

# Transition from Paediatric to Adult Services



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**This is our youth**

The modern British teenager is:  
 a) violent, oversexed, drugged-up  
 b) creative, loyal, misunderstood  
 c) both a) and b) and more besides  
 A special **102** investigation

# Mind the Gap!

## HEALTHCARE

## After 16 – what's new?

### Choices and challenges for young disabled people

**What's it all about?**

- lots of things including
  - getting your views across
  - equality
  - learning choices
  - daytime activities and work
  - budgeting
  - getting around
  - health
  - leisure and holidays
  - finance and housing
  - you and the law
  - social regulations

**Who's it for?**

Young disabled people and their parents and carers who want vital information to help them make decisions about their future.

**How to get it!**

FREE to young disabled people and their parents or carers, 0711 or 01111.

**How do I get a copy?**

Simply fill in the order form on the other side of this booklet and return it to us at the address above.

# What young people say about transfer

Dumped

Hurtling  
into a void

Cut off

Tossed out

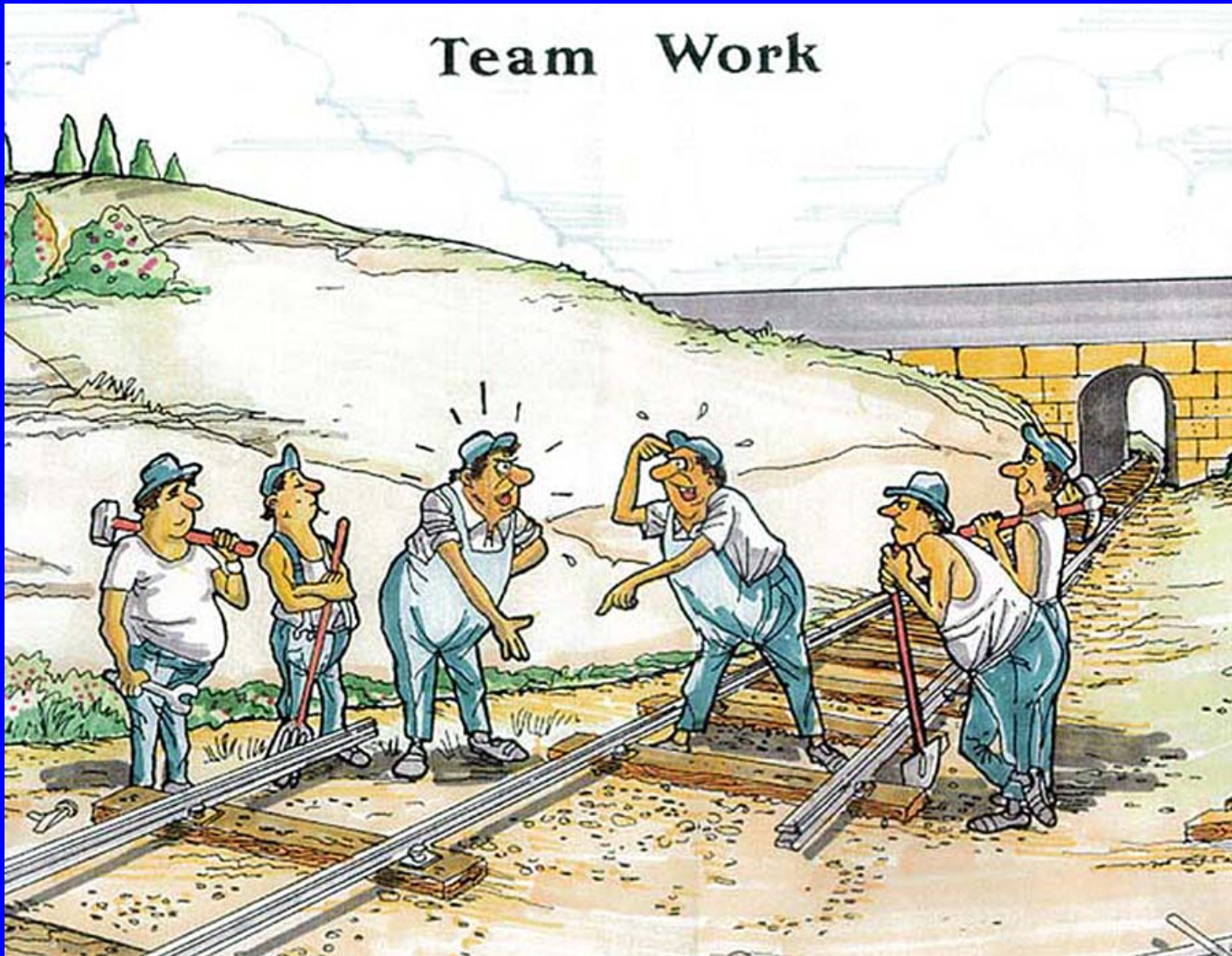
Lost in the  
shuffle

Sudden

Thrown  
out

Abandoned

# Team Work



# Definition of transition

"the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems."

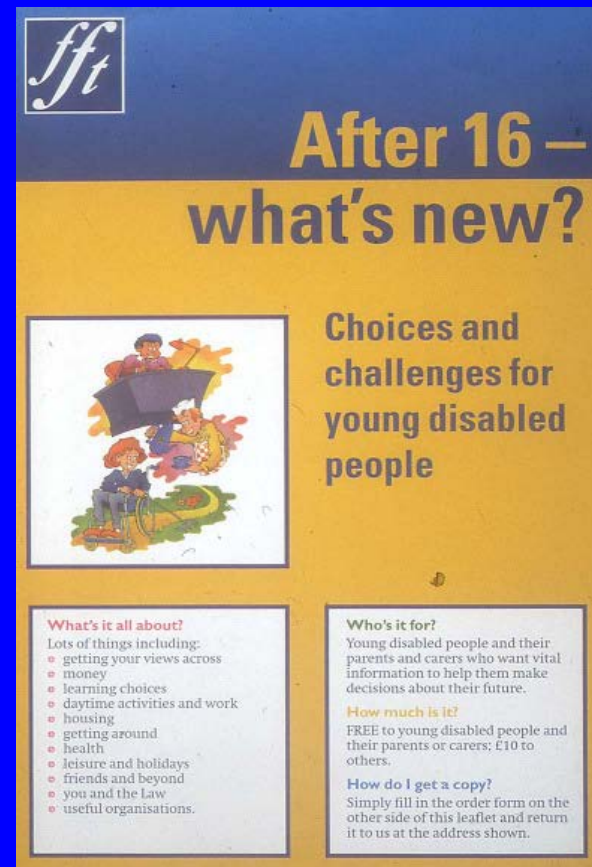
American Society for Adolescent Medicine



# Young adults with physical disabilities


Quality of medical care  
declines after transfer

- *Bax MC, 1988*
- *RCP report 1990*
- *Fiorentino L, 1998*
- *Stevenson CJ, 1997*
- *Ko B & McEnery G  
2004*



**fft**

## After 16 – what's new?



### Choices and challenges for young disabled people

**What's it all about?**  
Lots of things including:

- getting your views across
- money
- learning choices
- daytime activities and work
- housing
- getting around
- health
- leisure and holidays
- friends and beyond
- you and the Law
- useful organisations.

**Who's it for?**  
Young disabled people and their parents and carers who want vital information to help them make decisions about their future.

**How much is it?**  
FREE to young disabled people and their parents or carers; £10 to others.

**How do I get a copy?**  
Simply fill in the order form on the other side of this leaflet and return it to us at the address shown.

## Bent N et al, *Lancet* 2002

- retrospective study in 4 districts
- Young Adult Team (YAT) v *ad hoc* services
- interviewed 254 physically disabled young people and 124 controls
- young people cared for by MDT or YAT team 2.54 times more likely to participate in society than ad hoc services

# Conclusion

- Young Adult Team approach costs no more than *ad hoc* and more likely to enhance participation in society of young disabled people



