



"A voice for families of children and young people with disabilities"

HOW HEALTH PRACTITIONERS CAN SUPPORT FAMILIES

1. Ensure that parents never leave an appointment where their child has been diagnosed without further information about where to get support.
2. Have someone contact a family 4-6 weeks after diagnosis to answer any questions they have and remind them where to get support.
3. Clear pathways for different therapies so that parents (and school staff) can easily access support for their child.
4. In the last year, 84% of excluded children have had Special Educational Needs, either with a statement or identified as needing support in school (School Action). Parents are having to collect their child from school at unscheduled times, frequently losing their jobs and/or suffering stress related illness as a result.

Most of these excluded children have emotional and behavioural problems or autism. The quicker children's needs can be assessed at CAMHS and the more support that can be put in to support the child will help the child to achieve at school and reduce unnecessary stress on the family.

5. Other important supports for parent carers include manual handling training, hoists and counselling.

SUPPORTING CHILDREN TO ACHIEVE AT SCHOOL

1. Ensure that there is sufficient OT time for children with statements. This is key to children being able to access their learning in the classroom. Currently one community OT for children on statements in Reading while colleague is on maternity leave.
2. Ensure that disabled children can access IT in the classroom. At the moment, parents are being told that OTs can't do this as it is a Local Authority responsibility but that there is no one within Reading Borough Council to do this.

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3. Reduce time lost at school to attend medical appointments such as more joint clinics and practitioners visiting children at school.
4. Providing specialist wheelchairs where needed so that the child is comfortable and able to learn.
5. Review policy on provision of incontinency aids so that children have sufficient to ensure their comfort in school.
6. Provide information to schools and families about:
 - The side effects of medications where this might affect their ability to learn.
 - Clear targets for school staff to carry out speech and language therapy exercises and physio.

IDEAS FOR JOINT COMMISSIONING

1. Work with voluntary agencies to ensure families who agree are contacted post diagnosis to offer support.
2. Support for children with emotional and behavioural difficulties and autism to be extended to minimise school exclusions.
3. IT specialist to assess children's needs to access IT.
4. Training for child to use their wheel or power chair.
5. Three different OT departments confusing for families (Dingley, RBH & BHFT) and assessments of child's seating needs etc. are often duplicated.
6. Clear transition plans at 18. This can be a major source of stress for families and young people who are often left without support while things get sorted at 18. Young people with mental ill health also need access to ongoing support when they turn 18.

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