



Bristol and South Glos Adults and Children & Young People's Voluntary Sector Network Meeting

6 October 2009

Transition from children to adult's health and social care services

Attended: Rachel Banks, CLIC Sargent; Jane Barnes, Barnardos; Carola Bennion, SW Development Centre; Daniel Button, KIDS; Brenda Cooke, South Glos Council; Liz Cooke, Mencap - Avon North; Ann Cooper, Connexions; Judith Craddock, Dart - South Glos; Sue Dolby, University Hospitals Bristol NHS Foundation Trust (UH Bristol); Diana Elliott, National Autistic Society; Susan Everett, National Autistic Society, The; Chris Frost, Bristol City Council - Health & Social Care; Michaela Fudge-Quinlen, Self Help Community Housing Association; Catherine Gane, University Hospitals Bristol NHS Foundation Trust (UH Bristol); Shamala Govindasamy, The South West Regional Improvement And Efficiency Partnership; Margaret Gray, Women's Forum; Jane Guvenir, Bristol City Council; Mark Hamilton, Bristol City Council - Children And Young People; Julia Hammond, Barnardos; Sam Hancock, KIDS; Mike Hatch, South Glos Council - Community Care Department; Alison Hender, Brislington Neighbourhood Centre; Matthew Iles, Mencap Pathway; Mahedi Jeraj, Black Carers Project; Alana Johnston, Bristol City Council; Alice Low, Barnardos; Vicky Mackinder, Barnardos's; Kathryn Mason, National Autistic Society; Caroline McAleese, Bristol Link; Mark McNally, Safer Bristol; Lorraine Millard, Wellspring Healthy Living Centre; Sarah Louise Minter, Bristol Lesbian, Gay & Bisexual Forum; Valerie Mower, Bristol & South Glos People First; Bobby Owen, Contact A Family; Holly Paice, Hop Skip And Jump; Sarah Pitt, Beat; Helen Pocock, South Glos Council - Children And Young People; Margaret Price, Rethink; Jenny Smith, Bristol Crisis Service For Women; Steve Spiers, South Glos Council - Leisure & Community Resources; Quentin St Clair, Help! (Bristol) Ltd; Shirley Stephen; Chris Walker, Encompass; Louise Winn, NHS South Gloucestershire; Rachel Robinson, Kate Oliver, Leon Quinn, Louise Hudson, Katharine Gonzales, Gillian Turner, The Care Forum.

Apologies: Kim Ash, South Glos Crossroads; Ash Bearman, Shirehampton Community Action Forum; Maureen Betts, North Bristol NHS Healthcare Trust (NBT); Karen Black, Bristol Drugs Project (BDP); Sarah Booker, South Glos Link; Andrew Bright, Brandon Trust; Leah Burt, Bristol Drugs Project (BDP); Janet Byrne-Goddard, North Somerset Professional Carers; Liz Chapple, South Glos Council - Community Care Department; Mike Connolly, South Glos Council - Children And Young People; Joan Cox, West Of England Centre For Inclusive Living (WECIL); Rebecca Cross, Bristol City Council - Children And Young People; Natasha Curtis, North Bristol NHS Healthcare Trust (NBT); Pam Davies, CLIMB - Children Living With Inherited Metabolic Diseases; Margaret Deering, South Glos Disability Equality Network (DEN); Mark Earl, Rethink; Sarah Eliot, Whole Baked Cafe; Frances Fox, Bridge Foundation, The; Paul Frisby, NHS South Gloucestershire; Gabbi, Bristol Link; Michael Gadd, HFT; Janet Byrne Goddard, Action For Children; Sandra Grant, South Glos Council - Councillor; Karen Green, Working In Southmead For Help; Rosemary Greenwood, North Bristol NHS Healthcare Trust (NBT); Zehra Haq, Dhek Bhal; Max Harris, Bristol City Council; Jenny Hendy, The For All Healthy Living Company; John Hesketh, South Glos Council - Community Care Department; John HW, ; Adrian Inker, B&NES Council - Councillors; Shagufta Kasour, Bristol Women's