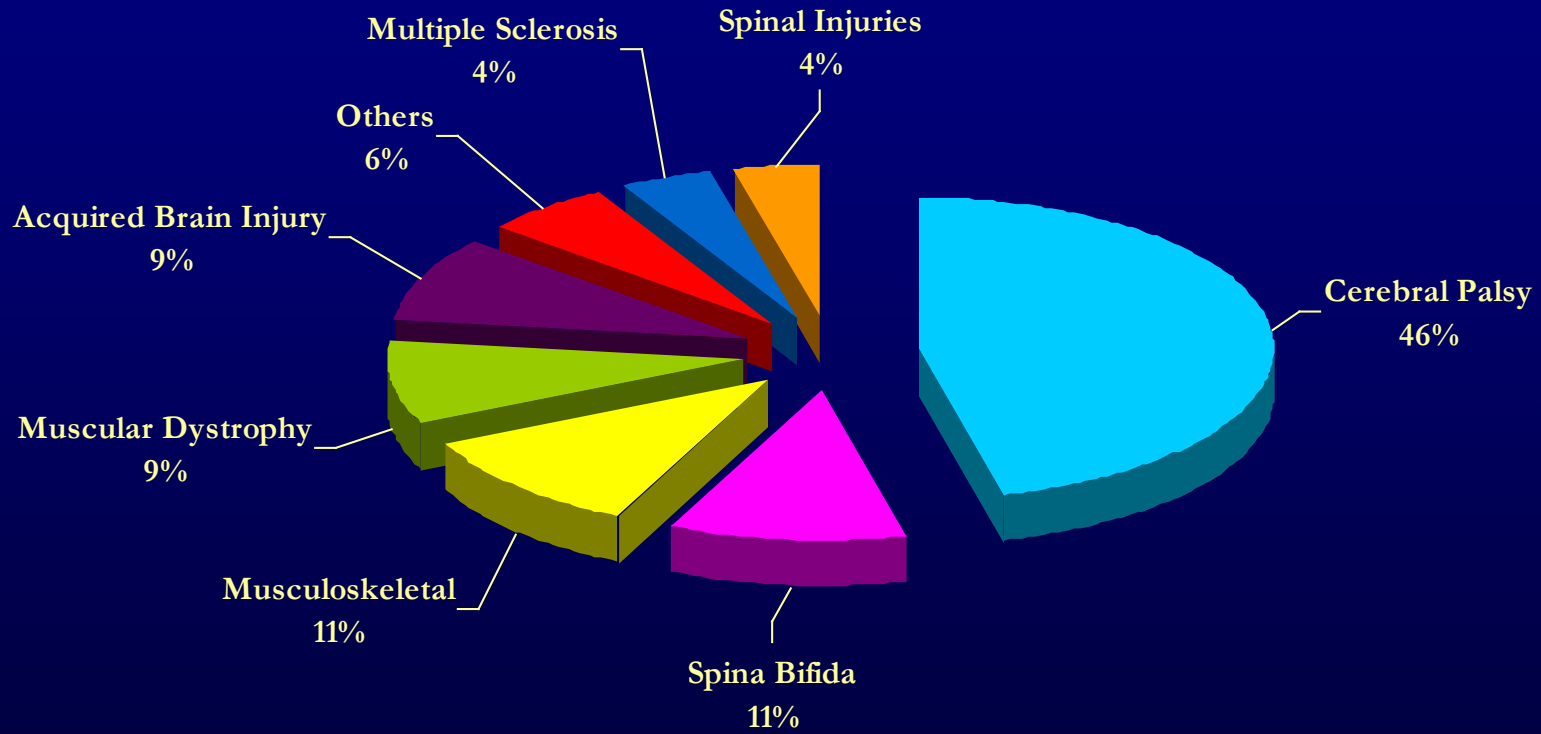
# Fife Rehabilitation Service

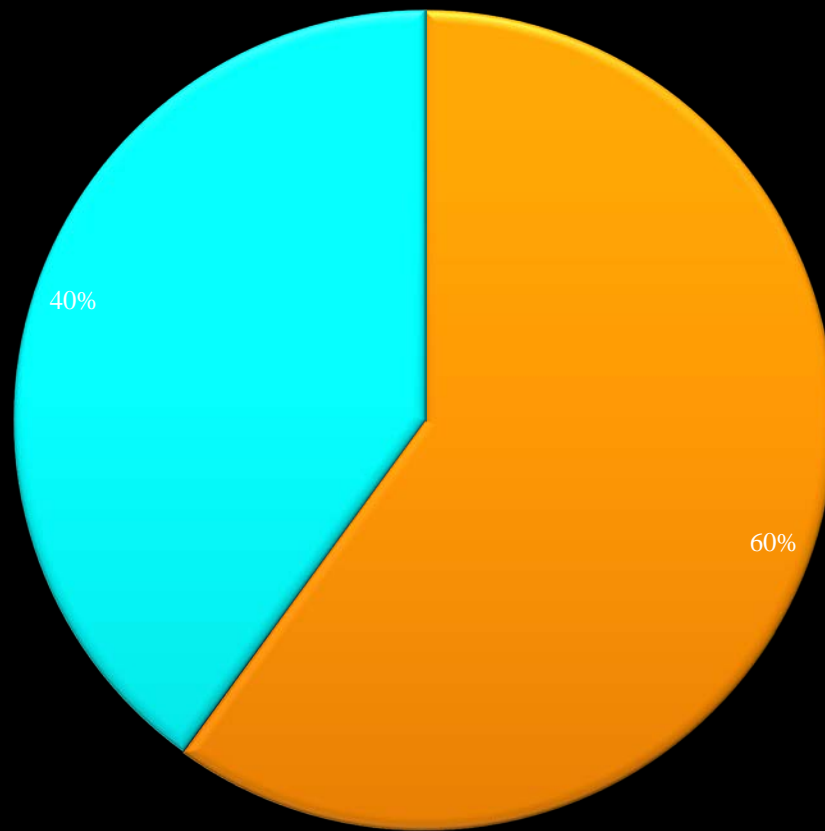
- 12 bed active rehabilitation ward (80% ABI)
- Service for patients with multiple sclerosis includes MS Nurse Specialists
- Brain Injury Service includes outreach nurse
- **Young Disabled School Leavers Service**
- continuing care of severe brain injury e.g. PVS at Glenrothes Hospital
- vocational rehabilitation
- environmental control

# Young Disabled School Leavers service

- Meeting with Education and Social Work in early 1990s
- Fortnightly clinic
- Quarterly meetings with Education and SW until 2006
- MDT
- Aim to be point of contact

