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Note of Meeting – Cross- Party Group on Epilepsy, 27 February 2020

In Attendance:

Alasdair Allan MSP	Arron Ashton – Scottish Government
John Bruce	Jan Campbell – UCB
Shona Cardle – Glasgow Children’s Hospital Charity	Rhona Figures, Epilepsy Connections
Ian Forbes – UCB	Gerard Gahagan, Scottish Government
Kenneth Gibson MSP	Paul Gillon – Veriton Pharma
Susan Goldwyre – Muir Maxwell Trust	Alan Guild
Pat Graham, PAMIS	Keely Hetherington, Mindroom
Andrena Hughes	Jen Irvine – NHS Lanarkshire
Rona Johnson – Epilepsy Scotland	Sylvia Lawrie
Rachel Lloyd – NHS Lothian	Dr Anne MacDonald – Scottish Government
Rebecca Marshall – Mindroom	Pamela Martis – NHS Lothian
Ann Maxwell – Muir Maxwell Trust	Shirley Maxwell, Epilepsy Connections
Beth Morrison - PABSS	Hilary Mounfield – Scottish Epilepsy Centre
Jennifer Mutch – NHS Fife	Ann-Marie Nelson – Muir Maxwell Trust
Brendan Nisbet – Scottish Government	Audrey Noble – GW Pharma
Emily Ord – Eisai Ltd	Derek Robertson – NHS Lothian
Sarah Silk – NHS Lothian	Jane Stuart – NHS Lothian
Charlene Tait – Scottish Autism	Kerry Thompson – NHS Borders
John Thomson – Eisai	Anissa Tonberg – Epilepsy Scotland
Rodger Watt – Scottish Government	Ian Williams – Quarriers

Apologies:

John Heaney	Chris Jeans – SUDEP Action
Jude Kilbee, Bial Pharma	Ailsa McLellan, NHS Lothian
Michael McCulloch	Barbara McCulloch
Lorraine MacKenzie, Observer	Annette Parker – Sense Scotland
Brian Rocks	Jay Shetty, NHS Lothian
Gillian Smith, Scottish Learning Disabilities Observatory	Lesslie Young, Epilepsy Scotland

1. Convener Alasdair Allan MSP welcomed attendees to today’s meeting and gave an update since the last meeting in November:
 - Neurological Care and Support in Scotland: A Framework for Action 2020-2025 has now been published. This framework includes seventeen commitments which aim to improve neurological care across Scotland.
 - Following Alasdair Allan’s letter to the Scottish Government asking for support to nationally roll out the epilepsy database being piloted in NHS Greater Glasgow and Clyde, Epilepsy Scotland, Dr Craig Heath and colleagues met with teams from the Scottish Government to present the database and discuss steps for national rollout. This work is ongoing however, the teams feel positive about future steps.
 - Alasdair Allan met with consultant paediatric neurologists, a representative from the Royal College of Child and Paediatric Health and Epilepsy Scotland to discuss Epilepsy12, an audit system which analyses and benchmarks paediatric epilepsy care across the UK. He has

written to the Cabinet Secretary for Health asking what help the Scottish Government can give to support Scotland to join this audit.

- The Scottish Medicines Consortium (SMC) are scheduled to meet to discuss licensing Epidyolex. They are inviting submissions on whether it should be prescribed in NHS Scotland.
- Epilepsy Consortium Scotland are hosting an event at the Scottish Parliament to mark National Epilepsy Week. The event will take place Thursday 21st May 1pm-2:15pm. The Secretariat will be in touch with further details shortly.

Minutes from the November meeting were approved.

2. Alasdair Allan MSP introduced Dr Anne MacDonald, Senior Research Fellow at the University of Glasgow. She presented her Coming Home Report which was commissioned by the Scottish Government. The report analyses out of area placements and delayed discharge for people with learning disabilities and complex needs.

Dr Anne MacDonald: This is a learning disability focussed report however, there is some overlap with epilepsy. The project came from learning disability policy, Keys to Life which came out in 2013. This had a number of recommendations including investigating individuals in out of area placements as well as those in hospital with delayed discharge.

It was not known how many people were affected by this issue and the Scottish Government wanted to build the capacity to bring these people home if that was their choice. Scottish Government wanted to take a national strategic approach to this issue. The aim of the report was to gather accurate national data on adults with learning disabilities who were out of area or had delayed discharge from hospital. Additionally, identify what support they might require if they were to return home.

