

Transition planning for full lives

Pathways to getting a life

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Getting A Life
helensandersonassociates
National Development Team for Inclusion

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DH INFORMATION READER BOX

Policy	Estates
HR / Workforce	Commissioning
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Planning /	Finance
Clinical	Social Care / Partnership Working

Document Purpose	Best Practice Guidance
Gateway Reference	15614
Title	Pathways to Getting a Life: transition planning for full lives
Author	Department of Health
Publication Date	14 Mar 2011
Target Audience	Directors of Adult SSs, Directors of Children's SSs
Circulation List	Young people with learning disabilities and their families
Description	This document sets out best practice in transition planning for young people with learning disabilities. It shows what needs to change in order to improve the life chance outcomes for this group of young people, and suggests ways to make these changes. The outcomes focus on the Valuing People Now priorities of health, housing, social inclusion and employment.
Cross Ref	N/A
Superseded Docs	N/A
Action Required	N/A
Timing	This publication will be launched on 14th March 2011
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For Recipient's Use	

Foreword

For young people with learning disabilities, the transition years are crucial. Research shows that we can set young people up for the rest of their lives and make a huge difference to their life chance outcomes if we share with them a range of choices, good information and support around housing, employment, health, and making friends and social relationships, while they are still at school. We must make sure that we do not let their window of opportunity pass.

If we do not get it right, lost opportunities, inappropriate services and unresolved anger can have a lifelong impact on people themselves and their families. It is therefore important that through personalised approaches and best practice evidence, we provide the support that people need to live the lives they have chosen.

This document sets out the best of what we know about how to help young people to have the lives they really want. It is based on the transition work undertaken by Valuing People Now, and on the work carried out by the Getting a Life demonstration sites.

We commend this document to you as a way of achieving much better life chances for young people with learning disabilities as well as a way of using resources much more effectively.

We would like to thank the hundreds of young people and adults with learning disabilities and their families who have shared their experiences with us and helped us to understand what needs to change, some of whose stories are included in the document. We would also like to thank Helen Sanderson Associates, the National Development Team for Inclusion, and Centre Events, for running the transition events that took place in the Autumn of 2010 as well as colleagues from the Transition Support Programme and the people who took part in those events. Finally, we would like to thank Pen Mendonça for her fabulous art work.

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Background and introduction

When Valuing People¹ was published in 2001, “transition” was one of its 11 priorities. Transition had been identified by people with learning disabilities and their families as problematic. Valuing People expected Learning Disability Partnership Boards to appoint a transition champion and to develop a strategy to improve young people’s experiences and life outcomes as they move into adulthood. In 2003 the Valuing People Team produced a guide for transition champions and began the person-centred reviews training programme. Most areas of the country have taken part in this programme. Person-centred transition planning is now widely acknowledged as an important aspect of good practice in transition. Many other Cross-Government strategies, including the Transition Support Programme, have highlighted the importance of high quality person-centred transition planning.²

Valuing People Now,³ published in 2009, consolidates and builds on this work. It expects all young people with learning disabilities:

- To have person-centred transition reviews and plans by 2012.
- Young people and their families to have a strong voice at review meetings.
- To know what is positive and possible in terms of the future, and that clear actions have been set in the areas of health, housing, jobs and careers, and friends and relationships.

While progress has been made, the above work has also led us to become even more aware of the issues and barriers faced by young learning disabled people. It is clear that this group of young people want the same things in life as everyone else: to travel, to get a good job, have friends and relationships, to live independently, to have a good social life and to be valued citizens. Individual budgets, person-centred planning and advocacy are important ways of helping young people to plan for themselves and to have control over how they want to be supported.

Valuing People Now work has found that statutory planning does not lead to the life outcomes that many young people want. This means they are not supported to forge a career path. Their options after school are usually based on fixed, long-held assumptions about what learning disabled people should do, lack a clear goal, and are restricted to a day centre or a particular type of college course. Many young people, as adolescents, enter residential provision because a) local colleges do not perceive themselves as having the necessary skills and b) there is not close working between social care, education and health.

Young people want to be able to move into adulthood with real opportunities for work, housing choices and a social life in the community, and for this they need high quality support. Increasingly, the support will be self-directed and delivered via individual budgets. We therefore need a much better approach to planning with young people, so that they can explore the possibilities and make decisions about their future life. Post-16 education, training and support for employment must all be able to respond to the young person’s individual aspirations.

¹Valuing People, a new strategy for learning disability for the 21st Century, Department of Health, 2001

²Person-Centred Approaches in Transition Planning, National Transition Support Team, 2011

³Valuing People Now: a new three-year strategy for people with learning disabilities, Department of Health, 2009

Supporting young people as they move into adulthood is complex and presents a challenging management task. This is partly because the current legislative requirements have produced a very complex and bureaucratic system, but it is also partly because of the values held about people with learning disabilities in society. The challenge requires leadership at the most senior levels of management. During the five years of the person-centred transition reviews programme, front-line service workers and middle managers have expressed frustration at the lack of priority given to this area.

Getting a Life started in 2008, and became one of three Valuing Employment Now⁴ demonstration programmes. Each of these is working to show how we can increase the number of people going into full-time paid employment. Getting a Life has been working in 12 areas⁵ with a project team including all local services and 30 young people and their families, to identify what needs to happen for young people to get jobs and full lives. Using research evidence about what works, the young people, their families and local agencies have worked with Getting a Life to design an employment pathway that is represented graphically. The employment pathway sets out the most critical things that need to happen during transition and the Getting a Life sites have been working to implement its many aspects. The sites have concentrated on enabling young people to have work experience, person-centred transition planning, using personal budgets, bringing supported employment into schools, developing the capacity of supported employment services and widening what is on offer at college.

The pathway has proved to be very popular, and has led to the development of similar pathways for housing, health, and friends and community.

