External input

Professionals who specialise in supporting CYP with Usher syndrome can provide support and input at different stages. Each bring different expertise. Please be aware, services are not available consistently in all areas of the UK, and may operate under different names / providers in different areas. Please discuss with your local Sensory Support team.

"As parents new to this diagnosis, we didn't know what support is out there, and who should be involved. It was so helpful to find professionals that had experience of Usher syndrome and could help us understand the path ahead"

A range of sensory support professionals can be involved, and the following wording can be used in Education and Health Care plan (EHCP) to specify the input required:

- ☐ Regular XX* hrs per XX [week/month/half term/term] with **Qualified Teacher of Multi-Sensory Impairment (QTMSI)**(* to be agreed with Sensory Support Service). If no QTMSI available in local authority, this provision can be commissioned by the local authority from another provider.
- ☐ Regular XX* hrs per XX [week/month/half term/term] with **Qualified Teacher of the Visually Impaired** (*to be agreed with sensory support team).
- ☐ Regular XX* hrs per XX [week/month/half term/term] with **Qualified Teacher of the Deaf** (* to be agreed with Sensory Support Service).
- ☐ All teachers / support staff to be trained annually on needs of child (to gain an understanding of Usher syndrome, key impact on child, and strategies which must be used in school). In secondary school, all core subject teachers must receive training by end first half term of school year (offer virtual / follow up sessions to cover all)
- ☐ Access to Speech and Language Therapy as required.
- ☐ Access to Occupational Therapy as required.
- ☐ **Habilitation Specialist / Orientation and Mobility Specialist** to identify priorities and programme for skill development and training (e.g. travel to school / social activities), including organisational skills needed in existing / future settings.
- ☐ Access to a Teaching Assistant / practical assistant to support the CYP as required: as note taker, to read back work, act as a scribe, help with practical demonstrations.
- ☐ Trained Intervenors / Communicator Guides can be helpful for CYP that need them.
- ☐ Access to **social, emotional and mental health support (SEMH)** in school setting or outside school as required.
- ☐ Access to **peers and role models** living with Usher syndrome / sensory loss.
- ☐ Parents can request a Deafblind Guidance assessment to be completed by the local authority ahead of key transitions (e.g. in year 5 , year 10) to assess the full range of needs, including social and emotional considerations.
- ☐ Travel grant to be given for CYP to travel throughout the academic year.(e.g. during winter months when vision loss increases) to the school that is able to meet their needs.

Key: CYP = Child or young person