Forum; Faiza Khaliq, Avon & Wiltshire Mental Health Partnership NHS Trust (AWP); Genevieve Laure, ; Liz Lewington, Jessie May Trust; Mandie Lewis, ; Charmaine Lynch, Barnardos; Karen MacVean, Shelter; Rob Martin, University Hospitals Bristol NHS Foundation Trust (UH Bristol); Dianne McCarthy, Age Concern - Bristol; Susannah Mcleay, Bristol City Council - Children And Young People; Sharon Moore, Bristol City Council; Sally Morrissey, Novas Scarman; Julie Mytton, NHS Bristol; Douglas Naysmith, Members Of Parliament; Julia Nibloe, Brook Bristol; Arthur Panton, Bristol Royal Hospital For Children; Richard Parsons, Bristol & South Gloucestershire People First; Amy Phipps, National Autistic Society; Margaret Price, Rethink; Amanda Reading, Brandon Trust; Ann Remmers, North Bristol NHS Healthcare Trust (NBT); Angie Robbins, National Autistic Society, The; Inge Shepherd, NHS Bristol; Liz Small, Barnardos; Jane Taylor, Bristol City Council - Children And Young People; Cath Twine, Supported Independence Ltd; Hazel Volunteer, The Vassall Centre Trust; Jackie Williams, Time 2 Share; Mark Williams, Bristol Disability Forum; John Wood

Notes of the Meeting

Rachel Robinson, Chief Executive of the Care Forum, chaired the meeting.

Speaker:

Carola Bennion, SW Development Centre - Aiming High for Disabled Children's Transition Workstream: a regional perspective

This presentation is on The Care Forum's website. Go to:

http://www.thecareforum.org/publication_uploads/Oct%206th%20Care%20Forum%20-%20CB.pdf

Carola explained that the South West Development Centre is supporting local areas in the south west and that she is personally working with both South Glos and Bristol amongst others. The Transitions Support Programme (TSP) is part of the wider Aiming High for Disabled Children programme which aims to transform local services for all disabled children and young people and their families and there is a big commitment to getting things right. The Aiming High for Disabled Children Review found that more needed to be done to coordinate services for disabled young people in transition to adult life, and to ensure young people and families can access high quality information at key points. There was a lack of coordination between children and adults services and currently people have different experiences across the country. The Transitions Support Programme aims to raise the standards of transition support and provision in all local areas and to support them to do this. It also wants to see greater consistency across the country and to change the culture around transition.

Local support needs have been identified through a Self Assessment Questionnaire (SAQ). The first one was carried out in 2008/9 and the second one is in the process of being completed. The SAQ assesses how much support a particular area needs and they are then offered support to improve their transition arrangements. This year's SAQ is asking for evidence to be produced for what is being done. Carola recommended looking at the website for some exciting examples. www.transitionsupportprogramme.org.uk

Speaker:

Sue Dolby, Bristol's University Hospital Trust – Transition Service Development Group, Bristol Health Services Plan: a clinical perspective

http://www.thecareforum.org/publication_uploads/6%20October%20Care%20Forum%20presentation%20oct%20-%20SD.pdf

Sue said that the aim of the Transition Work Stream Group was to improve transition for young people by using specialist secondary health care services.

She posed the question - Why include transition in the work of the Children and Young People's Services Development Group (SDG)? This is because young people with long term health conditions often fare less well when they transfer to adult services. There is a variety of experiences across specialities and meeting the adult specialist(s) before transfer can help to improve the experience of transition. There have been lots of opportunities to ask young people how their medical condition(s) impinge on their lifestyle. If someone needs to attend for treatment three times a week it will affect their education. Better management of their condition(s) nearer home would help.

In the past the emphasis was on the transfer and whether it had been done correctly. It is a whole process of preparation and integration, not a one day event and now the transition process is around when people are actually ready for it rather than when they 'should' be. Developmental trajectories can be put off by medical conditions. It is also a factor that paediatricians are sometimes reluctant to let patients go from their care. Integrating 'Choosing Health' has meant young people taking responsibility for themselves too. A policy is being written which will lead to an information sheet. This conference is part of an ongoing consultation process – young people and staff have already been consulted.

