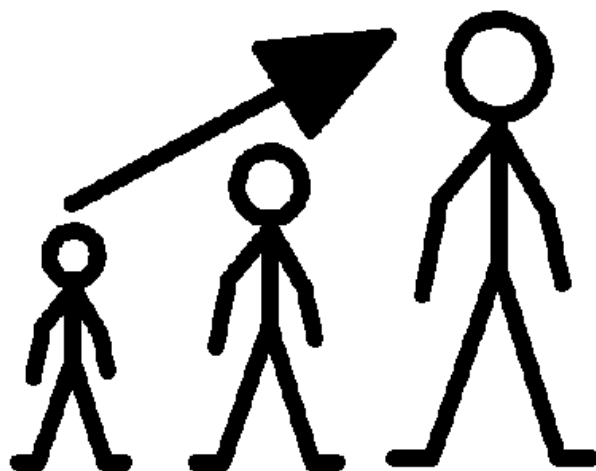




LINK Report

The way ahead

An investigation by LINK members into the experiences of transition from child to adult services in North Tyneside



October 2010

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1. Introduction

Why was the report done?

In October 2009 North Tyneside LINK commissioned a report to investigate issues regarding the transition from child to adult health and social care services. This issue was raised with LINK by young people as well as their families and carers and voluntary sector staff who support young people. This issue mainly concerned young people with physical or learning disabilities.

The brief

To provide a comprehensive written report for North Tyneside LINK members, detailing the nature and range of concerns in this area. To conclude the report with recommendations for improvement by LINK members, service users and interested groups.

When was it done?

This study was carried out between January and April 2010. This report draws upon five aspects of research: data collection; desktop research and literature reviews; qualitative surveys; first-person interviews and focus groups.

Who was involved?

58 submissions were received by the time the data was analysed.

Of the submissions included in data analysis:

- 28 were from parents;
- 15 were from young people aged 14 to 18 years;
- 7 were from young adults aged 19- 27 years; and
- 8 were from practitioners in both the voluntary and statutory sectors.

2. Background

What is transition?

Young people with additional needs usually have to make important decisions about their health, social care services and education between the ages of 14 and 25. Planning should start well in advance of leaving school, so that the young person's needs and choices are fully explored.

What professionals can be involved?

The following professionals, departments and organisations contribute to transition planning and assessment for young people:

- Children's social workers
- Adult social workers
- Community learning disabilities team
- Local authority special educational needs staff
- Educational psychology
- Transition worker
- GPs
- Community matrons
- Community nurses
- School nurses
- Physiotherapy
- Speech and language therapy
- Occupational therapy
- Psychology team
- Behaviour and therapy team
- Leaving care team
- Child and Adolescent Mental Health Service
- Independent Advocacy Service
- Adult service providers
- Voluntary sector organisations.
- Short break services
- Learning and Skills Council
- Transport
- Housing
- Connexions information advice and guidance services

3. Moving from children's to adult social care services

When?

18 years old.

What does this mean?

The young person is seen as an individual in their own right.

The needs of the young person are assessed rather than the needs of the whole family. This is likely to mean a move to a physical, sensory or learning disability team as adult social care is usually structured in this way.

Implications for young person

Section 17 of the Community Care Act states that there is no statutory requirement for the same eligibility criteria agreed in children's services to be used by adult services

Quote from focus group:

“My son’s assessment for adult social care has been a nightmare, it seems to be a lottery how much service you can get, where and how you can get it, it is so confusing. My son has been offered 3 days service, how are we supposed to cope with that?”

4. Moving from children's to adult health care

When?

The process of planning the transition to adult health care starts at different ages depending on the disabled young person's condition.

What does this mean?

If the Primary Care Trust (PCT) determines that a young person receiving children's continuing care is not eligible for an adult NHS continuing healthcare package when they reach the age of 18, they should be advised that they are not eligible and of their right to request an independent review.

The drawing up of a Health Action Plan can make sure disabled young people continue to have access to services they need to stay healthy and not 'fall between' services.

Health Action Plans (or health plans) can provide a useful focus for bringing together the planning of support from a range of health services. This too should be part of the main transition plans.

Implications for the young person

Transition in health services was felt to be particularly abrupt, with young people suddenly losing access to key specialists who may have worked with them throughout their childhood.

Quote from focus group:

"We have received excellent care from specialists such as the community paediatrician and child health team; My daughter's paediatrics service ceases this week and I have no idea about the adult medical care she is to receive and if it is set up adequately to support her health conditions associated with Down's syndrome."

5. Continuing care arrangements

The term 'continuing care' has different meanings in child and adult services.

