

# Parliamentary Review of Health and Social Care

Report of citizen panels November 2017

**Practice Solutions Ltd**

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## 1. Introduction

This report has been produced to inform the Panel advising on the Parliamentary Review of Health and Social Care. It is based on the views of citizens who participated in citizen panels in November 2017.

Seamless, community focused health and social care and well-being for older people in Wales is at the heart of the review. We sought the perspectives of people who had experience of using health and social care or who were or had been carers of people using health and social care to inform the Panel on what worked well and what were they key messages for improvement. These perspectives would then be used to help test the models and principles that are being developed as recommendations for Welsh Government.

We are very grateful to Monmouthshire and Swansea Social Services Department, Barnardo's and MIND Merthyr Tydfil for supporting this project to bring together individuals to join the citizen panels.

## 2. Methodology

Three citizen panels were held; two specifically for older people – one in Swansea and the other in Monmouthshire. A citizen panel formed of young carers was held in Merthyr Tydfil. We also had contributions from a small number of people who had been invited to the panels, but due to caring and other responsibilities, were unable to attend. Their feedback has also been incorporated into the report.

The citizen panel members were not required to be familiar with the interim report of the Parliamentary Review or the work of the Commission, although some were. We identified and brought together people who had knowledge and experience of engaging with health and social care services, and a willingness to participate in the discussion.

We facilitated broad ranging discussion based on the experiences of those attending the panels, seeking to identify their views on the delivery of seamless local health and social care services focused on what matters to people.

## 3. Common themes

Some messages came through both sessions of the citizen panels for adults. These were:

- Putting people at the centre of any model is critical for success.
- Continuity of care and effective co-ordination is vital for positive outcomes.
- Services should be designed with people, for people and the caring element of both healthcare and social care is fundamental.
- The importance of all products of the review being accessible and co-produced.
- They welcomed the introduction of the Social Services and Well-Being (Wales) Act 2014 as the basis for new models of service. It is important to review the implementation of the Act, and some individuals felt that this could have been an alternative to the process currently underway.
- The value of the contributions that are/ could be made by the third sector and volunteers in any new models.
- The training and quality of staff and the caring approach is crucial to achieving positive outcomes.
- The contribution that people themselves are making now to their own health and social care – one person described this as “DIY NHS” and reflected on the benefits of being proactive in one’s own care.
- There must be a consistent approach to, and rigorous monitoring of, implementation of changes.

## 4. Importance and key features of seamless care

From the discussions, we have identified some key features that citizen panel members consider will support new models of care. We have grouped these into the following headings:

- The importance of seamless local health and social care in delivering positive outcomes for people;
- improving the experience and outcomes of people who need care and support and carers who need support;
- funding health and social care;
- workforce.

We asked them what works now and what needed to change for the future. Where we identified good practice, this has been included.

### **The importance of seamless local health and social care**

The importance of care integrated around the individual was supported and underlined. Services should design care with people themselves and with carers. Some people commented that “services are designed around system and staff convenience”. Panel members shared their personal experiences. Seamless integrated health and social care was identified in the form of the reablement service provided by Mardy Park Resource Centre. This had enabled individuals to move from hospital back to home, receiving the right support at the right time. As one member said, “the service provided by Mardy Park constantly surprises me in a very good way.” Examples of this were in the relationship between therapists and social care, with the installation of appropriate aids and provision of home care in a sensitive and timely manner.

On the other side of the coin, there were several experiences where the lack of seamless local health and social care led to adverse impacts on individuals. One person was unable to leave hospital because of delays of putting suitable home care arrangements in place, and this led to an adverse incident in a hospital setting. Delayed discharges were felt by several panel members to be commonplace.

Any successful model should focus on prevention and early intervention. Some people felt services were focussed on crisis management at the expense of supporting people to support themselves in their own homes.

Counselling was seen as a key enabler to prevent escalating need, however there is a long wait for counselling. Some people felt that GPs were spending too much on prescribing drugs which they described as “crisis management” and they could better target limited resources at counselling.

Assessment is a key aspect of the current model of care and support. People felt that assessments need to be holistic, and there should be one plan of care to follow the person through their care pathway. Having a new assessment every time you deal another professional was inefficient and wasteful of resources, plus it did not evidence that care was centred around the individual. Telling their story once and having all their information in one place was important to them.

The need for independent advocacy was highlighted. People were not clear when they could get the support of an advocate or where that support would come from. When people who used services or carers felt they weren't being listened to, independent advocates provided support to help them with statutory services.

There was some evidence of teams trying to work closely together across health and social care, but it was felt that in some cases, separate strategies and policies are being written by senior managers in different organisations which do not support this. The value of services sharing governance and strategic plans was underlined. Sharing information across organisations is vital, and people themselves should be able to say that they want this to happen e.g. across health and social care.

