Resetting Services
to Disabled Children

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Recommendations for future emergencies

The recommendations presented here were developed from research commissioned by the NIHR Policy Research Programme on how to reset and remodel services for disabled children and young people and plan for future emergencies, following the COVID-19 pandemic [Resetting Services to Disabled Children | Resetting Services to Disabled Children | Newcastle University (ncl.ac.uk)]. The research reviewed international evidence on the impacts of changes to services during the pandemic and interviewed families, professionals, service leads and commissioners about which changes worked well and/or were not helpful. The recommendations were agreed in a national Delphi survey of commissioners; service leads and practitioners from health, social care and education; parent carers and disabled young people.

Commissioning and Guidance

1. Department of Health and Social Care and Department for Education should provide clear, consistent, and joined up guidance to commissioners and service providers about delivery of services. Any changes from previous guidance should be clearly highlighted. All guidance regarding children and young people should include specific guidance for disabled children and young people and those with special educational needs.
2. There should be designated, identifiable senior leaders responsible and accountable for implementing guidance on disabled children's health, education and social care provision in each area.
3. The impact of proposed changes to service provision should be assessed and reviewed with feedback from families and frontline professionals to senior managers. Plans to continue providing services should be agreed across health, education and social care.
4. The provision available locally from health, education and social care and how to access it should be clearly communicated to families, including through the local offer and local SENDIASS. It is critical that any changes to this are swiftly communicated, including any reduction in services to disabled children.
5. Priority should be given to ensure education settings are kept open for disabled children.

Communication

6. Families should be contacted by a person or service known to them, to inform them about service access. The content and delivery of the message should be co-produced with families.
7. There must be a specific contact, including telephone, in each area. They should provide information and signposting for families of disabled children who require advice and / or provision.
8. A local communication system (e.g. messaging service, online enquiry form and telephone) should be established to enable families of disabled children to seek advice from professionals.

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Whittington Health NHS Trust
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PenCRU & Family Faculty
University of Exeter Medical School
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Delivery of services

9. Designated spaces / settings should be maintained for assessing an agreed set of conditions or circumstances in person. More than one carer may be required to meet a child’s needs.
10. Local budgets should be used to enable digital connectivity for families of disabled children.
11. Telehealth, including phone and video consultation, should be used where possible and appropriate. Families of disabled children should be supported to manage telehealth safely and confidentially.

Cross service and sector provision

12. Information about indivduals must be shared across health, education and social care in the best interest of children’s health and safeguarding. There should be multiagency virtual or in person meetings across services to share relevant information about families.
13. Local Area services should have a process in place to agree the coordination of services and ensure a child is seen in person as needed. Seeing a chid in person should be done by the service or setting that knows the child best or who has the highest RAG rating.
14. Services should adopt an 'Every Contact Counts' approach. When appropriate, a professional who has had contact with a family should update other professionals involved with the family.
15. Health, education and social care providers should engage with community leaders and Third Sector organisations (charities, social enterprises, and voluntary groups) to ensure information about access to services is shared effectively with families.
16. Safeguarding and/or health-related risk assessments should be undertaken by health, education and social care for all identified disabled children and families and findings shared as appropriate across agencies. All risk assessments should be reviewed regularly and on request.

Identification, referral and intervention

17. Diagnostic assessments and assessments of worsening conditions should be prioritised. Universal providers (e.g., GPs, health visitors, early years service) should continue to prioritise identifying needs of children and families and refer or signpost to appropriate services.

Supporting parent carers

18. Accessible support for health and wellbeing of parent carers of disabled children should be provided. Third Sector (charities, social enterprises, and voluntary groups) resources and help lines e.g. Contact Listening Ear Service, should be identified and publicised in local information to families of disabled children.
19. Parent carers of disabled children should be in a priority group for support and interventions to enable them to maintain their caring role (e.g. short breaks, talking therapies, vaccines).

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