

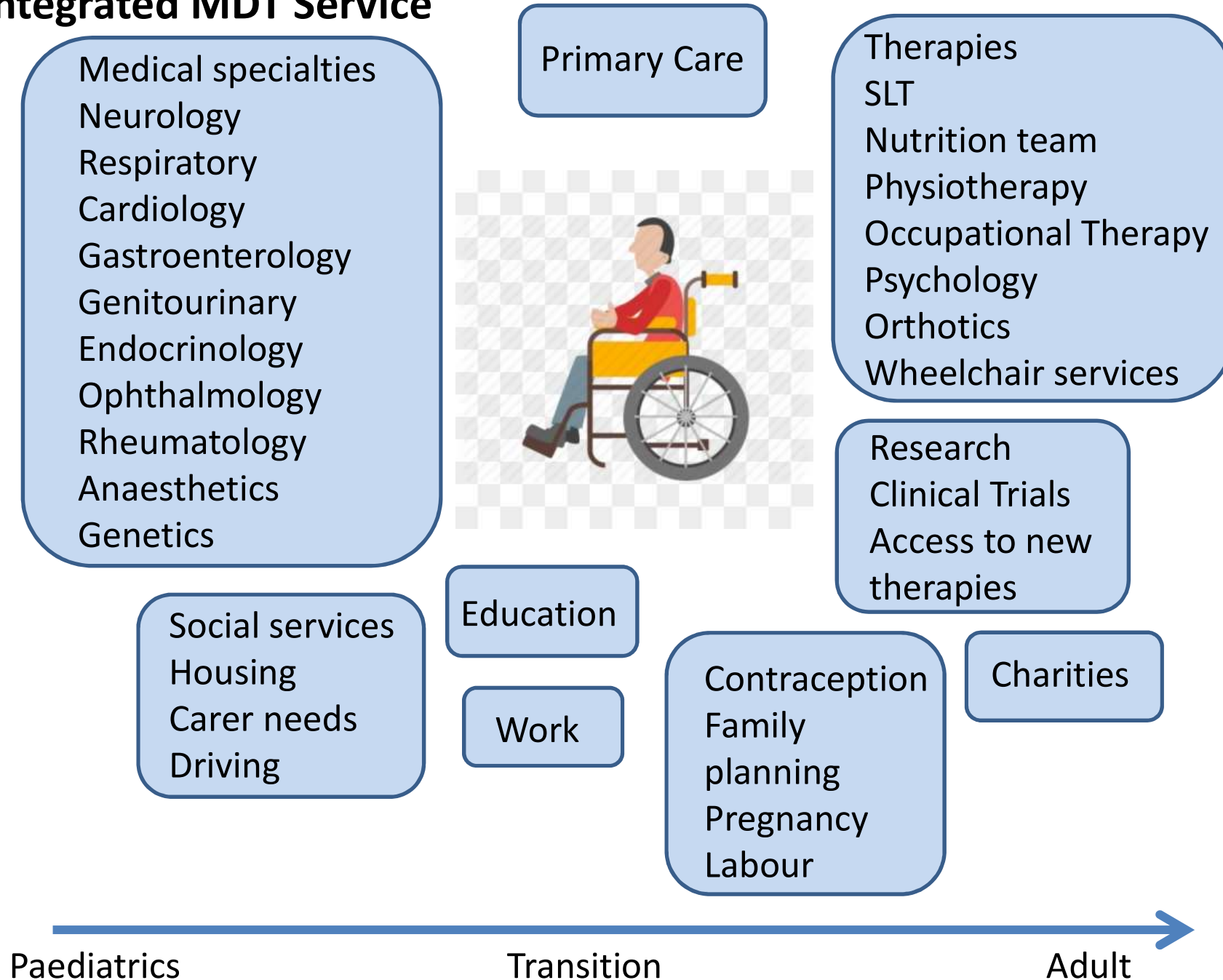


# Challenges in Transition: the adult perspective

Dr Emma Matthews  
Consultant Neurologist and Reader  
Neurology Lead SE GMSA

ST. GEORGE'S HOSPITAL

# Integrated MDT Service



# Challenges - Transition Clinic

- Advertising
  - Blogs, charity, GP Newsletters
- Transition clinics with paediatrics (?)
  - SGH, GOSH, Evelina,
- Communication between MDT, hospital and community
  - Neuromuscular care advisor, email
- Experienced staff
  - Training with community teams, invest in education
- Burden of appointments
  - Daycase co-ordination, outreach
- Infrastructure
  - Clinic templates, room size
- Patient trust and reputation
  - Forum, open evenings
- Age 16 or 18?





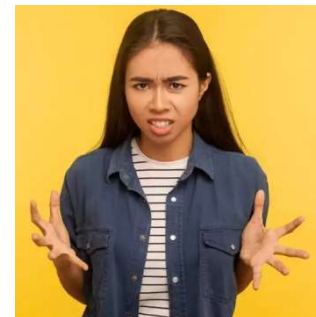
# Challenges – specialised treatments

- Exciting new gene therapies for SMA
  - Nusinersen (intrathecal)
  - Risdiplam (oral)
  - SMA service (Dr Clare Galtrey)
- Entirely new service
- Limited resource – referrals outside region
- In-patient facilities (transition units)
- Funding



# Focus on transition

- Complex genetic disorders – pilot neuromuscular disorders and epilepsy
- Equity in access – NGS
- Multisystem or MDT needs
- Equity in care – paediatrics and adult
- Supporting primary care
- New genetic therapies
- Clinical trials



# Transition Nurse

- recognise transition nursing as a new and unique role
- generate an exemplar post in rare genetic disorders that can be adopted nationally
- map existing services and pathways
- standardise transition pathways across the region ensuring equity of access to diagnosis, and appropriate care indicated by diagnosis
- reduce bottlenecks and waiting times
- be responsive to the patient and family voice
- cross cut social, primary, secondary and tertiary care to create an attractive model for new integrated care system funding



**Dr Ruth Williams**  
**Evelina Children's**  
**Hospital**

# Summary

- Transition is a unique service
- Management on board
- Resources to include infrastructure, clinical staff and admin/co-ordinator support
- Integration is key – integrated care systems (opportunity)
- Transition NOT transfer
- Patient expectation
- Challenge historical pathways and share experience
- Patient informed choice
- Agree standard age of acceptance into services