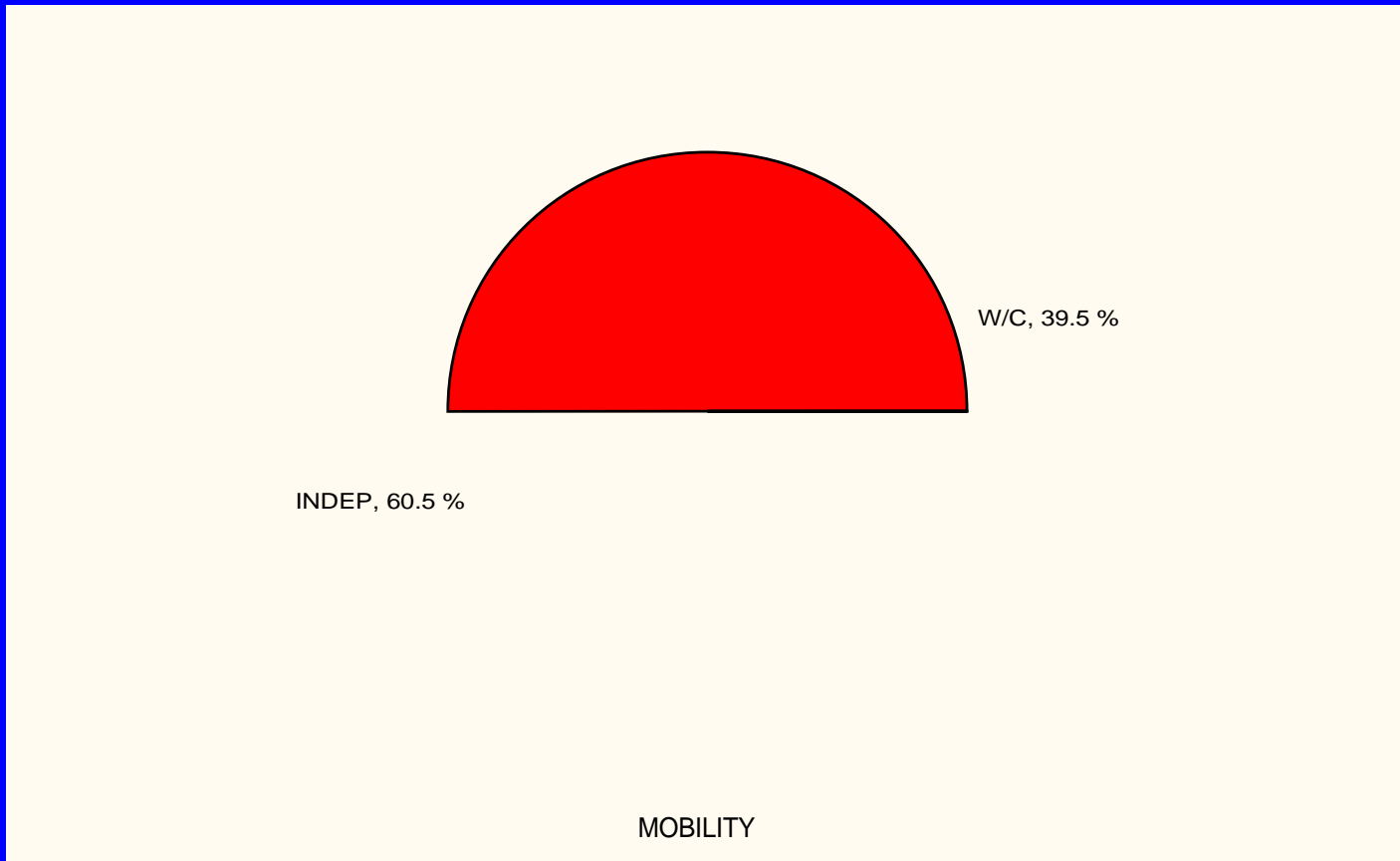
# Diagnostic Groups in YDSL clinic





■ Male  
■ Female

# Independent walking or wheelchair

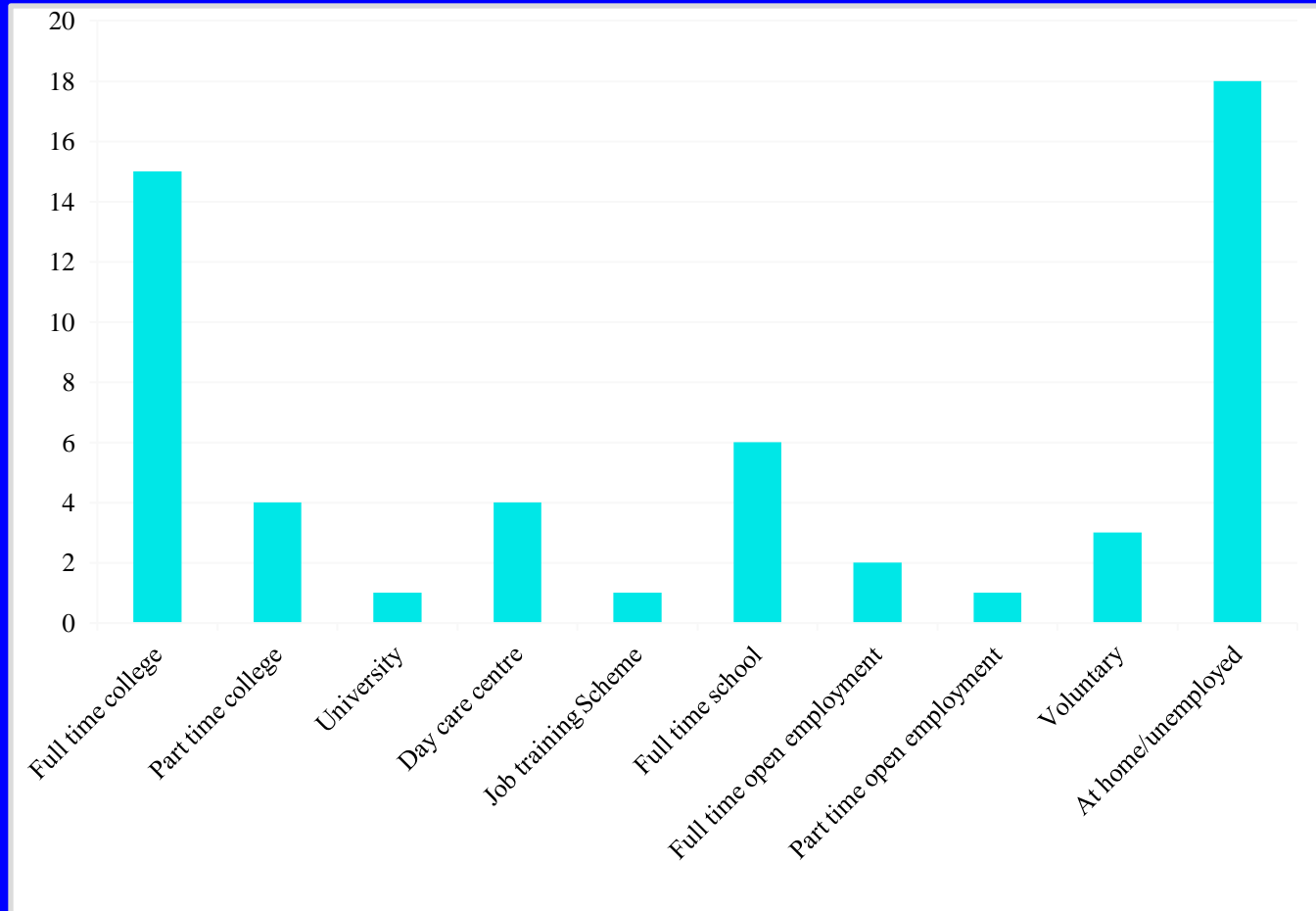


# Social situation

- 93% living with parent/s
- Only 16% have any additional care support



# Educational/vocational status





University of  
St Andrews



Do Younger People with Cerebral Palsy have a different Perception of their Social Integration compared to Older People with Cerebral Palsy?

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University of St Andrews

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Honorary Senior Lecturer, University of St Andrews

