ALL PARTY PARLIAMENTARY GROUP ON RARE, GENETIC AND UNDIAGNOSED CONDITIONS

Social care hearing: minutes

Date: **23 January 2019**

Venue: **Room O, Portcullis House**

Parliamentarians

Catherine West MP
Rt Hon Baroness Neville-Jones
Alex Sobel MP
Lord Rogan

Guest Speakers

Dr Jayne Spink, Genetic Alliance UK
Karen Harrison, Support Services Manager, ALD Life
Liz Toft, mother of a child affected by an undiagnosed condition
Anders Olauson, Chairman of Agrenska Centre, Sweden, and Honorary Chairman for the European Patients' Forum

1. **Welcome from Catherine West MP**

2. **Guest speaker: Karen Harrison, Support Services Manager, ALD Life**

Karen provided the All Party Parliamentary Group (APPG) with her experience of accessing social care for her two sons affected by adrenoleukodystrophy (ALD). ALD is a rare genetic condition affecting 1 in 17,000 people in the UK, resulting in a loss of movement, sight and hearing and a need for 24-hour care.

Karen explained some of the challenges she has faced in accessing social care services when affected by a rare condition. Social care service providers have a poor understanding of rare conditions, and therefore consequently struggle to understand the service user's needs. Care plans, once developed, are rigid and unable to adapt to the fast changing progression of rare diseases such as ALD. Any requests for adaptation to care plans must go to a panel composed of health and social care professionals, which the family are not permitted to attend. If this request is declined, families go through long and lengthy appeals to fight for the improvements they need. This panel process is also present in disability assessment procedures, where families are not permitted to attend, limited information is presented and it is not possible to advocate for all of a service user's needs.

Transition from childhood to adult services presents its own challenges. Many families find that the first option they are presented with is residential care, and alternative options for care in the

home seen as too costly for Local Authorities. This often results in a traumatic battle for many families, who want to keep their children at home.

3. **Dr Jayne Spink, Chief Executive, Genetic Alliance UK**

Jayne informed attendees of Genetic Alliance UK's preliminary examination of the social care need of those with rare conditions. INNOVCare is a European project looking specifically at the unmet social care need of those living with rare conditions across Europe. EURORDIS (the European Organisation for Rare Diseases), a partner of the INNOVCare project, provided Genetic Alliance UK with the breakdown of statistics from the UK, which found that 79% have difficulties with daily activities and tasks, 61% find personal care difficult to manage, and 78% felt badly informed about social care services. These results point to a significant unmet social care need for people affected by rare diseases in the UK.

4. **Guest speaker: Liz Toft, mother of a child affected by an undiagnosed condition**

Liz described the challenges in understanding what social care support is available and how it can be accessed. She outlined her experience of applying, and being turned down for, direct payments. Throughout the application process she came up against a series of challenges, such as the inclusion of false medical history and inaccurate personal information about herself and wider family – information that is key in determining a family's eligibility.

The social care system struggles to consider the specific needs of individuals. This can be especially problematic for families affected by undiagnosed conditions, and seems to be related to the computer system used to analyse needs failing to account adequately for their experiences, as they do not fit into pre-defined categories. Further, the specific complex medical nature of undiagnosed conditions and their impacts, mean that social workers may not have the knowledge to advocate for, and support, families affected by these conditions.

The unpredictable nature of undiagnosed conditions bring uncertainty in terms of what presentations of the condition may occur over time. Changes to care plans need to be implemented quickly, which can be difficult for social services to organise.

5. **Dr Jayne Spink, Chief Executive, Genetic Alliance UK**

The National Institute for Care and Excellence (NICE) are developing 'Children and young people with disabilities and severe complex needs: integrated health and social care support and service guidance'. The APPG will feed findings from the social care hearing into the development of the guidelines and meet with NICE to discuss the outcomes. The proposed publication date of the guidelines is February 2021. The APPG hope to engage with NICE to make the case for faster publication of the guidelines, in addition to an accompanying funding stream for implementation.

6. **Guest speaker: Anders Olauson, Chairman of Agrenska Centre, Sweden, and Honorary Chairman for the European Patients' Forum**

Anders Olauson offered the APPG a perspective of the social care system within Sweden. Anders has been involved in the development of a national centre that provides support for families and patients combining health, social care and educational needs. Key activities of the centre

include the training of health and social care providers, so they can better understand patient's needs; and educating patients and families so they are more informed on their rights in accessing health and social care. Anders highlighted that an absence of coordination between the health and social care systems mean there are gaps in the care experienced by many. By successfully linking both health and social care, the system can be made more efficient for patients and families.

7. Discussion

During the discussion attendees further evidenced the challenges raised by guest speakers and noted that this is made worse by the chronic underfunding of social care services.

The nature of rare conditions means social care needs can be extensive and unpredictable as the condition evolves. The social care system is not meeting the needs of those affected by rare conditions and has an inability to respond to changing needs of rare disease patients. This is also true of the disability assessment; the process can be complicated, time-consuming and stressful for families. Families need to be aware of the sources of support available and how to access them. Attendees of the hearing shared their experience of lengthy challenges with Local Authorities to access support. Families worry about being judged for needing additional support and sharing personal information with strangers. They often find little sensitivity offered around this issue. Transition from children to adult services is an additional challenging area for families, especially for conditions where the life expectancy is increasing. Consequently, there is an increasing number of patients requiring input from adult social care services – provisions of which are not suitable.

Attendees described vast differences in access and quality of social care across the UK. One attendee experienced loss of social care provision when moving from one local authority to another, despite care needs remaining the same, highlighting a 'postcode lottery' of social care services. Further challenges include the segregation between health and social care; this leads to a strain on health services as those not accessing social care turn to emergency departments and experience unnecessary extension of in-patient stays at hospital.

8. Next steps

The APPG will feedback the outcomes of this hearing to NICE and seek to engage with them on implementation of their upcoming guidelines and campaign for an accompanying funding stream. The APPG will write to the Local Government Association to discuss the social care needs of those living with a rare disease, and the importance of training for healthcare professionals undertaking disability assessments. Genetic Alliance UK will collate discussions from the hearing to develop a report that provides a spotlight on the experiences of those with rare conditions in accessing social care.

9. Close