Preparation for transition checklist for parents/carers of a young person with an intellectual disability

Use this checklist to identify the skills you already have and the areas where you may need to increase your knowledge before you and your child leave the paediatric health services.

☐ Know about your child’s current health status and how to manage any new symptoms.

☐ Update their health history – use health history forms or the Australian website for personal health information, MyHealth Record.

   Visit: myhealthrecord.gov.au

☐ Connect with a GP close to home. Your GP can do an annual “Health Assessment for people with an Intellectual Disability” which helps monitor and manage chronic concerns.

☐ Prepare a “Top 5” list for your child which enables communication of your carer knowledge to health teams.

   Visit: bit.ly/2hmlJUL

☐ Get an idea of what ongoing treatment will involve after leaving the children’s hospital. Ask for copies of relevant test results and clinic letters. Ensure that a detailed medical summary is prepared for the new adult care team.

☐ Learn how to order equipment/supplies – there may be major differences.

☐ If relevant, find out about private health insurance and whether your child will be covered.

☐ If relevant, talk to your doctor about how your child’s condition might impact on their fertility and conversely the impact of puberty on their condition.

☐ Find out how the adult system works e.g. making appointments.

☐ When possible, meet with members of the adult team before you move and find out about parking/access, location of clinics, staying overnight.

☐ Be aware of the National Disability Insurance Scheme (NDIS) and its role and relevance for your child. Know how to apply and to seek a review.

☐ If leaving school, find out NDIS supported post-school options.

☐ Find your local health district’s Transition Coordinator. Find your local hospital’s Carer Support person.

☐ Check Centrelink details as some concessions and financial support changes at 16 years old.