

Cross Party Group on Dementia

Minutes: November 2017



Seminar Rooms 1 & 2, Y Pierhead

12 noon – 1.15pm, Tuesday 28 November 2017

Chair: Lynne Neagle AM

Topic: Dementia Action Plan

Present

Lynne Neagle AM (Chair); Dr Dai Lloyd AM; Craig Lawton (for Suzy Davies AM); Heledd Roberts (Rhun ap Iorwerth AM)

Sophie Douglas (Alzheimer's Society Cymru – secretariat to the CPG); Dr Rosslyn Offord (British Psychological Society); Catrin Edwards (Hospice UK); Ruth Chamberlain (Older People's Commissioner Wales); Daisy Cole (Older People's Commissioner Wales); Sharon Ford (Amgueddfa Cymru); Ceri Williams (Social Care Wales); Rachel Niblock (DEEP); Stephen Boyce (National Assembly for Wales Research Service); Nesta Lloyd-Jones (Welsh NHS Confederation); Paul Harding (Marie Curie Wales); Dr Chineze Ivenso (Incoming chair – Faculty of Old Age Psychiatry); Dr Natalie Elliott (Senior Specialist Speech and Language Therapist, Cardiff & Vale UHB)

Ceri Higgins, Nigel Hullah, Madeline Phillips (people affected by dementia / carers / volunteers).

Chair's welcome and apologies

- **Lynne Neagle AM** welcomed everyone to the meeting
- Apologies: Simon Thomas AM

Update on previous meeting

- **Lynne Neagle AM** tabled a question to the former Cabinet Secretary for Social Services and Well-being (Rebecca Evans AM) on 9 October regarding the consultation process for the Carers Strategy (question and answer circulated with minutes)
- **Lynne Neagle AM** wrote to the new Minister for Children and Social Care (Huw Irranca-Davies AM) on 28 November recommending a more thorough consultation process incorporating the views of carers (letter circulated with minutes)
- **Huw Irranca-Davies AM**, Minister for Children and Social Care, made a statement on 24 November 'A Carer Friendly Wales' (circulated with minutes)

The Cabinet Secretary for Health and Social Care presented an update on the progress of the Welsh Government's Dementia Action Plan

- Around 1200 people and 119 organisations responded to the consultation
- Publication has slipped from original timeline, due to be published in the New Year
- It is understood that there is a desire for a rights-based approach, however this must be balanced with realism
- There is emphasis on the 'team around the person' approach
- Emphasis on actions and progress being measured and monitored throughout the life of the document – in 3 years' time there will be a review of what has been achieved against the actions set out

- The hope is that the plan will be produced ahead of Local Health Boards submitting their Interim Integrated Plans
- There will also be a Dementia Action Plan Delivery Assurance Group, made up of a variety of stakeholders, to monitor progress regularly
- The language is technical, however this is based on evidence that came directly from stakeholders – and there needs to be a balance about who the document is aimed at
- There is largely agreement around the action points but disagreement around the use of language
- The Cabinet Secretary hopes that the published plan will contain real and meaningful actions, which are measurable and set to a timescale, and that the balance of language will be right – however he recognises at the outset that he will need to make a compromise on this, not everyone will be satisfied.

Discussion

- **Nigel Hullah** commented that the language throughout the draft document is clinical and not user-friendly, although the content is reflective of the consultation process and comments made by people affected by dementia
- **Rachel Niblock** thanked the Cabinet Secretary for DEEP's involvement in the consultation process, and offered further consultation with people affected by dementia to help 'find the balance of language'
- **Daisy Cole** suggested there are difficulties with an understanding of human rights within Welsh Government – that a rights-based approach is not the same as stating that the government is signed up to the Glasgow Declaration. She offered time and assistance in incorporating a rights-based approach into the plan.
- **Dr Natalie Elliott** suggested that the [Dementia Statements](#) would be a valuable addition to the document
- **Catrin Edwards** highlighted the importance of working across services, and incorporating end of life and palliative care into the plan – and **Lynne Neagle AM** pointed out that end of life care formed a large part of the response of the CPG to the consultation
- **Dr Rosslyn Offord** welcomed detailed action points as, as psychologists felt it was important to have clearly defined actions that Health Boards would be accountable to. She also welcomed the consideration of qualitative evaluation in addition to 'hard data', as psychologists have seen the distortions created in services driven purely by data such as waiting time targets.

AOB

- **Catrin Edwards** – CPG on Hospices and Palliative Care has launched an enquiry into inequality of access – would welcome submissions of evidence from attendees of CPG on dementia (information circulated with minutes)

Actions for next meeting

- It was agreed that **Lynne Neagle AM** would write to the Cabinet Secretary on behalf of the CPG outlining concerns about the lack of a rights-based approach throughout the draft document (copy circulated with minutes)

Dates of future meetings

- Tuesday 6 March 2017 – Seminar Rooms 1 & 2, Y Pierhead

- Tuesday 12 June 2017– Seminar Rooms 1 & 2, Y Pierhead

One of the future meetings will focus on intergenerational work with school children and people affected by dementia.