Transition will begin in school years 9 – 10 when young people aged 13 will begin to be prepared for the process. Information on what adult services will provide will be available for young people and their carers. At 16+ they will have the option of choice as to when they move to adult services, and the transfer and integration will begin within a determined timescale. There will be an evaluation of the process based on both the young person and the staffs' experiences. The aspiration is that services will work together for successful outcomes. Transition will have a self assessment framework which is basically a 'traffic light' system for agencies to self assess against. The main feedback has been that this should be jargon free.

The current position is that the outcomes of the consultations with staff and young people will be implemented. The pathways will be simplified and the testing of operational guidelines will take place with one service. The language of the self assessment framework will be revised and young people with more than one disability and/or complex needs will have their transition plans co-ordinated with the support of a named worker.

There will be further revisions taking into account comments from this meeting and a report will be submitted to the Children and Young People's SDG with recommendations for improving transition experiences and outcomes for young people requiring continued specialist adult secondary healthcare services.

Questions

Q: Is it possible to have meetings for young people on their own? There's often reticence when parents are there.

A: Some doctors have their own preferences. Young people need to be prepared gradually so that they can manage their own consultations

Q: Did you get good ideas from young people?

A: Yes, they said not to exclude their carers. It's not for us to decide when young people attend without their carer.

Q: When a young person is asked to write a transition plan, are staff aware of issues relating to sexuality?

A: We are challenging this. It's very easy to assume that young people are heterosexual.

Q: Did you consult with young people on how to do that?

A: I recently visited a Lesbian, Gay, Bisexual and Transgender (LGBT) youth group to get their views about hospitals. Their comments were circulated widely within the Trust. We are increasingly going out into the community, listening to young people and making sure their voices are heard.

Q: Were any specialist mental health teams involved in this process?

A: Because of the way the children and young people's steering group is set up, we were briefed only to look at children and young people in hospitals. We have consulted with the Child and Adolescent Mental Health Service (CAMHS) and we do recognise that the combination, for example, of diabetes and mental health is an issue.

Speaker:

Cathy Gane, Children and Young People's Involvement Worker

http://www.thecareforum.org/publication_uploads/care%20forum%20presentation%20-%20CG.pdf

Cathy showed a DVD giving young people's views of transition within hospital services.

In hospitals, traditionally, the transfer to adult services takes place between the ages of 16 and 18, which is a particularly vulnerable age.

A young person's event was held to consult on the proposed new Transition framework. Following the event three young people came to a Rapid Service Improvement event for healthcare professionals to help feed back the issues raised.

Feedback from both young people and parents highlighted that the timing of the transfer often takes place at a time of stress such as exams or starting higher education.

Another concern raised was that often patients undergo regular intimate procedures and in adult services they have to get know new staff as well as possibly a different way of carrying out procedures and treatment.

Some of the comments made by young people on the video included: "We should be able to choose when we move up"; "The colours could be more happy"; "Tell the nurses to be really nice"; "I know my body more than you know my body".

Daniel Button, KIDS in South Glos, introduced a DVD made by young people giving their views on community health and social care services. He said that KIDS supports young people through transition and the vision of the organisation is to support young people and their families to achieve their aspirations. Twenty five young people meet regularly in Chipping Sodbury. Consultation enables disabled young people to give their opinions. The video is called *Aspire* –and in it the young people discuss their problems and how their disabilities or learning difficulties affect their aspirations, as well as showcasing their abilities. They talked about feeling safe in their club and how they worry about moving on to the next step. They described their activities and how much fun they have. They talked about their hobbies and things they liked and didn't like. The leaders listen to the young people in the KIDS group to ensure that each person has their needs met.

Workshops

There were three workshops

Workshop 1, Bristol facilitated by Rachel Robinson.

Workshop 2, Bristol, facilitated by Leon Quinn

Workshop 3, South Gloucestershire facilitated by Louise Hudson.



the care forum

The notes of the workshops are on separate pages.