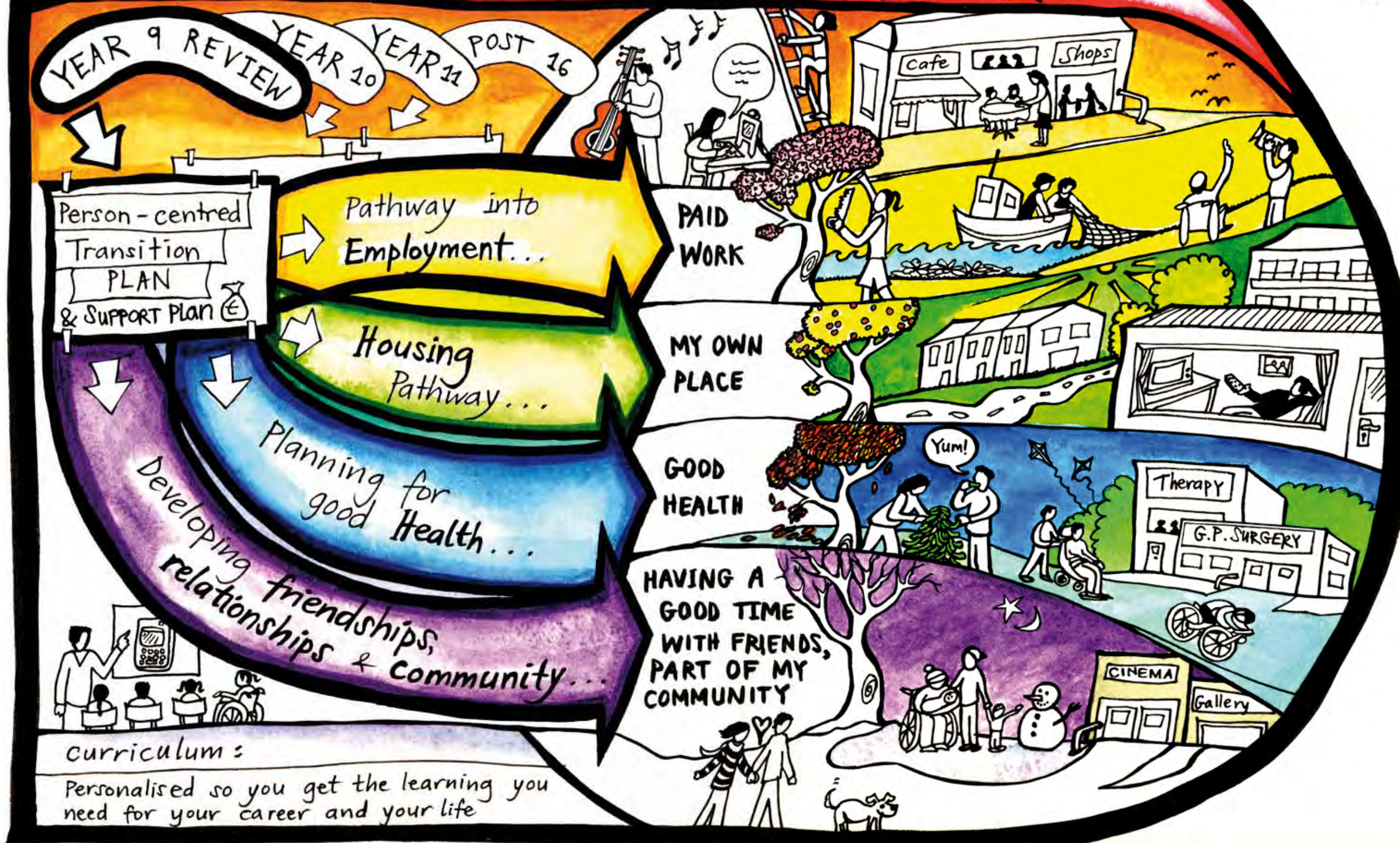
Purpose of the document

- To bring together what we have learned about transition from Valuing People and Valuing People Now during the past 10 years, and in particular from Getting a Life.
- To set out clearly the key things that need to happen to support young people to move into adulthood, with the information, experiences, confidence and skills they need to fulfil their aspirations, enjoy equal opportunities and have good lives.
- To introduce the Pathways to Getting a Life.

The work of Valuing People and Getting a Life has been with people with learning disabilities. The pathways into adulthood, however, are relevant to all young people with additional needs. The pathways address barriers faced by many young people, and they set out what we know needs to change to improve outcomes. By focusing on those most vulnerable to exclusion and furthest from the labour market, it is far more likely that the system will improve for everybody.

The pathways focus on outcomes and activities rather than services. What is important for young people is that things happen. It is not important who makes them happen, as long as they do. We have found that if local services concentrate on what needs to happen rather than on service structures, they become more creative in making the necessary changes. The Pathways To Getting a Life graphic highlights the importance of focusing transition planning on employment, housing, health and community participation from school year 9.

PATHWAYS TO GETTING A Life



We hope that you will find the pathways helpful in improving the support young people receive as they move into adulthood.

In Autumn 2010 a series of five workshops took place in each of the English regions, attended by all local authority areas, to introduce the pathways to a wider group of people. Participants at the events included young people and adults with learning disabilities, families and people working in education, social care, health, supported employment and the voluntary and independent sector. The five workshops were on: person-centred transition planning, employment, health, friends, relationships and community and personalisation with discussions about housing taking place at all of them. This document includes feedback and ideas from the workshops.

Feedback and ideas from Valuing People Now transition workshops on person-centred transition planning and personalisation

General points

- Transition planning needs to start early.
- Young people and their families need to take the lead role in transition planning.
- Person-centred planning tools offer a proven way to deliver high quality, creative and holistic transition plans.
- In many areas, education, children's and adult services are still not working together to promote smooth transition and weave personalisation into the process such as identifying and agreeing personal budgets.
- The foundations of personalisation (including resource allocation systems and provider development) are not consistent across the country. Some people still don't have access to personal budgets.
- It sometimes feels as if we are planning to meet organisational targets rather than for individual aspirations.
- Someone needs to take an effective leadership role that draws in partners, ensures timely delivery and monitors quality and outcomes.

Challenges

- Professionals across education, children's, adult and transition services are weak at communicating about transition planning, outcomes and delivery plans. This is in part down to each having very different cultures and working practices.
- Schools may not be as committed to person-centred planning as they could be because they do not have a long term stake in the outcomes of the planning.

- Many people in children's services do not know what is possible for people with learning disabilities to achieve and have little or out of date knowledge about the support that is available.
- We do not have robust structures for monitoring the quality, creativity and delivery of transition plans. Nor do we have mechanisms to ensure that desired outcomes are achieved.
- Transition falls into the gap between children's and adult services, which means that no one takes responsibility for making sure actions happen.
- Young people and their families and service professionals report a lack of timely information about planning, services and budgets. This hampers their ability to plan effectively and creatively.
- Now that we have personal budgets, it is even more important that we start transition planning early and that planning is person-centred.
- We need to get better at identifying how a personal budget works with natural and unpaid support. Circles of Support are crucial.
- We still lack the necessary mechanisms to monitor the quality of person-centred planning.