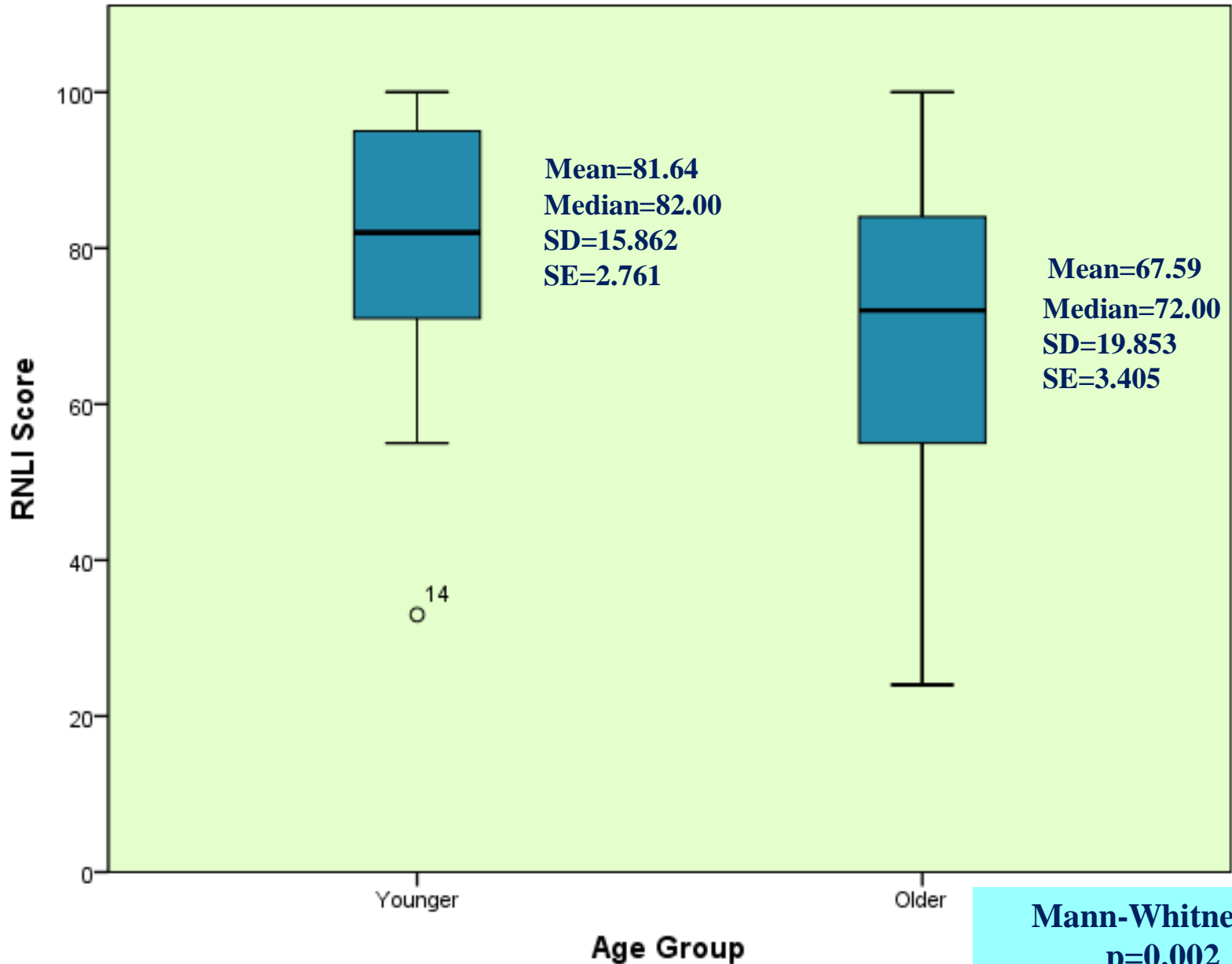
# Aim

- To determine if there is a difference in perception of social integration between younger and older people with CP

# Results

- 67 participants included
  - ❖ **Younger age category** (age 25 years and under)
    - 33 participants
    - Mean age=19.21 (Range: 16-25 years, SD=2.746)
  - ❖ **Older age category** (over age 25 years)
    - 34 participants
    - Mean age= 42.06 (Range: 27-60 years, SD=9.461)

## RNLI Scores in Younger and Older Participants



# Key elements

- Early start – individuals should know when they can expect to leave paediatric service
- Key worker for each individual
- Written transitional policy
- Flexible re time scales
- Improve skills in self management
- Education programme for patient and parent for medical, psychosocial and educational/vocational issues
- Written individualised healthcare transition plan by age 14
- Administrative support
- Training programme in adolescent health and transitional care for paediatric and adult team members
- Primary and preventative care involvement

McDonagh and Viner, 2006



# Key elements (Binks et al, 2007)

- Timing with some flexibility
- Preparation – include skills training and support for autonomy
- Co-ordinated approach – involve all and good documentation and planning
- Transition clinics
- *Interested* adult centred health care service
- Need to apply prospective study designs to evaluate transition interventions and determine long term health outcomes

# Aims of Transition



- 1) Provision of **co-ordinated, un-interrupted** healthcare
  - Young person centred
  - Age and developmentally appropriate
  - Culturally appropriate
  - Comprehensive, flexible, responsive
- 2) Promotion of **skills** in communication, decision-making, assertiveness, self-care
- 3) Enhance **sense of control** and interdependence in health care
- 4) To maximise **life long functioning** and potential
- 5) To support **both young person and family/carers**

# On the road to nowhere? Young disabled people and transition

Existing research

– “persuasive of need to improve”

Further research needed

- specific service/model evaluation
- holistic, long-term follow-up



Beresford B, 2004