In adult services it means care provided over an extended period of time, to a person aged 18 or over, to meet physical or mental health needs that have arisen as a result of disability, accident or illness.

'NHS continuing healthcare' means a package of continuing care that is arranged and funded solely by the NHS. The actual services provided as part of that package should be seen in the wider context of best practice and service delivery for each individual.

Entitlement to adult NHS continuing healthcare should initially be established using the decision-making process set out in this adult continuing care framework, including the checklist and the decision support tool. The decision on eligibility should be made using the PCT's usual adult NHS continuing healthcare decision-making processes.

Quote from focus group:

“The review panel could not agree the social workers report and recommendation, they turned it down saying a nursing assessment was required so the meeting was adjourned for 4 weeks. How long does to take for a nursing assessment? 4 weeks later the recommendation returned to panel but still no nursing assessment, they said there was no appropriate nurse to do it. 16 weeks since the assessment we were no further forward.”

6. Users and carers experiences of transition

The report 'Improving Life Chances of Disabled People' (Office of Disability 2005) says that, to ensure that disabled young people enter adulthood able to participate and be included, the following support is required:

- Planning for transition focused on individual needs.
- Continuous service provision.
- Access to a more transparent appropriate menu of opportunity and choices.

Quotes from the surveys:

“Disabled young people want the same things as other young people – yet services are not able to support their needs.”

“My son has not had speech therapy since leaving school”

“We have never been offered such a menu and the only choice you are left with is to accept what is offered”

Impact on parents

Quote from the surveys:

“Many families don't know how they are going to cope once their young person no longer attends school or college, and this rules out any chance of getting a job or life outside the caring role.”
Health professional

Inequality in service assessment and service delivery

Quotes from the surveys:

“We did have exceptional services when our son was in children's services, leisure needs met, good respite service but since he's gone into adults – nothing.”

“My son's assessment for adult social care has been a nightmare, it seems to be a lottery how much service you can get, where and how you can get it, it is so confusing. My son has been offered 3 days service, how are we supposed to cope with that?”

“We are not sure where he can have the service. He wants to go to 'z service', it had been indicated for 2 years that service is the chosen place in his plans, 'z service' is expecting him. Now they say 'z service' is not on some framework, so if my son wants to

go there he has to have a direct payment. The problem is the direct payment is probably not enough money to pay 'z service' costs. Yet if 'z service' was in the framework the cost would be paid without question. This surely discriminates against my son's choices"

7. Report findings and initial recommendations

The report's findings can be broadly placed into six categories:

1. Strategic
2. User and carer involvement
3. Choice and control
4. Information
5. Joined-up ways of working
6. Celebrating success

This report gives a summary of the report findings. For the detailed report of the findings contact North Tyneside LINK on 0191 200 1429 or email link@voda.org.uk

Initial recommendations from the report's findings are in **bold**.

This is followed by information supplied by North Tyneside Council on the services they provide or commission.

Quotes from the surveys of parents, carers, young people and professionals which have led to these recommendations are in bold and are headed 'quotes from the survey'.

7.1 Strategic

Recommendation 1

Funding approved at strategic level should transfer more quickly to actual service provision at operational level.

Recommendation 2

Specific programme funding for the transition officer should be sustainable.

Information from North Tyneside Council

The transition officer post is a substantive Health and Social Care (Children, Young People and Learning) funded post.

The purpose of the post is to develop, coordinate and manage a North Tyneside Council and NHS response to the Transition Planning needs of

children, young people aged 14 – 25 and their families and in partnership with them.

To lead on policy developments to support a whole-systems response (e.g. health, social care, education, independent sector) to Transition Planning and to project manage related service developments in line with national, regional and local policy initiatives.

To keeping abreast of national, regional and local policy initiatives, to translate objectives into practice, ensuring positive sustainable outcomes for children, young people and their families.

7.2 User and carer involvement

Recommendation 3

Disabled young people should be fully included in planning that is centred on their own needs.

Information from North Tyneside Council

At present, ways in which young people are fully included are:

- Multi-agency annual transition reviews are provided to children and young people aged 14+ (through to age 19) who have a statement of educational need (SEN Code of Practice).
- The majority of children and young people access annual transition reviews facilitated within the person centred transition review model (130 reviews using the model have been undertaken to date).
- The Connexions service carry out their duty to provide person centred transition information, advice, guidance and support to all children and young people from year 9+ who have a statement of educational need (SEN Code of Practice).
- All children and young people with additional needs and their families have been provided with opportunities to develop a person centred transition plan.
- Young disabled people from North Tyneside have designed their own standards for both mainstream and specialist services that provide for young disabled people in transition. Several services have received an inspection by young disabled people (Quality Checkers – Tickers Award).

