised and directed.

There are still many people who do not have access to these rights, in particular people who are in long-term hospital settings including Assessment and Treatment Units, out of area placements, and people at risk of losing their housing and support due to labels of being 'challenging'.

We meet as a collective every six weeks, on Microsoft Teams, to share practice, develop campaigns and find solutions.

To find out more about New Routes Home visit our website:  
<https://newrouteshome.wixsite.com/scotland>