Workshop 1

**Facilitator: Rachel Robinson, The Care Forum
with Chris Frost, Mark Hamilton – Disabled Children's Team Managers, Bristol**

How does transition impact on the groups the VSOs work with?

- It works with young people for whom there are medical/educational/social issues. In special schools, it can be more straightforward than if getting support in mainstream schools. It affects many different channels. I have worked with young people with arthritis and their parents have to let go once they are sixteen. Consultants like to see them on their own, but for parents who have physically supported young people, it is hard to give them independence. Parents need support too at this stage.
- 16 year olds are saying that they don't want to go in on their own.
- 18 is better, they have grown up a bit in those two years.
- There are lots of opportunities for 18+ but far fewer for 17 year olds. Funding streams, risk, legislation, militate against opportunities for 16 year olds. With mental health, the 16-20+ transition period has a number of gateways that are different, with not a lot of convergence between housing, criminal justice and recreation. Despite legislation, at a local level, there could be help with this. Children with severe complex needs will be in various different pathways, but need to be as seamless as possible for young people and their families. In the drive to include them in mainstream services, how do we link with adult services for those that need specialised help?
- Inclusion is brilliant, but they miss out on mutual support.
- It's a big responsibility to manage a PA and direct payments; they don't always want to do this.
- Who could be doing the co-ordinating?
- A key worker could be drawn from a number of disciplines. In the past, there has been a social care worker, but it could be a professional who looks after young people's main presenting need.
- It is difficult to get all to talk with each other.
- All are aiming for the same thing, but the key issue is pulling it all together and the key worker needs to be at a level to coordinate budgets.
- How do "key workers" and "lead professionals" overlap? Could it be a one person/concept?
- The key worker was a health professional and the lead professional a social care worker. Now they are synonymous.
- It is rare to find a group of professionals working together.
- We are trying to link all those professionals, but we still have a long way to go.
- There is a drive for children and young people's services to co-ordinate all of the transition across all of the services from quite a narrow base. Will try to resource a wider group of adult services involved in transition. Legally adult services have different requirements.
- The transition team in Bristol City Council is only for young people with learning difficulties with a whole team of different specialisms.

- There are many young people in hospitals who are not known in children and young people's services.
- But the school would know and be responsible for the transition plan for every child with a statement.
- But they are moving away from statements now.
- Are we missing a whole group of young people now?
- We shouldn't be if schools are taking a responsibility wider than educational responsibility.
- Young people liked the idea of a lead professional, but who would lead if they are not known to children and young people services?
- Families assume everyone talks to each other and are baffled when they find out that they don't.
- Families can refer themselves and every young person is entitled to a Connexions worker.
- How would the parents know who the key worker is?
- The school should identify this in the transition plan. If not delivering, any professional can make a CAF referral to panel. If a young person with a disability is being considered, a disability advisor would be on the panel.
- Are disabled children accessing the panel?
- In some areas they are not.
- They are in Bristol.
- How much do panels and processes draw in the VCS when moving away from specialist universal services?
- CAF panels are good at involving the VCS.
- Attendance at CAF panels is very up and down. It is especially difficult getting schools to do panels in the holidays, but it is a good model. Community-based services can provide added value.
- Are the universities involved in transition planning?
- Transition for young people with learning difficulties up to 25 years old. Bristol children post 19 will be attending specialist colleges out of area. When budgets come to LAs in future, they will be able to commission local specialist provision if they can afford to.
- Different young people will choose different things. Young people with physical impairments often choose to go away and funding is very difficult. They have to be strong to get what they want.
- Young people with pushy parents have the advantage.
- The processes are on paper, but in practice some 16 year olds such as looked after children at 16 are left without care or an after care worker or health check or sex education.
- How can disabled young people know about the opportunities available?
- At The Park, there is a transition project team which shares information.
- At a regional Aiming High event, those local authorities where information had the greatest reach had the biggest sign up to the Disability Register. 4,000 in Devon, only 200 in Bristol. If you are registered it ensures you get up-to-date information, newsletters etc, so it is a doorway. We need to encourage families to sign on to disability register.
- An information pack was given to every family registered but there was a poor take up. Young deaf people do not perceive themselves as having a disability, nor do autistic young people so poor registration. TIPs project is better because it is for everyone, not just disabled people.
- Find It Out is useful and is being updated on to the web by Children's Information Services.
- Do you know of any young people who have their own budgets?
- Gloucestershire County Council is a pilot.
- We found that young people could not manage their budgets. They need training.
- We do have young people with their own budgets, but who are supported by their parents to use them.