Opportunities

- Transition should be a time of creativity with great choices around where people live, how they spend their time in education, employment and community and their goals for adult life.
- It is great to have clear and widely shared transition pathways that detail the steps of planning and delivering plans.
- Be sure that everyone involved understands what makes a high quality person-centred planning process and outcomes.
- Before and during transition planning young people, families and professionals need access to good information about what is possible and what support is available.
- Ensure that young people and their families know that is OK to have high aspirations, be fully involved and where possible lead planning and feel able to challenge professionals.
- Experienced young people and families make great mentors for other people going through transition and can raise expectations amongst professionals.
- People working in services need to focus on sharing information, ideas and best practice regardless of their perceived role and responsibilities.

- Planning needs to include a new focus on outcomes and actions.
- We need to monitor the outcomes of and activities from planning with a focus on the quality of lives achieved by young people as they become adults.
- Through central access points, information sharing workshops and roadshows and clear policies, we can raise awareness of personalisation among young people, their families, educators and care workers.
- This needs to begin before the Year 9 Reviews. Ideally during or before year 8.
- Promote young people and family's leadership to take a lead in understanding and sharing best practice.
- Mapping and sharing opportunities, possibilities and stories will help everyone understand the possibilities of personalisation.
- Personal budgets' teams need to work closely with schools and children's and adult services. There needs to be a common agenda and strong leadership.
- Projects such as the Getting a Life Sites and Project Search offer real inspiration. We need to share the outcomes more widely and, ideally, ensure an inspirational project in every area.
- Highlight the various funding streams that feed into personal budgets and their use, such as Personal Health Budgets.
- Build the services and supports that promote best outcomes in both personalisation and transition, for example employment support, independent living and community building.
- Remember that a normal part of moving from childhood to adulthood is trying new things, making mistakes and trying again.

Clare - Somerset

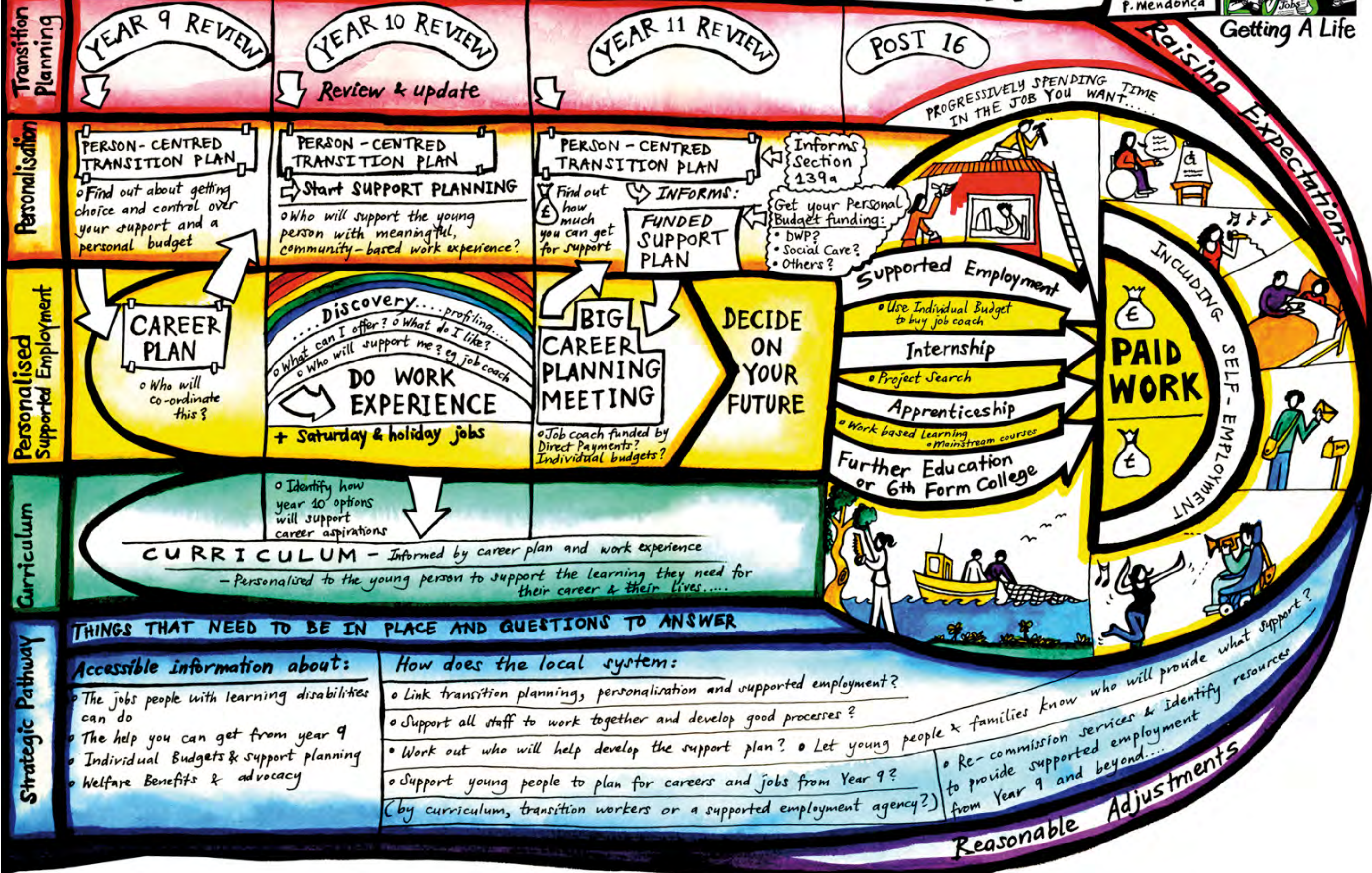


Clare is 18 and as part of the Getting a Life leadership programme, took part in a day of individual planning with her family and one of the programme leaders from the Foundation for People with Learning Disabilities. During the planning day, everyone found out lots of things about Clare – including that she loves animals and already has responsibility for looking after the chickens her family keeps.

Since the planning meeting took place, Clare's mum approached her school about work experience, and Clare now has a work experience placement at a local museum. In addition, Clare is gaining more experience of working with animals, grooming horses at a stable, and with a cat breeder helping to feed their cats.

PATHWAY IN TO PAID WORK

March
2010
P. Mendonça



1. Pathway into paid work

Valuing People Now says that people with learning disabilities should be able to work: “We know that less than 10% are in paid work and that of those, not many are working more than a few hours a week. And yet we know that more than 70% of people with learning disabilities want to work”.