Data was collected from each individual health and social care partnerships (HSCPs) across Scotland. Anne wanted to understand the cases behind the numbers, why were individuals out of area/delayed discharge and what were the challenges in bringing them back home. The report focussed solely on those with a learning disability.

There were 705 people who were out of area, 79 of those were out of Scotland. Out of the 705 people who were out of area, 453 had gone out of area not through their/their family's choice. 109 of the 454 were deemed by the HSCP as a priority to return. The report focusses on the 109 (those out of area not through choice and who are deemed as a priority to return).

Believes these numbers are a substantial underestimate for a couple of reasons – one HSCP did not participate and it was one of the biggest partnerships. Believe this significantly impacted the data. The question about whether those should be repatriated was often missed out. 109 is often quoted as the figure however, Anne suggests it is closer to 209. In terms of those delayed in hospital (those clinically ready to leave) 67 were delayed discharge.

The combined group is therefore 176 people. Nearly half the group have autism as well as learning disability, one in five have a "forensic label" which means they have had some form of contact with the criminal justice system. Half of the cohort were under 35. Physical disability was not a big feature and mental health needs were relatively low.

Behavioural challenges were significant, as this is often how this group communicate their needs and is often the cause of service breakdown – 68% had current behavioural challenges. Most common types of challenges were physical aggression (60%), verbal

aggression (43%), property destruction (36%), self-injury (31%) and disruptive behaviour (28%).

Types of support for these concerns were varied with negative ones quite common; physical restraint (27%), seclusion (11%), medication (51%), environmental restraint e.g. locking doors (39%). However, more positive forms of support were also present, positive behaviour support (39%) and psychological therapies (21%).

Challenging behaviour accounted for 48% of hospital admissions. Service breakdown (family/carers feeling they are no longer able to cope) also accounted for 9% of admissions. 22% of people have been in hospital for longer than ten years. Lack of accommodation and lack of service providers were the two most common barriers to individuals coming home.

130 people had epilepsy in the group overall group. People with epilepsy were much less likely to have a forensic background. Physical disability was much higher at 19% compared to 7% in the main group. However, age range and level of learning disability were similar.

91% of the 130 people with epilepsy were out of area whilst 9% were delayed discharge, 24 people were a priority to return. Behavioural challenges were less likely in the epilepsy group however, this was still high at 50%. Similar types of behaviour challenges and concerns about how they are supported were found in this group. Seclusion in particular was slightly higher in the epilepsy group.

Behavioural challenges are understood as communication from the individual, a product of the environment they live in, and of the support they receive. It is often an expression of unmet need. Restraint and seclusion are very restrictive interventions which have significant risks associated with them including death.

Positive behavioural support is an evidence-based and proactive approach to supporting people with learning disabilities. It analyses behaviour and assesses the person's life circumstances and develops strategies specifically designed to suit that individual.

Several recommendations were created after the report. Firstly, improving service commissioning which involves better planning for complex individuals, beginning at school. Secondly, strengthening community services which are already available, each HSCP develop an "at risk register" to proactively identify those at risk of hospital admission. Finally, skilling up the workforce so that they become more resilient, including the roll out of positive behavioural support.

Updates since the report was published last year:

- Recommendations supported by Health Minister, new Keys to Life Framework
- Ongoing support to HSCPs with implementation of the recommendations e.g. sharing good practice between areas and facilitating national events to provide support and impetus
- Partnership with Glasgow University to deliver Positive Behaviour Support (PBS) accreditations have been launched, PBS Community of Practice has been set up)

3. Alasdair Allan MSP thanked Dr Anne MacDonald for her presentation. He then invited Ann Maxwell of Muir Maxwell Trust to speak about her petition PE01545, residential care provision for the severely learning disabled.

Ann Maxwell: PE01545 was presented by Ann Maxwell to the Scottish Government in December 2013, it requests residential care for the severely learning disabled, currently missing in Scotland. The petition has been heard twelve times however, has not progressed far over the last six years.

The issue was always going to be the numbers concerned, how many people would like/need this kind of residential facility. She is not proposing traditional hospital care, or residential care in small groups. Instead, a bigger facility with specialist medical support onsite. We do not know how many people are affected by this issue. There is no accurate assessment of need to assist Scottish Government to identify who needs/wants residential care.

Scottish Government have recognised that there is a need for sophisticated residential care, which includes medical support within that setting. There needs to be a choice for families, some will not want it whilst others will. Once a facility is in place it is expected more families will want it after they have seen it.