- One of the problems Bristol City Council has is that even when young people are awarded an individual budget, they cannot find the staff to fill PA roles.
- More detailed work would be welcome on young people with mental health needs and their transition.

Workshop 2

Facilitator: Leon Quinn

With Alana Johnston, Bristol Council

How does transition impact on the children and young people with whom voluntary care sector providers work?

What gaps are there?

- All-female transition services/environments
- Bristol CYP services and autism - especially for girls are still looking at medical model, rather than holistically, and for boys who got on OK at school and so have no diagnosis
- Sexuality - lack of respect and support during and before transition
- Support for young people to express their views and make decisions
Could be a really positive opportunity, especially in mental health
- Some young people have more parental support than others - could there be the chance to self refer to support services?
- Drop-in services? Virtual services are really important

Solutions

- Introduce staggered transition (can do so already with respite services)
- More advocacy support for young people and possibly parents
- Expand existing learning disability drop-in service into a general transition help centre where no diagnosis is needed - could lead to better recognition of multiple transition needs (for service users with combinations of needs relating to, for example, mental health and substance misuse, or LGB and physical disabilities/diseases such as cancer, and so on)
- Sort out funding and Service Level Agreement stipulations that restrict flexibility in relation to the above two areas

Workshop 3

Facilitator: Louise Hudson

With Helen Pocock, Disabled Children's Team Lead, South Glos

How does transition impact on the children and young people with whom voluntary care sector providers work?

- Young people are used to having funding, this is not so available when they are adults.
- Direct payments is making a difference to social activities
- There is buddy support through CAMHS
- There is a need to get used to working with young people not just older adults
- There is limited funding of projects so there is a need to sign post and upskill young people so that they are prepared when the money runs out
- There should be links to make transition simple, transition is nothing to do with age Services must not assume that all people of a certain age have attained a certain stage, they may be physically but not mentally ready. Chronological age does not dictate ability
- Funding for support needs to be flexible and there should be funding for the voluntary sector to provide long term support
- Preparation with the young person is vital as they often do not have peer knowledge of developing, e.g. sexuality
- Education is needed with support
- There is some movement forward but there are so many pots of money. Not one for each condition which would be too expensive anyway. Many hoops to jump through
- Pathfinder is encouraging multi agency/partnership working via a 'dragons den' initiative, bidding for pots. Sustainability is difficult and one partner has to take the lead
- Individual budgets is good in that they have choice in how it's spent but there are problems around payments. There is confusion who the voluntary care sector invoice. Payments to providers needs to be via a simple system

Joining up the services, how can it be done better in terms of transition?

- Statutory link work needs to happen. It needs co-operation
- Multi agency support workers are needed
- By April 2010 a nominated health worker and multi agency link worker for each young person should be able to navigate/signpost. One for each condition would be too expensive.
- A co-operative approach is needed to ensure that it happens within the performance/budgetary framework
- Core health activities are what happens on the ward – it needs outside agencies to support social etc support
- The opportunity to achieve something is now high up in the statutory sector and the voluntary care sector needs to suggest models of practice that will work
- Information about services is beginning to happen around short breaks. This has led to a database but One Big Database is not sufficient. It doesn't have key searching on transition and needs sifting and sorting to get information
- Key workers know the young people and can help and advise
- Connexions can be that key worker for some young people

Conclusions

- The health side, amongst others, needs to improve as one size does not fit all.

- There needs to be a clear idea among the services as to who is the lead. The young people also need to know this.
- It can be a circular thing to get help and/or information.
- Involved agencies need to meet so that each knows what the other is doing.
- Transition may require advocacy.