# Transitional Care and Adolescent Health are Growing Up!

**Standard A: Growing Up into Adulthood**

**7. Outcomes**

**7.1** All young people have the opportunity to develop their own views and opinions on their own health and well-being, and to take responsibility for their own health and well-being.

**7.2** All young people have the opportunity to develop their own views and opinions on their own health and well-being, and to take responsibility for their own health and well-being.

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Department for children, schools and families | DH Department of Health

**Transition: moving on well**

*A good practice guide for health professionals and their partners in transition planning for young people with complex health needs or a disability*

NHS Scotland

**BETTER HEALTH, BETTER CARE**

**Hospital Services for Young People in Scotland**

DH Annual Report of the Chief Medical Officer

**Tackling the health of the young people**

**a transition guide for all services**

key information for professionals about the transition process for disabled young people

education and skills | DH Department of Health

National Service Framework for Children, Young People and Maternity Services

**Transition: getting it right for young people**

Improving the transition of young people with long term conditions from children's to adult health services

**Adult Health Services Employment Further Education Children's Health Clinic School**

*Every Child Matters - Change for Children*

DH Department of Health

**You're Welcome quality criteria**

*Making health services young people friendly*

Department for children, schools and families | DH Department of Health

**Securing better health for children and young people through world class commissioning**

*A guide to support delivery of Healthy lives, brighter futures: The strategy for children and young people's health*

**Think transition**

Developing the essential link between paediatric and adult care

RCPE Royal College of Paediatrics and Child Health

The Royal College of Paediatrics of Edinburgh Transition Steering Group

# Thank you



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