Muir Maxwell Trust is named after Ann's son, Muir who is now 23. The work of the Trust has always followed the experience of Muir. Muir was a resident of Donaldson's college (school for the deaf) from the age of 12 to 18. This was secured after a Section 23 assessment, which took 18 months to complete. Following Donaldson's, Muir then moved to Young Epilepsy where he was supported by clinical epilepsy specialists.

Muir is now at the David Lewis centre in Cheshire. The care Muir receives there is outstanding. Muir has two to one care; he lives in a house with eleven other people and is very happy. There is a farm onsite, a swimming pool, day centre, craft centre, sports hall. The majority of residents have epilepsy, the care received there is excellent. Ann wishes the facility was not in Cheshire as it is a long distance away.

There is no facility like this in Scotland, Ann believes this is a significant gap in care provision. Despite six years of her petition, no progress has been made. Her next hope is to provoke a debate in Parliament about this issue.

4. Anissa Tonberg (secretariat) thanked both Anne MacDonald and Ann Maxwell for their presentations. She advised that Alasdair Allan MSP had to step out of the meeting to ask a question in the debating chamber. Anissa Tonberg opened the meeting to questions from members.

Kenneth Gibson MSP – asked if there are people with complex needs from England residing in Scotland for specialist care or is it just Scottish individuals going to England.

Anne MacDonald – said she did not look at that in her research as it was out with her remit. Her feeling is that the services Scottish individuals are going down to England for do not exist in Scotland. Therefore, it is less likely English individuals are travelling up to Scotland for that kind of care.

Kenneth Gibson MSP – said there seemed to be a lot of movement within Scotland. Asked if there is an imbalance amongst some HSCPs?

Anne MacDonald – said it varies, some smaller/rural partnerships struggle if they do not have very many people with complex needs making it difficult to provide a service. Some of the island communities may be using Glasgow or Inverness, whilst smaller authorities may be accessing established services in Central Scotland due to the low number of cases. Other areas have "badged" specialisms e.g. National Autistic Society, which can be very important to some parents.

Anissa Tonberg – asked whether there is a sense of urgency around repatriating those individuals who are deemed as a priority to return.

Anne MacDonald – said there is a real desire to do something about it. Learning disability commissioners feel quite stuck about what to do as services needed by individuals are not available locally. There is a good example in Midlothian of a core and cluster model; people have an individual house, but they are grouped together so there is staff back up and support if needed. Austerity over the last ten years has had a significant impact on social care standards e.g. staffing and funds for high quality facilities.

Beth Morrison – Thanked both Anne MacDonald and Ann Maxwell for their talks. Said she has a 21-year-old who has complex needs and understands the issue very well. Said she has been campaigning for ten years on the use of seclusion and restraint, in schools in particular. Early intervention is key. Her report into seclusion and restraint found that 3/4 years olds are more likely to be subjected to restrictive practice compared to 13/14. More needs to be done to support families and teachers, happy children do not challenge.

Sylvia Lawrie – asked what individual services are available for this group who are expressing these kinds of challenges, in their own home and community near their families.

Anne MacDonald – Commissioners would like an individual service but the cost of that often poses challenges. Some authorities have looked at a cluster model, Moray have developed ten two-bedroom houses closely located to one another. They share staff during emergencies. Additionally, in challenging behaviour circumstances a change of face can sometimes help to diffuse the situation, additional staff is useful in these instances.

Sylvia Lawrie – said this type of model can often cause more problems which costs money.

Anne MacDonald – Said some authorities are struggling to make the Moray/Midlothian model work financially. As health and social care is still in the process of transition, budgets are not shared between hospitals and social care. This is then difficult to transfer someone in hospital to a social care setting due to budget restrictions.

Sylvia Lawrie – said that nothing has changed.

Anne Macdonald – said that change is happening slowly.

Ann Maxwell – said that the figures on epilepsy in Anne's report might not be accurate because (in some cases) epilepsy is not listed as the main condition meaning it is not reported. There has been a move away from specialist schools to inclusion. Said she is concerned that this problem is only due to get worse as there are far more children not being supported at an early enough age. Said this is a matter of urgency.

Anissa Tonberg – said that Ann had proposed to seek a debate around the issue, asked members if they would welcome this and there was broad agreement. Said there are no guarantees surrounding debates, but her team will follow up with Alasdair Allan's office.

The Secretariat stated that:

- The next meeting is due to be at the end of May, exact date and topic will be available shortly

She thanked all for their attendance and closed the meeting.