The employment pathway shows what should be the five main routes into employment for young people with learning disabilities. They are internship (such as Project Search), supported apprenticeship, supported employment, work-related learning at college, and self-employment. The pathway sets out the key things that need to happen at each stage to make sure that young people can access these routes.

Valuing People and Getting a Life have found that employment has not been seen as a priority for young people with learning disabilities in transition. The young people and families involved with the Getting a Life programme have identified the following barriers:

- There are low expectations and aspirations about work throughout the system.
- Discrimination - year 10 work experience or choice at college are not offered routinely.
- There is no agreed approach between agencies about supporting young people to plan and live their lives.
- There is currently no pathway into employment, and no agency has responsibility.
- Supported employment services are not usually available to support young people from work experience into employment, especially from age 14.
- The current system highlights people’s difficulties rather than focusing on their interests and capabilities.
- Personalisation, supported employment and transition planning happen in parallel, rather than by working together to make sure that people go into paid employment.

Making it Happen

School year 9

In year 9, when young people reach 14, they start their transition plan. This is an excellent opportunity to begin to plan for jobs and careers. If the review meeting and plan are person-centred, the young person and their family will be talking about what is important to them now and in the future, including work. It is necessary at this stage to identify who will support the young person to develop their career plan. This could come

from the school curriculum or be supported by a Connexions adviser, a supported employment service, the young person’s family or circle of support. Research shows that the most successful outcomes happen when best practice in supported employment is used: i.e. in-depth person-centred vocational profiling, planning, job searching, job coaching, and on-going support.⁶ For many people with severe learning disabilities, job coaching would usually need to include systematic instruction.⁷

Year 9 is clearly too soon to be looking for a job, but it is important to plan for work experience the following year. Meaningful work experience is based on the young person’s interests and abilities in a real work environment. By using supported employment methods, it is much more likely that work experience will be successful. This will then provide a basis for building and developing the career plan, so that the young person has the opportunity to start working part-time while they are still at school, and to have a good idea of what kind of work they enjoy.

The year 9 review meeting is also an ideal opportunity to provide the young person and their family with good, accessible information about jobs that local people with learning disabilities are already doing. This could be in the form of written stories, or they could hear directly from people with learning disabilities who are already working. Young people and their families also need information about welfare benefits, to ensure: (a) that they are claiming all the benefits they are entitled to, and (b) that they understand which benefits are affected by earnings. They also need information about the variety of funding streams, and about personalisation. The local jobcentre plus and supported employment services can produce information about how the system works in the local area, and what support and funding is available to help people to get jobs. If they are already in receipt of a direct payment or personal budget, they could be thinking about how that might help with their planning for work.

Strategically, local services and organisations can work together to:

- Link transition planning with personalisation and supported employment.
- Support all staff to work together, in order to prioritise employment and to understand the part they can play.
- Clarify roles and responsibilities so that young people and their families know who will support them to develop a career plan, get work experience, part-time work and employment after school or college.
- Provide clear information about welfare benefits, personalisation and funding for employment support.
- Commission services and support that lead to employment.

⁶What Works? Good practice in transition to employment for young people with learning disabilities, Beyer et al, Welsh Centre for Learning Disabilities, Cardiff University, 2008

⁷Scoping study on existing courses and qualifications for job coaches, Beyer, Welsh Centre for Learning Disabilities, Cardiff University, 2010

School year 10

At the year 10 review meeting, the career plan can be built on. Work experience will have already taken place or will be planned. This can then be the basis for the discussion about curriculum options, part-time work and what the young person will do after age 16.

Many young people have said that they do not feel they have learned the things they need for employment. It is therefore important that the school curriculum take account of young people's aspirations for the future, so that opportunities are maximised for them to develop the skills they will need (such as travelling, telling the time, using a mobile phone, using money).

At this stage, it is important that young people and their families know about the usual routes into employment and how these can be accessed. For example, they need more information about how the local system supports people into employment. Does the local supported employment service work with young people while they are still at school? Does the local system enable young people to use their personal or individual budget to purchase employment support? They need to know if there is a local internship programme (for example Project Search), and what apprenticeships are available locally. Staying at school or going to college are the most common options for young people with learning disabilities, but often the courses they do are not explicitly based on their employment aspirations. Self-employment is becoming an increasingly attractive option for these young people, and information about this needs to be available to them and their families.⁸

School year 11

By year 11, the career plan will be based on work experience and some part-time work, and will set out clearly what the young person is going to do in the following year and beyond, based on their career aspirations.

In some areas, young people are given their indicative personal budget at this stage, so that they are able to develop their funded support plan before they leave school or college. They can therefore plan how they will use some of their budget to support them with employment. Employment funding such as Access to Work can also be included as part of the support plan.

The person-centred plan and support plan usually provide enough information to enable good planning for the next stage. If the young person decides to go to college, it should not be necessary for the Learning Difficulty Assessment (S139a) to be carried out separately. Ideally, there will be a single transition plan/support plan that the young person takes with them into their next place, whether it is an internship, college course, supported employment, apprenticeship or self-employment.

⁸In Business: Developing the self employment option for people with learning disabilities, Keith Bates, Foundation for People with Learning Disabilities, 2009

Feedback and ideas from Valuing People Now transition workshops on employment

General points

- Through Valuing Employment Now there is an expectation that more people with learning disabilities can and will work.
- High quality education and transition planning needs to include and encourage employment.
- Employment planning should start to be formalised in the Year 9 Review.
- Young people with learning disabilities need access to the same range of employment options as all other young people, including part-time or 'Saturday' jobs while still in education, vocational training and apprenticeships.
- Young people have stories to tell about their work that will inspire other young people.

Challenges

- Most professionals supporting young people and their families have very limited and sometimes, incorrect knowledge about employment options for young people with learning disabilities.
- There is a lot of incorrect information in the system about what support is available, the impact of work on benefits and the welcome from employers and the wider community. This culminates in the belief that very few young people with learning disabilities will work.
- There needs to be more positive stories about young people having great experiences at work.
- There is generally not an expectation that people with learning disabilities will enter employment, especially if they are identified as having more complex disabilities or health care needs.
- Families are not given information to raise their expectations about their children, in fact most of the information they are given is about the more traditional routes of colleges and day centres.
- Where there are expectations of employment these may not encompass all the employment options available including part-time work while at school/college, full time work, and setting up your own business.
- Many, if not most, young people do not have access to high quality work experience while in school or college. The experience available often does not give a true insight into the possibilities and challenges of work.

