

## **Results of survey on pre-school key working for complex health needs Hosted by HPCI (Herts Parent Carer Involvement) Oct 2020**

This survey was open to parent carers of children up to age 11 who have complex health needs across Hertfordshire, looking at key working for families in the pre-school phase. The survey was publicised to parents on HPCI's parent network and social media, and directly to key support groups, PNI advisory teachers and occupational therapists and selected Hertfordshire special schools. A total of 39 parent carers completed the survey from across the county (except for Broxbourne and Welwyn & Hatfield).

### **The results:**

- 72% of respondents said that they had not had any help in the pre-school age with organising, managing or coordinating their child's healthcare appointments or ongoing health needs (either from professionals or friends / family).
- Only 15% reported that someone from a health service does or did help co-ordinate their child's appointments or care.
- All respondents reported that they currently undertake the co-ordination of care for their child (with a small number reporting additional help from school/nursery (6), social care (1) and a family member (1)).
- Many respondents identified support received in the pre-school years – most frequently service referrals and support with multidisciplinary meetings. However, 39% of people answering this question said that they had no support at all.
- Parent carers were asked to rank types of help, according to which they think are the most useful for parents of preschool children with complex health needs. These were ranked as:
  1. Co-ordination of appointments
  2. Support with multi-disciplinary meetings
  3. Emotional or wellbeing support for yourself or your family
  4. Referrals to other services
  5. Signposting to other services in your local area

### **Other key points made** by parents were that:

- "This keyworker service would be invaluable to our family."
- It can be incredibly difficult to find the support that is needed.
- It often feels like a fight to access services and support.
- Services need to be available based on the needs of the child, not just after diagnosis.
- Many families reported feeling isolated or abandoned.

**What next?** The results have been shared with the working group and will be used by the parent rep and others working on the project.