

# Transition to Adult Services for Disabled Young People and those with Complex Health Needs

---

**Dr Linda Cusworth and Dr Nicola Moran**

**Making Research Count Seminar Series**

**21<sup>st</sup> July 2011**

**Keele**

# Research team

---

- ◆ Professor Patricia Sloper†
- ◆ Professor Jennifer Beecham‡
- ◆ Ms Susan Clarke†
- ◆ Dr Anita Franklin\*
- ◆ Dr Nicola Moran†
- ◆ Dr Linda Cusworth†

† SPRU, University of York

‡ PSSRU, University of Kent

\* The Children's Society

# Funding

---

- ◆ This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

# Outline of presentation

---

- ◆ Background
- ◆ Government policy
- ◆ Study aims
- ◆ Methods
- ◆ Results
- ◆ Relevance to policy and practice
- ◆ Conclusions and further research
- ◆ Questions for small group discussions

# Background

---

- ◆ Evidence that transition can be problematic due to:
  - ◆ Lack of multi-agency working
  - ◆ Lack of an holistic approach
  - ◆ Lack of information for young people and parents
  - ◆ Insufficient attention to the concerns/priorities of the young person
  - ◆ Lack of appropriate services/provision onto which young people can transfer

# Government policy

---

- ◆ *The NSF for Children, Young People and Maternity Services (2004)*
- ◆ *Improving the Life Chances of Disabled People (2005)*
- ◆ *A Transition Guide for All Services (2007)*
- ◆ *Transition: Moving on Well (2008)*
- ◆ *Aiming High for Disabled Children (2007)*
- ◆ *Transition Support Programme (2008-11)*

# Study aims

---

- ◆ To investigate existing arrangements for multi-agency transition services across English LAs
- ◆ To compare the implementation and operation of different models of transition services
- ◆ To assess outcomes for parents and young people of different models of transition services
- ◆ To investigate sources of funding and costs of different models of transition services

# Methods

---

- ◆ A national survey to identify multi-agency transition services in England
- ◆ In-depth interviews with managers and staff in the five selected case study areas
- ◆ A postal survey of parents and young people pre- and post-transition in each area
- ◆ In-depth interviews with a sample of parents and young people post-transition
- ◆ Analysis of the costs of the services

# Results: (1) National survey

---

- ◆ Wide variety of models and approaches
- ◆ Many young services
- ◆ Different understandings of transition
- ◆ Eligibility criteria
- ◆ Structure and organisation

# Results: (2) Case study sites

---

## ◆ Similarities

- ◆ Aims
- ◆ Referral arrangement
- ◆ Multi-agency plans and steering groups

## ◆ Differences

- ◆ Coordinating service with generic workers/  
Transition team with transition workers
- ◆ Direct to adult services/negotiating the support package and funding

- 
- ◆ An overview of the Services ...
  - ◆ Some positives
    - ◆ Better multi-agency working
    - ◆ Increased communication and better understanding between agencies
    - ◆ Continuity for families and a central point of contact on transition issues
    - ◆ Less duplication of assessments and visits

---

## ◆ Some difficulties

- ◆ Under-staffing and vacant posts
- ◆ Little in adult services to transition to
- ◆ Information sharing between agencies
- ◆ Pressures of generic social work duties
- ◆ Engagement from some services/agencies
- ◆ Lack of training
- ◆ Differing ages at which young people may access and cease to access services

# Results: (3) Family Survey

---

- ◆ Descriptive analysis
- ◆ Bivariate analysis
- ◆ Multivariate (regression) analysis
  
- ◆ Outcome measures
  - ◆ Satisfaction with the transition service
  - ◆ Young people's unmet transition needs
  - ◆ Parents' unmet transition needs
  - ◆ Impact of the transition service on parental stress.

- 
- ◆ 3 key factors were related to better outcomes for parents and young people at transition:
    - ◆ Having one transition worker
    - ◆ Having a written transition plan
    - ◆ Strategic level involvement of the transition service manager

- 
- ◆ Other factors associated with positive outcomes for families:
    - ◆ Having a designated transition worker
    - ◆ Clarity of the transition worker role
    - ◆ Use of person-centred planning
    - ◆ Involvement of transition workers in setting up the adult service package, negotiating funding, and supporting the young person until settled in adult services
    - ◆ Parental involvement in the steering group

---

## Other comments

- ◆ 13 further comments from young people  
(8/73 pre-transition, 5/24 post-transition)  
(N.B. Most comments written by parent/other adult)
- ◆ 65 further comments from parents  
(46/110 pre-transition, 19/33 post-transition)

---

## Some positives

- ◆ Securing appropriate placement
- ◆ Involvement of family in transition planning

Comment from a mother:

*'My daughter's transition period started one year before my daughters 18th. I was kept up-to-date, visited at home, given contact numbers if I had any queries. I was invited to attend all meetings. I felt I was involved in every aspect. It was all in place by her 18th birthday and the changing period was less stressful and went smoothly and my daughter remained happy throughout!'*