- Job coaches and employment support workers do not connect with schools, transition workers and others to share experiences, build expectations and find solutions.
- Most planning does not include an expectation of a detailed conversation and outcomes about employment, career related training or the connection between work and the rest of young people's lives.
- We often fail to inspire and seek creative person-centred outcomes.

Opportunities

- Young people and families need an indication of eligibility for funding as early as possible. This may include an indicative budget.
- Start with an expectation of work. This expectation needs to begin early, it needs to weave through school life and lessons and children should be given real images of possibility through stories. Any low expectations that a young person will not go into employment need to be challenged.
- There needs to be positive and correct information about all the ways that work can be found, gained and supported and that work is an option for all young people.
- Introduce young people to older young people who have great jobs and who get to use their wages for all the normal things that young people spend their money on - new trainers, clothes or holidays.
- Ensure that all young people get access to high quality work experience with real employers in community settings. Research shows that when supported employment agencies are involved, young people experience better outcomes so it is important for schools and colleges to link with employment services at the work experience stage.
- Ensure that examples and evidence reflect the range of employment options available to other young people. Show how the welfare benefits system can support rather than hinder employment.
- Remember that many people's first experience of work is not when they leave school/college. Lots of young people have part-time jobs while they are still in education. This helps young people learn good employment habits.
- Start to formalise employment planning in the Year 9 Review. Use this as an opportunity to consider how further education can support career plans and identify likely employment outcomes.

- Plan early, involve supported employment services and ensure that housing, leisure and other support plans make employment possible. Ensure that young people have access to the full range of employment supports include apprenticeships and vocational training.
- Prioritise employment in local strategic planning and make sure that it is regularly discussed at the Learning Disability Partnership Board and the Children and Young People's Board. Use resources well.

“ Young people at the workshops said

Lucy is not interested in catering, although the system tried to direct her into this type of work. She now works in administration, a job she got with the help of a job coach. She says that you need to start talking about work in year 9 and young people need to be asked, “what do you want to do when you grow up?” and to learn about payday and working with a team.

Malak does not like getting up in the mornings so, with the support of a great job coach, he found shift work that starts at 3pm. He likes getting paid now he can buy the computer games he wants.

Although Alistair's mum owns a supermarket where he could have got a job he wanted to show he could be independent so got a job trial at McDonalds and works in a pub on Saturdays.

Kirsty does things like photocopying at work. Some of the things she does other people were not doing or didn't want to do. Kirsty used her individual budget to employ a job coach.

”

Emrys

Emrys, 20, has two jobs as a caretaker and as a cleaner. He is the first young person from his school (a special school for children and young people with learning disabilities aged 4–19) to leave and go straight into paid employment rather than going on to college.

Whilst still at school, Emrys and his family got involved in the Getting a Life programme, and they started to think about employment and what job he would like to do when he left school. Emrys knew that he did not want to go on to college and wanted to get a job straight away.



When he reached 16, Emrys started to receive a personal budget from social care funding, and used this to pay for employment support from Mencap Pathways. He undertook supported work placements and volunteered at a local café, to help him decide what kind of job he wanted.

Once Emrys felt he knew what he wanted to do as a job, he applied for a variety of roles and succeeded in securing two roles – as a part time caretaker and a part time cleaner. He is really pleased with his jobs and is currently receiving on-the-job training to help him learn the different tasks. This support will gradually reduce with Mencap Pathways remaining in the background to review how the job is going.

2. Housing Pathway

Valuing People Now says that people with learning disabilities should be able to choose where they live and who they live with. Many people do not have this choice. The majority still live with their families or in residential care. Things have improved over the past ten years, but there is still much to be done if people are to be supported to have the same housing options as the rest of the population. Since the publication of Valuing People in 2001, the remaining long-stay hospitals for people with learning disabilities have closed, and the remaining NHS campus provision will have closed in 2011. Many more people are now living in their own homes, most as tenants and some as homeowners.

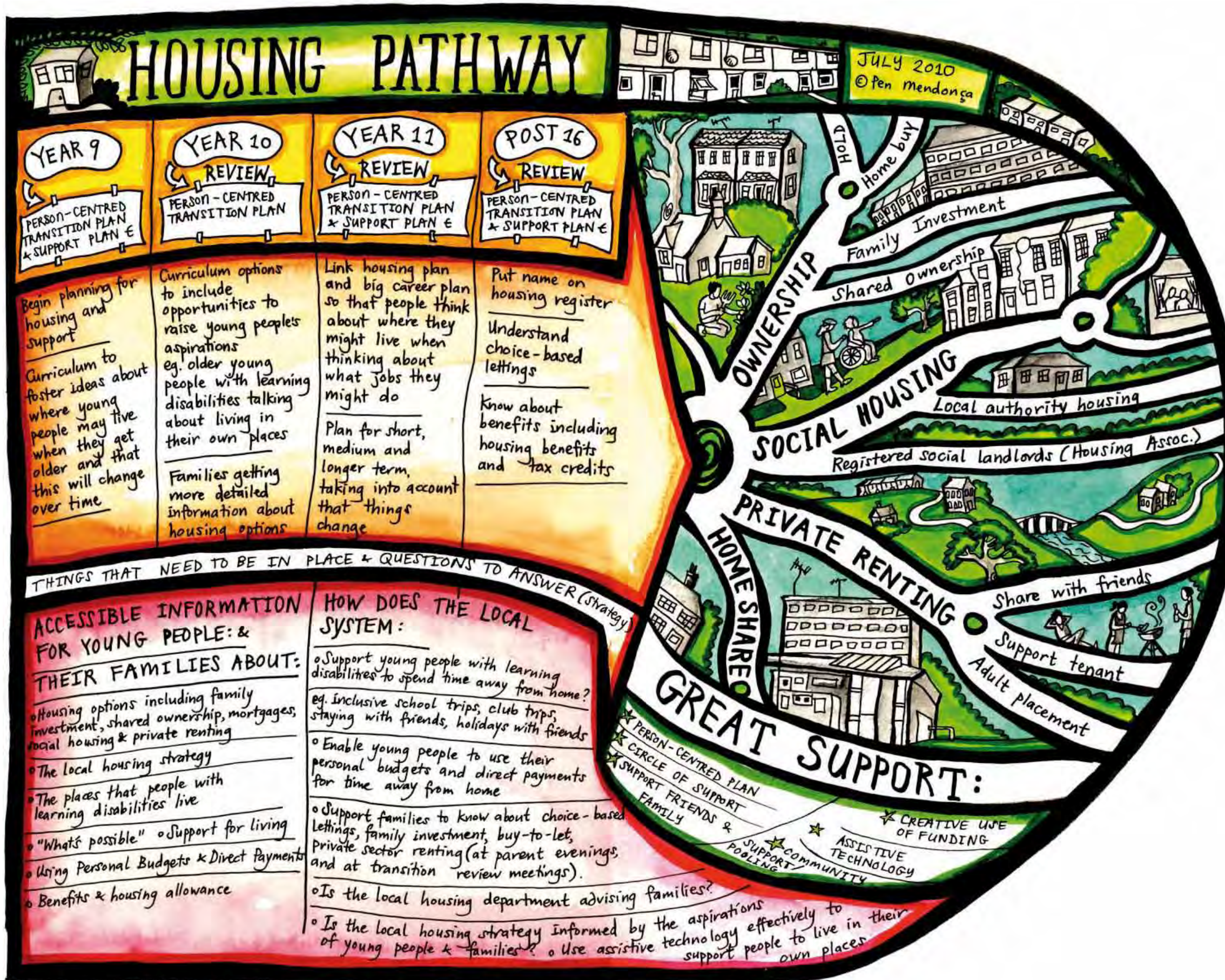
The Housing Pathway sets out the most important things that need to be in place so that young people and their families know about and can plan for the right housing option for them as they move into adulthood. This might be home ownership or shared ownership, private sector renting, home share or public sector renting. The pathway poses some vital questions for local systems to consider, so that they can provide good information and support.

