A person writing on a white board

Description automatically generated with medium confidence**Top tips for transition **

Patients with learning disability have poorer health outcomes and are at risk of premature deaths. Young people with complex needs are often looked after within paediatric services with little or no contact with the GP. Once young people turn 18 their care must transition to adult services. It is never too early to start talking about transition!

Why a good transition is important:

* Transition can feel like a cliff edge event to young patients, their supporters, and families
* Celebrates the change from childhood to adulthood focussing on the persons strength and opportunities when becoming an adult
* Prepare the change from paediatric services to adult services with much more emphasis on patient responsibility
* Transition is a process over time and should start early to give the GP surgery and patient and supporters time to get to know each other and build a good relationship and trust
* Poor transition and loss of confidence in GP service can lead to missed opportunities to improve health outcomes
* Avoid crisis calls that are stressful for patients and health care professionals
* Involves the whole surgery team- getting to know the team, how the surgery works and managing expectations.

Definition learning disability

Learning Disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with. a reduced ability to cope independently (impaired social functioning). This is not the same as learning difficulties like dyslexia, where a person has problems in specific area but a normal intellect.

Learning disability register

* Use the code “learning disability” or “On learning disability register”.
* Add the code at any age if you become aware that a patient has learning disability and keep your register up to date
* You do NOT need to test or refer the patient to confirm a diagnosis of learning disability. It is enough if you feel a patient has learning disability and that the person benefits from the inclusion in your register.

More information here: [remedy pathway (icb.nhs.uk)](https://remedy.bnssg.icb.nhs.uk/adults/learning-disabilities/annual-health-checks/) under resources “ learning disability register and coding”

Summary: [improving-and-updating-your-learning-disability-register.docx (live.com)](https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fremedy.bnssg.icb.nhs.uk%2Fmedia%2F5422%2Fimproving-and-updating-your-learning-disability-register.docx&wdOrigin=BROWSELINK)

The Annual health check

* Invite every young person on your learning disability register from the age of 14y for annual health checks.
* Provide easy accessible information about the annual health check to young people and their supporters

New on learning disability register children: [easy-read-patient-leaflet-learning-disability-register-child.pdf (icb.nhs.uk)](https://remedy.bnssg.icb.nhs.uk/media/5448/easy-read-patient-leaflet-learning-disability-register-child.pdf)

Pre check check list : [healthwatch-sg\_ld-annual-health-check\_checklist\_nov-2020\_compressed.pdf (icb.nhs.uk)](https://remedy.bnssg.icb.nhs.uk/media/4733/healthwatch-sg_ld-annual-health-check_checklist_nov-2020_compressed.pdf)

* Find out how the young person prefers to be contacted and invited for their health check, flu vaccination and other appointments. Update for emergency contact numbers.
* Find out and document reasonable adjustments

What to cover at the AHC of a young person

* Get to know them and their likes and dislikes
* Education/ employment and ambition
* Support and care needs
* Housing/finances including how to claim for free prescriptions
* Ask medical history and current health problems and involvement of secondary care. Can be helpful to ask paeds to share summary of needs and treatment plan.
* Check mental health needs
* Ask about sexual health and contraception needs
* Lifestyle factors, drugs, alcohol
* Vaccination- annual flu and check if up to date including rubella, HPV, meningitis
* Medication review (is it more practical to change liquids to tablets ?)
* Encourage increasing involvement in own health and make this part of their health action plan (example start keeping a folder with hospital letters)

Carer support: Check awareness of carer support and how to contact [remedy pathway (icb.nhs.uk)](https://remedy.bnssg.icb.nhs.uk/adults/social-care/carer-support/)

Capacity and consent

* There is a presumption in law that from the age 16y a young person can make their own decision about medical treatment and parents loose parental responsibility on a young person’s 16th birthday.
* If a young person 16y or over has no capacity to decide, then the mental capacity act comes into force.
* Every decision for a young person without capacity needs to be made in their best interest.
* Parents cannot without a court order, deputy ship or LPA make decisions for their children over the age of 16y and consent on their behalf.