---

## Some negatives

- ◆ Staff shortages
- ◆ Lack of adult provision
- ◆ Ineligibility for adult services
- ◆ Lack of information
- ◆ Not having a named social worker in adult services
- ◆ Lack of support/knowledge of the transition service: *'It has felt like having another social worker ... not entirely sure what the role is'*
- ◆ Duration of support from the transition service
- ◆ Lack of multi-agency working

---

- ◆ Gap in (health) services:

*'It's hard to believe that someone can be born with a disability and from 16-18 years they are denied services like physiotherapy, speech therapy and others. Their illnesses do not go away at 16 and come back at 18 years old'.*

- ◆ Similar concerns between pre and post-transition parents

- ◆ Comments reflect those made by staff

- ◆ However, comments are more likely to be left by those with a bad experience thus are not necessarily representative

# Results: (4) Family interviews

---

Based on their responses to the questionnaire, we interviewed:

- ◆ 6 sets of parents and 3 young people
- ◆ All post-transition
- ◆ All self-reported being 'satisfied' with support from the Transition Service

Sample of the case studies ...

---

## Factors that aided a good transition:

- ◆ Good relationship between parents and TW
- ◆ TW getting to know young person, advocate
- ◆ One named TW
- ◆ Introduction to the adult social worker
- ◆ Multi-agency meetings, holistic planning
- ◆ Involvement of parents, provision of information
- ◆ Support around sexuality and relationships
- ◆ Adult support package negotiated by TW from Children's Services

---

## Factors that hindered a good transition:

- ◆ Premature cessation of support
- ◆ Lack of a coordinated transition from child to adult health services
- ◆ Vacant posts
- ◆ Lack of information about Adult Services
- ◆ Little for young people to transition on to

- 
- ◆ *'We've got strong views on what we think should be good for [young person], but it's not available, and once they turn eighteen it gets worse, and once they get to finish college it gets dire, it gets suicidal. You stick your head in the sand and you have to pull it out at some stage because you could cry your heart out too much as to what should be but it isn't. Once they leave school that little, little safety net, life's bad ...'*  
*(Parent)*

These reflect the findings from the staff interviews

# Results: (5) Costs

---

- ◆ National survey
  - ◆ Average annual staffing costs of £220,000
  - ◆ Average cost per case £1800 per annum
- ◆ Case study services
  - ◆ Mean cost ranged from £22 to £52 per working hour
- ◆ Family survey
  - ◆ Parental reports of contact, adjusted for staff reported non-contact activities, gave average cost per case per annum of £700 – lower than the figure suggested in the national survey.

# Relevance to policy and practice (1)

---

- ◆ Dedicated multi-agency transition services can provide a valuable service:
  - ◆ Most likely when a family has one transition worker
  - ◆ The family has received a written transition plan
  - ◆ There is strategic involvement of the transition manager
- ◆ Information and good communication with young people and parents is crucial
  - ◆ TWs need time and training to communicate with young people and families

# Relevance to policy and practice (2)

---

- ◆ Staff shortages and lack of resources restrict the time spent working on transition issues:
  - ◆ Need to ensure appropriate staff and resource levels; replace staff that leave.
  - ◆ Better outcomes where young people are supported and settled into adult services.
  
- ◆ Despite some positive findings, substantial levels of unmet need remained:
  - ◆ Need to monitor unmet need and feed data through to commissioners.
  - ◆ Transition service managers need to champion services at strategic levels

# Relevance to policy and practice (3)

---

- ◆ Lack of consistent involvement of agencies = barrier to a holistic multi-agency approach
  - ◆ More recent policy initiatives may help to address these problems
- ◆ Multi-agency transition services are largely focused on young people with severe learning disabilities (SLD)
  - ◆ Need to extend such services to those with e.g. complex health needs, high functioning autistic spectrum conditions

# Conclusion and further research

---

- ◆ Some progress has been made in providing better coordination of services at transition, but this remains patchy and transition support requires further development
- ◆ Longitudinal research would help to further define good practice
- ◆ Further research: the impact of transition services on other agencies; support for young people without SLD

# Contact information

---

If you would like a copy of the Executive Summary or Full Report please contact us or visit the SPRU website:

- ◆ Dr Nicola Moran
  - ◆ nicola.moran@york.ac.uk
- ◆ Dr Linda Cusworth
  - ◆ linda.cusworth@york.ac.uk
- ◆ <http://www.york.ac.uk/inst/spru/>

# Questions for group discussion

---

1. What do you understand about how transition works in your local authority?
  - who has access to the service?
  - who is responsible for the service?
2. In an ideal world, what would your transition service look like?
  - what steps can be taken toward that ideal?
3. In a difficult economic climate, can the cost of a transition service be justified?
  - how might you ration/restrict the service?
  - Implications?