Better quality and easily accessible information on care and on wider issues like accessing various grants is essential to deliver positive outcomes. Mardy Park was considered to be a centre of excellence in the provision of information. One contributor described the review as a “great opportunity for more open and

transparent sharing of information with carers and service users". Discussing the limitations and shortfalls on an individual, regional and system wide basis openly and honestly would support a solid foundation on which to move forward.

Young people identified the way they would get information as via social media – using Facebook and websites. They knew about the Children's Commissioner but weren't clear when they would get support or information from that office. They also said they obtained information from friends and from some family members. They would be unlikely to approach statutory agencies for information on health and social services.

The comment was made that services do not work together enough, every service, hospital, GP social services seems to be working autonomously. Services should be 24 hour and GP surgeries should be accessible out of hours. The "invisibility" of GPs in supporting seamless care was commented on by one person, and there was a suggestion that GPs could play a stronger role in helping people receive "joined up" community services e.g. by effective signposting.

### **Improving the experience and outcomes of people who need care and support and carers who need support**

The responses of citizen panel members clearly supported the principle of improving experience and outcomes. Some people reported more positive outcomes when they "took control" of their care and proactively contacted consultants if they felt there was an issue, and sought out help from health and social care agencies and the third sector. Not everyone felt that they were enabled to take that approach. In exploring that, this could be because of a need for more information or support to get initial access to services. Networks were identified as important to gaining the right information to support better outcomes. Some people had either accessed local groups or set up their own e.g. Parkinson's Support Group. This is really helpful as a way to access information and gain support and eliminate isolation.

"Listen to me" was one of the threads running through all conversations with older and younger people. People didn't feel listened to and in the case of both older and younger people, age discrimination had been perceived. They felt that their views were not always valued and sometimes ignored. In one case, 18 months had been spent by a carer seeking to have the medication her father with vascular dementia received reviewed. She had seen a written comment from the consultant saying "the daughter is interfering in the medication" when from her perspective, she believed her parent to be inappropriately overmedicated and was trying to put things right.

There was considerable discussion about when things go wrong. Some people had experienced poor care, and had felt able to challenge it, and things had been put right. Others said that they were afraid to challenge poor care, particularly where they were carers and the care was being received by their loved one, as they feared "reprisals". No evidence of "reprisals" was given, but the fear was what was holding them back.

Services need to recognise that they are supporting people, and people's needs are complex and cannot be met unless they work together. One person said "they must remember we are people, not cases".

Dementia was cited as an issue where there was insufficient understanding across services. People with dementia were not always supported appropriately in hospitals; it could be challenging for people with dementia, other people on wards who did not have dementia and for staff who lacked training. An example of good practice was given, where a community dentist was very dementia aware, and delivered a very positive outcome for a person who previously could not get dental treatment. They exhibited a real understanding of the person with dementia, calming them so that after many years they were happy to have dental treatment. Another example of a nursing home where staff really listened to the families of residents, and tailored care around the person not the "patient" was given. This had led to positive outcomes, with a resident encouraged and happy and willing to wash and dress with a little help.

Aids and adaptations are crucial to better outcomes for people, enabling them to achieve independence in their own home. Telecare (alarms) were identified as being used. Various adaptations had been made and the specific adaptations made via the local reablement service enabled a couple who both have complex needs to stay in their own home.

Respite was a significant issue, be it short-term to allow carers to get chores done, or longer-term breaks. Adequate respite enabled carers to carry on supporting the cared for person in their own home. One person said it was wonderful that she could have one night a week where she could have unbroken sleep because of the respite care she received. Others commented that they did not know where to access this information or how to find out about the service.

Day time opportunities again were considered to be a lifesaver, allowing carers some free time for themselves. Some people feared cuts and changes which would cause them real concern.

End of life care was raised in one group. Panel members felt that it was important for people to know they could stay at home even if their needs were palliative. Support for carers at this time was identified as crucial, and a specific example was given where a person had numerous agencies calling at their home to "assess" various aspects, but little practical help with supporting them or their loved one e.g. with basics like washing, bathing, turning. This was described as "too many clipboards and no practical help". Together with this was the lack of post bereavement support resulting in a feeling of abandonment after their loved one had died. The opportunity to use skills and experience in a voluntary capacity as a way of handling some of the issues associated with bereavement was identified.

The citizen panel for young people looked at how their well-being could be improved. They felt that that it was difficult to get adults to listen to them whether in health, social services or school. This was particularly frustrating where they were carers for parents or grandparents with health and social care needs.

