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| **NSF Standard for hospital services 2004** | **NSF Standard for disabled CYP and those with complex needs - access to hospital services 2004** | **Healthcare For All 2008** | **GAIN: Best Practice Indicators 2010 (Northern Ireland)** | **Confidential Inquiry 2014** | **Research evidence**  |
| *Child-centred hospital services*1. **Integrated and co-ordinated care** around their **particular needs**2. Treated with **respect**3.**Support and information** to understand and cope4.Active **partners** in decisions about health and care5.Where possible, exercise **choice** | 1. **Appointments are synchronised** to minimise hospital visits, scheduled outside of school hours2. Systems are in place to ensure those who find it hard to wait **do not have to wait undul**y at out-patient departments3.Policies, practices and procedures are regularly reviewed in **partnership** with children and parents to ensure that disabled children and their families are not disadvantaged4.Timely, appropriate, accessible and accurate **information** is provided to enable CYP, parents or carers to make **choices** about treatment, care and services5. Disabled children, especially those with high communication needs are not excluded from the **decision-making** process. 6. Disabled children and their parents are routinely involved and supported in making **informed decisions** about their treatment, care and services and in shaping services. | 1. All health care organisations … should ensure that they collect the data and information necessary to allow **people with LD to be identified** by the health service and their pathways of care tracked. 2. Families should be involved as a matter of course as **partners** in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that **reasonable adjustments** are made to enable and support carers to do this effectively - will include the provision of **information,** but may also involve **practical support** and **service co-ordination**. 3. All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, ‘**reasonably adjusted’** health services.4. All Trust Boards should ensure that the **views and interests of people with LD** and their carers are included in the planning and development of services, and in decisions affecting the operation of services | 1. **Pre-admission assessment** completed involving child, parents & carers and relevant hospital and community staff2. Agreed **discharge plan** that starts on admission and involves hospital personnel, community services, child and family3. **Fast tracking procedures** for CYP with LD who use hospital frequently/have difficulty coping with prolonged waiting periods. 4. Parents/carers should be acknowledged as having **expert knowledge** of their child’s needs. CYP and parent should be i**nvolved** in all assessment, care planning and discharge processes. They should be **encouraged to ask questions** and **receive relevant information in** a format they can understand 5. There should be an identified **community keyworker** as key point of contact during admission | 1. Clear **identification of CYP with LD** on the NHS central registration system and in all healthcare record systems2.**Reasonable Adjustments** required by, and provided to, individuals, to be audited annually and examples of **best practice to** be shared across agencies and organisations 3. People with LDs to have **access to the same investigations and treatments** as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome | 1. Parents are not valued as **experts** 2.Parents want to be listened to and **respected** above all else3.Parents are not **involved in decision-making** 4.Parents do not feel **informed** 5.Caring role is not negotiated 6.**Appointments are not well managed** 7 Parents feel they have to **fight** to get what they need for their child8. **Appointments** need to be flexible and allow extra time 9. CYP want to be kept **informed** 10. CYP want to be **included in decisions** about their care 11. CYP do not want to miss **school** |

**Supplementary Material 1: Synthesis of existing policy and research**

 CYP = Children and young people, LD = Learning Disabilities, NSF =National Service Framework