GP records

* Young people from their 16th birthday have access to their primary care records
* Proxy access to primary care records for young people 16y and over requires consent from the young person or best interest decision.
* Existing parental access to a child’s primary care record should stop at age 16y.
* Resources: GMC guidance: [Accessing medical records by children/young people/parents - GMC (gmc-uk.org)](https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/accessing-medical-records-by-children-young-people-parents) RCGP “ online service “ toolkit [GP online services toolkit: Introduction (rcgp.org.uk)](https://elearning.rcgp.org.uk/mod/book/view.php?id=13455) has a link to the children and young people record access guidance [Children and young people records access v3.0.pdf (rcgp.org.uk)](https://elearning.rcgp.org.uk/pluginfile.php/179161/mod_book/chapter/770/Children%20and%20young%20people%20records%20access%20v3.0.pdf)

Hospital passport

Encourage all children and young people to have a hospital passport. His lists their likes and dislikes and how they are best supported when they attend hospital

Hospital passports easy read and for autistic people here: [remedy pathway (bnssgccg.nhs.uk)](https://remedy.bnssgccg.nhs.uk/adults/learning-disabilities/ld-autism-hospital-liaison/)

Children’s hospital website with information for parents and link to hospital passport: [Bristol Royal Hospital for Children | University Hospitals Bristol NHS Foundation Trust (uhbristol.nhs.uk)](https://www.uhbristol.nhs.uk/hospital-passport)

Resources for Patient and supporters

* Mencap website: [Transition into adult services | Mencap](https://www.mencap.org.uk/advice-and-support/children-and-young-people/transition-adult-services)
* National development team for inclusion: [Preparing for Adulthood: All Tools & Resources - NDTi](https://www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources)
* South Gloucestershire council website [Planning your child’s transition to adult health services | South Gloucestershire (southglos.gov.uk)](https://find-information-for-adults-children-families.southglos.gov.uk/kb5/southglos/directory/advice.page?id=H9htUTn5wA8) includes transition health checklist [health\_checklist.pdf (openobjects.com)](https://search3.openobjects.com/mediamanager/southglos/directory/files/health_checklist.pdf)
* Added to LD register child: [easy-read-patient-leaflet-learning-disability-register-child.pdf (icb.nhs.uk)](https://remedy.bnssg.icb.nhs.uk/media/5448/easy-read-patient-leaflet-learning-disability-register-child.pdf)
* Mencap for PIL, supporter info and posters etc encouraging AHC and joining register: [Join The Learning Disability Register - Read Our Guides | Mencap](https://www.mencap.org.uk/advice-and-support/health-coronavirus/dont-miss-out/dont-miss-out-join-learning-disability-register)
* My adult still my child [MASMC – MASMC (myadultstillmychild.co.uk)](https://myadultstillmychild.co.uk/)
* Together for short lives [Changing Lives - Together for Short Lives](https://www.togetherforshortlives.org.uk/changing-lives/) has a check list for young people and families: [A checklist to a good transition - Together for Short Lives](https://www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/a-checklist-to-a-good-transition/)
* What is a GP- [rcgp\_iyp\_full\_booklet\_web\_version.pdf (assets.nhs.uk)](https://assets.nhs.uk/prod/documents/rcgp_iyp_full_booklet_web_version.pdf)
* GP online services easy read ( not updated with changes to citizen access 1.11.22) [gp-online-services-a5-leaflet.pdf (england.nhs.uk)](https://www.england.nhs.uk/wp-content/uploads/2017/09/gp-online-services-a5-leaflet.pdf)

Professional resources

* NICE guidance [Overview | Transition from children’s to adults’ services for young people using health or social care services | Guidance | NICE](https://www.nice.org.uk/guidance/ng43)
* Leeds top tips transition [SBTOP-TIPS-FOR-TRANSITION-TO-ADULTHOOD-FOR-PROFESSIONALS.docx (live.com)](https://view.officeapps.live.com/op/view.aspx?src=https%3A%2F%2Fwww.learningdisabilityservice-leeds.nhs.uk%2Fwp-content%2Fuploads%2F2022%2F01%2FSBTOP-TIPS-FOR-TRANSITION-TO-ADULTHOOD-FOR-PROFESSIONALS.docx&wdOrigin=BROWSELINK)
* RCGP eLearning transition [Better transitions: improving young people’s transfer from paediatric to adult services (rcgp.org.uk)](https://elearning.rcgp.org.uk/enrol/index.php?id=485)