As part of the Valuing People, Valuing People Now and Getting a Life programmes, we have heard from hundreds of young people and their families about their aspirations for the future. They have often told us, however, that they were not aware of the possibilities open to them in housing and related support. As with employment and health, and as with friends, relationships and being part of communities, young people with learning disabilities need support to plan for their future housing. Many young people without disabilities live with their families until much longer than was the case in the past, and so it is often thought that planning for housing when young disabled people are still at school is too early. However, it is important that young people and their families have good information from the beginning of transition planning, so that they can think about housing alongside everything else.

Making it Happen

School year 9

In year 9, when young people reach 14 and start to plan for the future, they and their families need information about housing options. They need to know that it is possible for people with learning disabilities to live with friends, on their own or with partners. They can hear from adults with learning disabilities who are living independently and who can talk about how they achieved their homes. They also need to know about the support available to help with housing, including benefits and personal budgets. At this stage, the information will be fairly general and designed to ensure that young people and their families are aware of the possibilities.



The local system will therefore need to make sure that good, accessible information is available: the best information is written together with people with learning disabilities and families. In addition, the school curriculum can raise young people's aspirations for the future, including housing options.

The evidence is that when person-centred transition planning is in place, it becomes easier for young people, their families and professionals to think about all aspects of the young person's life, including housing.

School year 10

As young people develop their transition plans, they need the opportunity to help them think about becoming independent adults, and about how eventually they might want to move out of the family home. If they are already in receipt of a direct payment or a personal budget, it is important to make sure that this is used to maximise opportunities to prepare for adult life. The local system may wish to consider the following:

- How are young people supported to spend time away from the family home doing things they have chosen?
- Are they included in inclusive school trips and club trips?
- Are they supported to stay with friends on "sleepovers"?
- Is support planning being used to enable young people to have time away from home?
- Is the local housing department fully aware of the young people with learning disabilities at school, their numbers and location, so that it can give them good advice and make sure they are included in their housing plans?
- Are young people and their families aware of the local system and how to apply to be on the housing list?
- Are young people and their families aware of family investment, buy-to-let, private sector renting, home ownership and other housing options?

School year 11

During the final year of compulsory schooling, it is important that young people and their families have the information they need to move on to the next stage. They need:

- To know how to apply to be on the local housing register, as this is usually possible from age 16 and it can take many years to be offered a home.
- To have all the information they need about welfare benefits, housing benefits and funding streams that are available to support people to live independently.

Even if the young person is staying on at school, it is important that this information is available. If planning does not take place and information is not given at this stage, it could lead to the young person missing out on important opportunities.

As well as information about housing options, it is also important that the young person and their family know about assistive technology and community support. A good person-centred transition plan and support plan developed with a circle of support/friends will help to make sure that there is creative thinking around how to support them.

As the young person moves into adulthood, their transition plan/support plan can develop with the help of new people in their life. The planning that has gone on at school needs to be built on at college and beyond. It is therefore important that adult social care, health and education services work closely with the young people during the transition years, to avoid unnecessary and repetitive assessments.

Strategic planning and commissioning is much better focused on value for money and outcomes if it is based on the information from young people's person-centred transition plans. Getting a Life sites have held Working Together for Change days very effectively.⁹

Feedback and ideas from Valuing People Now transition workshops input on housing

General points

- Some young people will need significant specialist support to live in the community e.g. if they are technology dependent.
- Transition should be based on the idea that people with learning disabilities will live in inclusive communities – this means the use of 'mainstream' services.
- Plan early and make sure that housing, leisure and other support plans make employment possible.
- Young people and families need information about housing from the year 9 review.

Challenges

- What's on offer to young people in, for example housing, employment, day opportunities and travel are often poor quality and limited. What is available varies greatly depending on where the young person lives.
- Young people and families often lack information about housing support and services available.
- Families often leave young people with learning disabilities out of their considerations about inheritance because they think it will affect their benefits.
- People do not know enough about housing trusts.
- There is a lot of fear about young people moving out of the family home. Young people, families and people working in services need to know about the support that is available

⁹Working Together for Change: using person-centred information in commissioning, Department of Health, 2009

- Currently, people do not get information about all of the housing options and how to pursue them.

Opportunities

- Young people and their families need to hear from adults with learning disabilities living in their own homes.
- Transition could be a time of creativity with great choices around where people live, how they spend their time in education, employment and community and their goals for adult life.

Matthew

Matthew and his family completed a person-centred plan before he went away to residential college and he decided that when he returned, he wanted to live with friends in the local area where his family lived.

During the autumn break in Matthew's final year at college, Matthew and his mum visited some local estate agents and started to find three-bedroom properties where Matthew could live with a friend and a carer. Matthew chose some streets that he liked, and which were close to transport links, shops and other important places. As they found possible homes, Matthew's mum Kathleen kept Matthew's social worker informed but found it hard to get a clear answer about what was happening and what they needed to do next.

In December, the family found out from the social worker that Matthew's care budget had been agreed, but that they would need to find a place for three people to live in, rather than two as they had previously understood. The family started again, looking for four-bedroom houses that could accommodate Matthew and his friend, another young man, and a carer.

