Transition From Children's to Adults' Healthcare for Youth With (Genetic) Intellectual Disabilities

Summary ERN-ITHACA guideline

Overarching principles

- Involve the young person and their parents/carers
- Adapt to the young person's developmental level
- Provide person-centred care
- Provide culturally sensitive care
- Map the young person's circles of support
- Use plain language, augmentative and alternative communication (AAC)

Transition planning

- Start early and review regularly
- Appoint a named worker
- Involve young people
- Build independence (e.g. with Skills for Growing Up)
- Provide psychosocial support during transition
- Involve parents and carers

Support before transfer

- Ensure transfer of the patient health record
- Identify the interdisciplinary care team
- Provide clear Information
- Ensure the named worker provides support

Support after transfer

- Avoid loss to follow-up
- Provide prolonged consultation time for the first consultation(s)
- Appoint a care coordinator in adult healthcare

Supporting infrastructure

- Take ownership of transition policy
- Plan and develop transition services
- Provide developmentally appropriate service
- Define the role of Centres of Expertise
- Arrange policy training and education

Above figure is an adaptation of Figure 1 from Klein Haneveld MJ, et al. Transition From Children's to Adults' Healthcare for Youth With (Genetic) Intellectual Disabilities: An ERN-ITHACA Guideline. *Journal of Intellectual Disability Research*, 70: 29–47. The original work was published under the CC BY 4.0 licence.