They said that when they needed support as young carers, although they might be recognised in schools, no action was taken or support forthcoming. They said that doctors and hospitals should ask them what's happening and take time to listen to them.

They did not feel comfortable in asking for help. Some said they were afraid if they said they needed health care or social care support, they would be put into foster care. One countered this, explaining that social services had placed her with a grandparent when she was very young, so she knew they wanted to support her and keep her there and weren't about taking her away from home.

Trust was a key feature required in any service for young people to want to use it. Staff had to be reliable and keep their promises.

### **Funding health and social care**

The huge pressures placed upon health and social services were acknowledged. There were real concerns about short termism in funding, and the drying up of funding streams to the third sector, which was impacting locally. People felt more support and funding should go to the third sector who solely rely on bidding for funding, which is wasteful of limited resources with valuable services stopping when funding ceases. The example of Age Cymru funding for befriending ending in Swansea was identified. A small investment in third sector could give a huge therapeutic, preventative benefit.

Inequity was raised, linked back to funding, with different approaches for a married couple, one who qualified for continuing health care and one who did not. One was able to have free transport and the other required a taxi to the same day centre.

Citizen panel members discussed how we fund care and support in the future and talked about the need for taxation increases to support care.

Transport issues were discussed. They can be real barriers to accessing any sort of service or support. If services are going to be developed and centralised then transport needs to be considered. Rural areas particularly will be affected.

Most people stated that true integration will not happen without pooled budgets and single governance structures.

### **Workforce**

Staffing was discussed in detail. The importance of good quality, well trained and caring staff was emphasised. There were many examples of excellent staff, but several examples where people felt that staff either lacked training or “were in the wrong job”. They felt that there were too many bank and agency nursing staff on hospital wards, that has implications for funding and on outcomes for people. People had to feel they could trust staff and that means continuity and building a relationship over time.

The importance of being able to communicate with people in the language of their choice was emphasised. The ability to communicate in English or Welsh is essential, and in some cases, language skills were identified as inadequate. Furthermore, issues around this are heightened when people have dementia or cognitive difficulties.

A discussion was held regarding staff conditions and pay. The length of shifts with some staff doing 12 hours at a stretch was a real concern, as to sustain a high level of energy for that period must be challenging. People experienced some poor care from domiciliary care staff who they felt, were not happy in their job. They felt that zero hour contracts and the level of pay had a clear impact on the quality and ability to retain staff.

## **5. Conclusion**

The citizen panel members were able to share their experiences and they identified a range of issues which indicated that they support the need for change and better working together between health and social services, and also a stronger relationship with the third sector. The positive impact of being involved in the design and delivery of their own care was acknowledged by those who had experienced good practice within their service provision, which suggests a cultural shift is beginning to emerge in limited pockets of the workforce. Generally, a stronger role for citizens in the design and evaluation of future models of health and social care delivery was welcomed.

## APPENDIX

### Letter of invitation

#### Parliamentary Review of Health and Social Care in Wales

As an integral part of the Commission's work on seamless health and social care for older people, I am committed to involving citizens throughout the process. We are now at the stage where the Advisory Panel has developed proposals for integrated health and social care which we wish to test with groups of Citizens.

We have asked an independent team to facilitate three Citizen focus groups. These groups are to be made up of individuals who have experience of using health and social care services, or who are carers of people who use health and social care services.

I am writing to invite you to nominate people to join these focus groups. We plan to host groups of between 8 and 12 people, and will hold one group specifically for young people, one for adults specifically in rural areas, and another for adults in an urban area. The groups for young people will be in Cwm Taf in the last week of November, and for adults in South East Wales on 23 November and in South West Wales on 24 November.

While the review focuses on older people, it will have relevance to all people and we are seeking a cross section of views. It is likely that each session will last about two and a half hours.

It will not be necessary for focus group members to have knowledge of the work of the Commission, but to have knowledge and experience of engaging with health and social care services, and a willingness to participate. It would be useful, but not essential, if nominees have previous experience of participating in a Citizen Panel or Jury, or a Youth Forum or Cabinet.

If you wish to have some further information about the review, it can be seen at the link below:  
<http://gov.wales/topics/health/nhswales/review/?lang=en>

Expenses such as transport or pre-agreed costs of PAs will be reimbursed.

I would be grateful if you could send your nominations to Katie Lineham at Practice Solutions [katie@practicesolutions-ltd.co.uk](mailto:katie@practicesolutions-ltd.co.uk) or call 01443 742384 by 17 November. Please send the names, telephone numbers and email addresses of participants to Katie. If you yourself will be organising communication with the proposed jury members, please let us know.

DR RUTH HUSSEY