As they got closer to Matthew's return in July, the family got more worried about securing a house. Matthew's friend pulled out of the house share, and so they went back to looking for a three-bed house, knowing that he would have little time to get to know his new housemate after returning from college, as the young man was still living in the local area.

Matthew's mum had to negotiate with the housing association (which the social workers had selected) as they did not usually buy older properties in the area where Matthew wanted to live. The family found a house that they thought would be suitable, but after the survey, the housing association pulled out of the purchase without informing the family, and they had to start searching again.



Finally, in late May, Matthew's family found another house that needed very little work, and the housing association went ahead with buying and decorating it. Matthew and his new housemate picked the bedrooms they wanted.

On 20th September 2010, Matthew and his friend moved into their new home, in the community where they both grew up. The house is on a quiet pedestrian street with a garden at the front, and a yard at the back. There are many shops nearby and the area has good transport links.

Kathleen, Matthew's mum, says, "The house felt like home from the start. Things could have been far better planned but the outcomes have been much better than we could have hoped. Even though we got there in the end, the journey was not straightforward and certain things need to change, most importantly making things person-centred, to set a higher standard for the future."

TRANSITION PLANNING FOR GOOD HEALTH

JUNE
2010

Pen Mendonça ©



Getting A Life

YEAR 9

PERSON-CENTRED
TRANSITION PLAN

Health
PLAN

★ Who will
co-ordinate this?

★ Does this plan
bring all my
health needs together
in one place?

③ Begin engaging with
mainstream services

③ Develop a
communication
passport to help new
people who meet me

③ Arrange for me to
have all the
equipment I need
when I leave school

③ Will my current
staff transfer
with me?

YEAR 10

REVIEW:

PERSON-CENTRED
TRANSITION PLAN

Health
PLAN

is in place

★ It includes
information from
paediatrician, CAMHS,
community nurse,
therapists, hospital.....

③ My GP has my plan

③ The practice nurse
and community nurse
share information
about my health

③ It is clear how my
health needs will
be met

③ I know about
Personal Health
Budgets

YEAR 11

REVIEW:

PERSON-CENTRED
TRANSITION PLAN

Health
PLAN

is reviewed



③ Me and my family
and all my health
professionals are clear
about when I will be
discharged from each
service. We will have
the names of people
who will take over
responsibility.

③ I know how my
health needs will
be met

POST 16

I AM IN CONTROL OF THE
SUPPORT I NEED TO BE
HEALTHY £

I GET A HEALTH
CHECK EVERY YEAR
(this builds on my
health plan)

I KNOW HOW TO
KEEP HEALTHY

PROFESSIONALS
WHO SUPPORT ME
TALK TO EACH
OTHER ACROSS
SERVICES

PEOPLE KNOW HOW
TO COMMUNICATE
WITH ME

STRATEGY:

- How will specialist community paediatricians make sure that GPs learn about young people and are ready to take responsibility for their healthcare?
- How are GPs able to get to know young people before they are discharged so that there is shared care for a period of time?
- How are children's therapy services working with adult service colleagues to ensure that young people have a communication passport, communication aids, wheelchair, pastoral care...?

ACCESSIBLE INFORMATION ABOUT:

- Who will work with me when I'm discharged from children's services?
- Who is responsible for funding my equipment & aids?
- Who will make sure that things are in place in good time?
- Free prescriptions • Dental services
- OT & other therapies • Diet & exercise
- Opticians • Relationships & sexual health

HOW DOES THE LOCAL SYSTEM:

- Support partnership working between specialist children's health services & mainstream services?
- Make sure that health professionals understand person-centred planning & contribute to transition & health plans?
- Connect data about the needs of disabled children & young people so that strategy & commissioning can tackle poor practice & inefficiency.



- How are CAMHS working with adult mental health services to ensure consistent, high quality support?
- Is the SHA asking PCTs to connect data on disabled children's health outcomes?
- Does the PCT collect data on disabled children's health outcomes eg. premature death
- Does the PCT provide GPs with a training & development programme & information about common conditions?
- Does the local health service enable people to develop person-centred health plans & profiles with clear outcomes?

3. Planning for good health Pathway

Valuing People Now says that all people with learning disabilities should get the healthcare and support they need to live healthy lives.

The recommendations in Valuing People Now were informed by the Independent Inquiry into Access to Healthcare chaired by Sir Jonathan Michael, which followed Six Lives, an investigation into the deaths of six people with learning disabilities first highlighted by Mencap in their 2007 report Death by Indifference. The recommendations were also informed by and build on Moving on Well,¹⁰ published by the Government in 2008, which addresses the specific barriers faced by young people with disabilities and complex health needs as they move into adulthood. Moving on Well made a number of recommendations including:

- Person-centred transition planning should enable young people to have a strong voice and focus on their hopes, aspirations and goals.
- Young people with disabilities and complex health needs should have a health plan as part of their transition plan; this should enable them and the people who support them to become knowledgeable, confident and competent in understanding and managing their health needs.

The Pathway sets out the main actions needed at each stage of transition to maximise good health outcomes for young people as they move into adulthood.

We need to make sure that people with learning disabilities have good health, to collect statistics about health outcomes, and to monitor progress. They need:

- To be in control of the support they need for being healthy.
- To have a good health plan that can be fed into adult health services and can form the basis of their annual health check.
- To know how to keep healthy.
- To know that professionals who support them talk to each other across services.
- To know that other people understand how they communicate and how to communicate with them.

Making it Happen

School year 9

Transition planning is much more effective and meaningful for young people and their families if it is holistic and connections are made between health, employment, housing and community participation. Many young people involved with Getting a Life have said they are likely to be healthier

¹⁰Transition: Moving on Well, Department of Health, 2008

and happier if they have friends, good social lives and a job. The positive impact of employment on health is highlighted in a recent research report.¹¹

When young people start planning for the future, they need to know what the changes to their health provision will be over the coming four years. Most young people with learning disabilities will have been part of a local child development centre, where they are seen by a number of health professionals. Many are also seen by at least one hospital consultant, some by a Children's and Adolescent Mental Health service, and others by a children's hospice or similar community service. These specialist children's services discharge young people at varying ages, and it is important for young people and their families to know when they will be discharged, and to which service. They also need to know how adult health services work. If a young person has equipment and/or appliances, they need to know whether there will be a change of provider or whether they can keep their equipment.

