PE1789/C
Royal College of Psychiatrists in Scotland submission of 21 October 2020

1. Should the Scottish Government spend more money on supporting families with LDD?

- **Recognition of funding needs** – as highlighted in our recent webinar on the impact of the pandemic on children with LDD, there is a cross sector recognition that greater resources are needed for their care and support.
- **Assessing where resources go** – The need for CAMHS services is almost overwhelming current service provision. With increasing investment, the challenge for managers of these services to balance where money should be spent should by addressed by ringfencing a proportion of funding for our LDD children.
- **Example of where investment can go** – Sleep difficulties are common in this group of children and young people. Without support to manage these and adequate services (e.g. respite) sleep difficulties can result in significant caregiver stress and make parenting / caring overwhelming.

2. What type of support should be available?

- **Providing the care they are entitled to –** In order to provide children with LD the necessary care they need and are entitled to as a right under the UNCRC, there should be increased service provision across all tiers of support and care.
- **Staffing –** We require increased staffing in multidisciplinary, LD-specific health teams, including nursing, clinical psychologists, psychiatrists, speech and language therapists and occupational therapists.

i. Tier 1/2 Early interventions/1st line interventions

- **Importance of early intervention** – Learning disabilities usually present with a developmental delay in early infancy, often from birth in those severely affected and has a lifelong impact. The earlier the intervention the most chance of improvement.
- **What needs to change** – We feel this committee needs to recommend to colleagues and to the Scottish Government that the welcome moves to introduce positive behaviour support in adult LD services must be brought forward and adapted to early years and throughout childhood. Similar adaptation is needed for other universal programmes such as parenting and counselling.

ii. Specialist LD CAMHS multidisciplinary teams (Tier 3) when Tier 2 services are not sufficient

- **Experience** – Multi-disciplinary Professionals with LD expertise (see Point 2 – Staffing)

iii. Intensive Treatment services (Tier 4)

- **Necessity** – These services, based on positive behaviour support, are vital when parents/carers are unable to implement advice and strategies without additional support. A lack of these services means children with the highest level of need are unable to benefit from LD CAMHS, leading to an escalation of need.

iv. Supporting access to physical health care for children with LD/neurodevelopmental difficulties

- **Patchy provision** – These services are variable across Scotland, and reasonable adjustments to ensure equality of access to care for these children who often have complex physical and mental health co-morbidities. Close coordinated working between LD services and paediatrics would help.

v. Social care support

- **Importance of respite services** – If more respite provision was available, then parental and siblings mental distress and ill-health in relation to caring for these children without sufficient support would be reduced. Families may then be able to implement Tier 2/ Tier 3 guidance and prevent the need for Tier 4/ crisis intervention.
- **Variation** – Access to social care support is also highly variable even within the same local authority. The phenomenon of "*exclusion by social inclusion*" is often present for the most complex children and young people.

vi. Transition to adult services

- **Support throughout this process** – Clear multiagency pathways should be in place. Children should be highlighted for transition prior to age 15 and no later, with a professional named person (teacher, social worker, nurse) assigned to them until transition is complete.

3. Who should make assessments of LDD children and families' needs?

- **Multiagency approach** – There should be a multiagency approach to assessments recognising that expertise lies across the services. This should be embedded within GIRFEC and fit with work on coordinated neurodevelopmental assessment pathways underway in a number of health boards.
- **Need rather than diagnosis** – Interventions should not be dependent on a diagnosis but based on presenting need. The ESSENCE model can be used early on to recognise that a child has neurodevelopmental difficulties and requires interventions.
- **Learning difficulties** – Assessment of children with learning difficulties can be made by educational psychologists, occupational therapists and speech and language therapists. If presenting with additional mental health needs, then mainstream CAMHS should have the expertise to work with these children.

4. When should these assessments take place?

- **Joined up working** – Children with LD have complex needs, with involvement required from many agencies. Good coordination is required locally with clear pathways to ensure the right help at the right time, rather than multiple referrals to different professionals in an uncoordinated way.
- **Co-location –** The co-location of Paediatrics, specialised social workers and multi-disciplinary LD CAMHS teams would be an ideal way to provide effective and efficient services.
- **IT** – To facilitate this there needs to be investment to develop a proper joined up IT platform across Scotland. Child Health, CAMHS, Education and Social Work all use IT systems that don't currently link into each other, so safely sharing information is difficult and time consuming.
- **When need is first identified** – Families should not be forced to present their children in complete crisis to a paediatric hospital to prompt an emergency assessment. They should be able to access support when the need is first identified.