- The Young Disabled People's Network meets every two months. The group informs service planning which will impact on their lives
- North Tyneside Council has commissioned Independent Advocacy to support young disabled people with transition plans. The Advocacy Project has three main strands: case advocacy; self – advocacy; and peer advocacy. Since being established in November 2009, the project has provided independent case advocacy to 15 young disabled people who are in transition.

Quotes from the research include:

“Transition plans not really talked about”

“Heaven help the young people who are without support”

“Staying Put team excellent - before the Leaving Care Team had no other information”

“What kind of support have I had? None – kind of sad isn't it?”

“We've really done it ourselves with support letters offered if asked for”

“At Person Centre Planning Review I didn't get the chance to speak as ran out of time.”

Recommendation 4

Young people and parents should be supported to be involved in timely transition planning, across health and social care, rather than 'just in time' or crisis planning.

Information from North Tyneside Council

North Tyneside Council has a multi-agency tracking group which meets every two months to enable Adult Services to plan and prepare for eligible young disabled people being transferred to Adult Services at age 18. Where allocated, children and young people are supported by social workers to explore transition options. Children, Young People and Learning and Adult Social Care social workers jointly work together at age 16 to carry out this function in readiness for transfer at age 18.

Multi-agency transition planning reviews are provided to children and young people from aged 14 who have a statement of educational need (SEN Code of Practice). Families are invited to attend and participate.

All children and young people with additional needs and their families have been provided and will continue to be provided with opportunities to develop a person centred transition plan (41 have participated to date).

Quotes from the research include:

“The whole process appears to be disjointed.”

“They should speak to each to other.”

“Lack of communication between Children’s Services, Social Worker ad Leaving Care team”

“Delay in adult social work support.”

“Confusion over transport to adult respite resulting in delays in funding clarification.”

“Problems with social work support, problems with OT assessments with respite, problems with financial support (mismanaged) – lack of support in general. I have had to self manage my daughter’s transition.”

“Six month information gap to where my daughter was going next – I had to do the chasing.”

7.3 Choice and control

Recommendation 5

To maximise independence and control, Direct Payments and Individual Budgets should be considered as an option during the transition planning process. To maximise the take up of self directed support, brokerage services and advocacy should be introduced at an early stage in transition planning.

As part of the study we were unable to identify any families or young people who felt they had received sufficient information about personalisation to make an informed decision. No one had received an indicative budget. Only one parent interviewed knew what one was.

Information from North Tyneside Council

North Tyneside Council has told us it has processes in place to offer eligible young people a personal budget at age 18. Workshops and information

sessions have been provided to service users, their families and other stakeholders. To build on this, North Tyneside Adult Social Care has produced a draft personalisation training plan.

At present, as part of North Tyneside's National Transition Support Programme Year 3 development plan, a further individual budget (building on the outcomes of the Dynamite Project) is underway within Children's Services to promote self-directed support for eligible children and young people aged 14 to 18.

Independent advocacy is available to all relevant children, young people and young adults.

Quotes from the research include:

“Transport is a problem for meeting friends.”

“We were a willing guinea pig on the Dynamite project.”

7.4 Information

Recommendation 6

Local agencies should ensure that young people and their families have access to good quality local information during transition.

Information from North Tyneside Council

Both a multi-agency Transfer Protocol and Transition Planning Pathway (both under review) are in operation to steer coordinated transition planning across all agencies.

More detailed information about how North Tyneside Council informs young people and their families follows recommendation 7.

Quotes from the research include:

“Keep me more informed – better communication”

“There's a lack of information.”

“I think there is a Transitions Protocol – well on paper– but that is no good if you are not sure”

“No ongoing support from Connexions.”

Recommendation 7

Parents need to be given enough information in user-friendly formats about the process to enable them to participate fully.

Information from North Tyneside Council

School and college parent events are arranged that provide information and advice specific to transition planning. An annual North Tyneside Transition Information Event for all young people with additional needs and their families is held. Up to 50 agencies are in attendance offering information, advice and guidance to disabled children, young people and their families on transition options they can explore post school or college. The average attendance of young people and their families at these events is 75.

In school and college the Connexions service undertakes a duty to provide transition information, advice, guidance and support to all children and young people from year 9 + who have a statement of educational need (SEN Code of Practice).

Six parents attend the bi-monthly Transition Sub Group (sub group of the Learning Disability Partnership Board) and through this membership contribute to protocols and other Transition developments. Three of these parents are also members of the Learning Disability Partnership Board Carers Forum. Through this association they represent the views and experiences of the wider parent's network. Two parents are members of the Children, Young People and Learning All Together Better Parents Network (Aiming High for Disabled Children) which also has a transition focus group and which arranges a twice yearly All Together Better Parents Conference where transition planning is a theme.

An accessible North Tyneside transition DVD, designed, directed and developed by young disabled people in transition, has been disseminated to all children and young people aged 13 to 21 and their families. The DVD describes the transition planning process (SEN Code of Practice).

Where allocated, children and young people are supported by social workers to explore transition options. Children, Young People and Learning and Adult Social Care social workers jointly work together at age 16 to carry out this function.

Although the above provides an extensive programme for information giving on transition, North Tyneside is committed to exploring all other options available to provide parents and carers with the information they need. Consideration will be given to information being given at the right time for any particular family, to the transition aspirations that families have for the young

person they support, their expectations of services and other priorities a family might hold at any given time e.g. caring responsibilities.

Quotes from the research include:

“Confusion over future post college plans.”

“Thanks to the Transition Officer I have been able ask questions and check that the information I’ve been given is correct.”

“Not enough information for young people and family.”

“Our son is now 18 and has had a statement of special educational needs whilst at school, but we have never been invited to a transition event or sent a DVD”

“Connexions were not able to help us at all with University applications or the Disabled Student Allowance process. Indeed they found it difficult to understand our son’s ambitions to go to University and advised him to re-think his choices. He is now studying at University and has been awarded a very helpful DSA package, but we had to negotiate this minefield ourselves, there was no assistance from Connexions”

7.5 Joined up ways of working

Recommendation 8

The National Transition Support Programme Team and Valuing People Now are leading an awareness and training programme to assist all local areas to embed Health Action Planning within plans for Transition. Local plans are in place to carry this out and should be closely monitored to ensure this is delivered and progress shared.

Information from North Tyneside Council

A Continuing Health Care Assessor post was vacant for a period of time. This did lead to continuing health care assessments for a small number of relevant young people being undertaken at a later than planned date. This led to delays in finalising joint Health and Adult Social Care funded transition plans. This post is now being filled and continuing health care arrangements in North Tyneside are currently being reviewed.

Quotes from the research include:

“Delay in completing epilepsy plan for adult respite resulting in missing first stay.”

Recommendation 9

Transition planning should be carried out using a full multi-agency approach to ensure that young people and families do not have to continuously repeat themselves and receive multiple assessments.

Information from North Tyneside Council

Where appropriate the Common Assessment Framework is utilised in transition planning. An integrated children’s disability service is being developed that will include key worker and lead professional roles. The role of the lead professional is to work primarily with families who have some identified need but do not meet the eligibility criteria for specialist services and support. The role of the key worker, who will act as a single point of contact, will be to work with families who have children with complex needs over an extended period of time.

Transition planning spans agencies and by definition is carried out using a multi-agency approach. As such, the different agencies involved, usually with a duty placed on them, need to gather information from assessments they are required to undertake. Guidance from national programmes, such as ‘Getting A Life’, tells us that the important principle here is that assessments are underpinned by person centred approaches.

Quotes from the research include:

“What would we like? To find a health professional who can co-ordinate M’s health needs as paediatrician did in Children’s Services.”

Recommendation 10

Local agencies should put in place multi-agency protocols, agreements and training that set out how they will work together to support young people and their families throughout the transition process

Information from North Tyneside Council

An agreed multi-agency transfer protocol (Children’s Services to Adult Services) is in operation. In addition a multi-agency transition planning

pathway is also in operation to steer wider transition planning arrangements. Both are being reviewed, as part of North Tyneside's Year 3 National Transition Support Programme Development Plan and further training will follow.

Quotes from the research include:

“The main problem was transport to college but mum sorted that out.”

7.6 Celebrating success

Recommendation 11

The development and dissemination of models of good practice in transition service provision should be actively encouraged.

Information from North Tyneside Council

North Tyneside has some excellent examples of good practice it would like to share including:

North Tyneside has been selected as one of 10 pilot sites for the National Getting a Life programme (GAL). At a regional and local level, 'Getting a Life' aims to find ways of ending disjointed and bureaucratic practice among government agencies. For this reason, the project gives a particular focus to transforming the experience of young disabled people in transition. A local multi-agency GAL project team, with support from national programme advisors, is tasked with developing and disseminating models of good transition practice.

The National Transition Support Programme (NTSP), in partnership with Valuing People Now, is also leading on the dissemination of good practice in Transition.

As with all local authority areas, North Tyneside has been assessed by the NTSP in year 1, year 2 and year 3 of the programme. In year 1 North Tyneside was assessed as being in the 10% of local areas exceeding minimum standards in transition (Band 3). In years 2 and 3 of the programme North Tyneside has remained in Band 3. Although there is still significant work to be done, this recognition informs us that arrangements for transition within North Tyneside are improving.

Models of good practice that have been implemented within North Tyneside include the following:

- An internship scheme into the Department of Work and Pensions is being developed. In Sept 2010, it is anticipated six young adults with learning disabilities who are in transition will commence a placement at the DWP Tyne View Park Offices for an academic year period. They will experience and train for three roles. There is a possibility that real employment opportunities will follow.
- An Employment Transition Support Officer post is being deployed to support employment developments for young disabled people in transition. Work will begin from year 9 (age 14). This post is funded through North Tyneside's Year 2 National Transition Support Programme grant.
- The Getting a Life and National Transition Support Programme Project Team, with support from Government Office, continues to develop a transition pathway that includes employment for young disabled people in transition. It includes both a family and young people leadership programme. The benefits of both programmes will impact on all disabled children and young people (aged 14+).
- A North Tyneside advocacy project for transition has been commissioned using North Tyneside's Year 1 National Transition Support Programme grant. From being established in November 2009, the project has advocated for 15 young people in transition.
- Young disabled people from North Tyneside have designed their own standards for both mainstream and specialist services that provide to young disabled people in transition. Several services have signed up to receive an inspection from young disabled people (Quality Checkers – Tickers Award).
- The person centred model for annual education reviews is being rolled out across the borough. The model provides for inclusion and participation in transition plans. Training has led to 45 professionals involved in transition planning being equipped to facilitate the person centred review model in special schools. This has subsequently led to approximately 130 transition planning reviews being conducted using the person centred model.
- All young disabled people and their families/carers have been and will continue to be offered the 'Big Plan' events. These events support young people and families to develop person centred transition plans for adulthood.
- A Changing Our Future project is underway. Young disabled people in transition design and present a series of classroom based lessons through which their own important messages are delivered. This provides young disabled people in transition with the opportunity to show their non-disabled peers that they are interesting, independent individuals who want

to be accepted as one of the crowd and not be singled out or excluded for being 'different'.

- Funding has been secured for the Young Disabled People's Network to continue to meet every two months. The group informs service planning which will impact on their lives.

Quotes from the research include:

"The Learning Disabilities Federation are once again my 'life line', pulling together services and coming up with a cohesive strategy for my son's transition."

"Staying Put team – excellent"

"Good support from my daughter's 6th form with taster days at Percy Hedley arranged"

"Getting a Life has been useful"

"There was a lot of support out there to help me move on, I found it very helpful and very supportive as I'm not very good with change."

8. Report recommendations

Following from the report findings and feedback from North Tyneside Council there appears to be a gap between what North Tyneside Council is offering and supplying and what parents, carers and young people are experiencing at a local and indeed personal level.

It is suggested that North Tyneside Council look at the services it provides around transition and attempt to plug the information gap highlighted by parents, carers and young people.

North Tyneside has a lot of exciting initiatives and good work is happening in transition but they need to be fully inclusive all families and young people.

"I would hope that transition planning is now fully embedded in the system and that young people and their carers would get the information and support for a smooth and good transition they deserve."

Parent of adult with profound learning disabilities

"Help and support me to make decisions"

Young person going through transition

8. Acknowledgements

Annette McGlade of The Learning Disabilities Federation prepared this report.

Special thanks are extended to Ian Walton, North Tyneside Transition Officer for his comments, shared contributions, advice and insights.

The research received many contributions and assistance from a large number of collaborators as young people with a learning disability, parents and carers and multi agency practitioners. Warm thanks go to all of the people involved who offered their sincere views and time in these discussions. The research also received a series of contributions from senior professionals involved in transition this was led by Heather Riley who is a family carer.

Surveys provided key contributions, from the perspectives of disabled young people themselves and family carers; these were carried out by Peter Ellis, Amanda Durrant and Jay Hare. A research consultant Janice Hale was commissioned to guide the study process. Other qualitative research aspects for the study included focus-group discussions and related follow up interviews, which offered valuable insights into the quality of services, particularly of health-related services.

The report could not have been carried out without the help of the data team, Joanna Harries at North Tyneside Council. Encouragement and unfailing support for this study have been provided by my colleague Alison Chalmers and special thanks to Johanne Mears lead officer of North Tyneside LINKS and her board for their patience.

Produced by



North Tyneside Local Involvement Network

The Shiremoor Centre, Earsdon Road

Shiremoor NE27 0HJ

Telephone: 0191 200 1429

Email: link@voda.org.uk

www.linknorthtyneside.org.uk