It is also important that the young person and their family know who will support them to develop their health plan. Will this be the school nurse, a community nurse or a therapist? Will it be developed as part of the curriculum or will the circle of support begin it? The essential ingredients of the health plan are that all the young person's health needs are brought together in one accessible document, and that this enables mainstream health services to get to know the young person and their health needs. Most young people will have a much closer relationship with their GPs as they move into adulthood. It is important for children's specialist health services to work with GPs and other mainstream health services. The health plan needs to contain information about who supports the young person now and who will do so as they move into adulthood.

Strategically, it is important to give young people and their families good accessible information, and for services to work together across disciplines and across children's and adult services. There needs to be a clear understanding of who will attend transition planning meetings, who will support young people to develop their health plans, and how all staff working with this group of young people will be supported to implement local protocols.

School year 10

The health plan needs to be reviewed and further developed. By now, the plan should have brought together information from all services that know the young person, and all the young person's health needs should be set out. It is advisable to share the plan with the GP at this point, as the young person may soon be discharged by some of their specialist services.

Some young people need a communication passport setting out how they communicate and what other people need to know in order to be able to communicate with them. This will avoid false assumptions and the failure to recognise the young person's abilities and aspirations.

Young people and their families need to know about personal budgets and whether the local area is giving personal health budgets to people with complex health needs or lifelong conditions and to those eligible for continuing health care funding.

¹¹The role of supported employment in promoting positive health behaviour in people with learning disabilities at work, Vigna, Beyer and Kerr, Welsh Centre for Learning Disabilities, Cardiff University, 2011

School year 11

By year 11, the health plan should be clear about when the young person will be discharged from services, and about who will be taking over responsibility for their health care. The young person and their family should also have good accessible information about how to keep healthy and how to manage their health needs.

The local system needs to have protocols that set out clearly how specialist children's health services liaise with mainstream and specialist adult health services, both strategically and with respect to the individual. It is particularly important that GPs are closely linked into children's specialist health services and are aware of the young people they will become responsible for, their healthcare needs and how these can be met.

It is critical that the local health structures (e.g. GP consortia) gather information about young people's health needs from their person-centred transition and health plans, so that these can inform strategic planning and commissioning. This will involve staff development, particularly around person-centred planning.

The health plan is regularly reviewed and updated, so that the young person can share it with the people who support them.

Learning Disability Partnership Boards should make sure that their work around the health of adults with learning disabilities is closely linked to the healthcare needs of local children and young people, and that the services work well together across the age range.

Feedback and ideas from Valuing People Now transition workshops on health

General points

- We need to stress the importance of health checks and connecting young people with GPs and ordinary NHS health systems.
- Person-centred approaches to health planning with young people moving from children's to adult health services are critically important.
- Young people and families need to know about personal health budgets and the possibilities these present for those with associated complex health needs.
- Gaps in the current health care system need to be evidenced e.g. postural care, Fetal Alcohol Spectrum Disorder.

Challenges

- Person-centred plans should include important aspects of health planning but still, lots of young people don't have a person-centred plan and the people who support them don't know about planning tools or how to do the planning.

- Only a minority of young people with learning disabilities have Health Action Plans.
- Young people with learning disabilities are not often known by their GPs and wider primary health care team because they have been supported throughout childhood by 'specialist' child health services. It is very important that GPs know disabled children and their families.
- Planning and commissioning of health care services for young people with learning disabilities in transition are often weak because they are unsupported by evidence of outcomes and underpinning data. The key to good planning is to have robust data. Some areas have established a register.
- Across health, transition and education providers there can be low expectations of people with learning disabilities and myths about capabilities and opportunities. As a result, we do not always put enough emphasis on good health supports to live the fullest life.
- Health care professionals can lack knowledge and training about learning disabilities and there is evidence of discrimination across all health care provision.
- Most young people do not receive annual health checks with their GP because they are supported outside ordinary health care services. This leads to systemic problems in the NHS, including poor data collection, poor planning and missed health care needs within primary health care systems.
- There are real geographical differences in the range and quality of health care supports available to children and young people. Often this is based on historical commissioning rather than evidence and outcomes.
- The advice some young people and their families receive about health is often poor, uncoordinated and sometimes wrong.

Opportunities

- Raise expectations about good health among young people, families, medics and other professionals. Using this as an opportunity to develop local champions and best practice.
- Provide young people and their families with good information and empowering support. Ensure that they are at the heart of person-centred planning for health.
- Ensure that all young people develop a person-centred plan in which they and their family are fully engaged.
- Health plans need to carefully balance what is 'important for' young people's health with what is 'important to' the young person. Health professionals need to be centrally involved.

- Person-centred Transition Planning needs to be in place by year 9, and to have senior level and cross agency sign up. This needs to include a commitment to monitor the outcomes of plans and learn from them.
- We need to ensure that all young people with learning disabilities who need them have effective Health Checks and Health Action Plans with their GPs. These should be holistic with a focus on both health and wellbeing and engage all the relevant health professionals including specialist health care support and paediatricians.
- At a senior level we need to be checking on the availability and quality monitoring of health planning and ensure that any plans are actioned.
- Raise knowledge about personal health budgets among young people, their families and health professionals and promote the best use of them. Young people and families should meet and spend time with positive role models i.e. young people and their families who have personal health budgets.
- Strengthen the knowledge and confidence of GPs. This may include having dedicated nurse practitioners to help with the implementation of health checks and planning or providing information about young people in their area and emerging practice.
- Develop local strategies that engage all the right people in health planning and support. This may include school nurses, allied health professionals and sexual health specialists.
- Strategically, identify areas of current and emerging greatest need or gaps in provision and develop local action plans. Examples could include: postural care, epilepsy support, dysphagia services, identification and prevention of Fetal Alcohol Spectrum Disorder, pain and distress recognition in young people who don't communicate in traditional ways, personal health budgets supporting young people with complex or continuing care needs.

Chris

Chris Kirk- Health Information

My friends say I'm a comedian

My health history

- I have a partial subluxation of my atlas. My neurosurgeon said that this was stable and I haven't had any surgery for this. I am used to having CT scans and MRI scans because of this.
- In 2009 I first got Sydenham's chorea. I lost the ability to control my limbs and took I have penicillin daily to help this re-occurring.
- I have unexplained vertigo episodes. When this happens I need antibiotics quickly.

What's Important to Me

- I love films and watching the T.V
- I also love playing on games consoles- Nintendo ds, Wii, Ps3, X-box. I'm not fussy!
- I read a lot at home and play with Lego- It's a bit difficult with Sydenham's. I'm happy to listen to a talking book instead but leave the Lego for another time please!
- I adore food! Sunday roast type meals are the best ever in the world.
- I have lots of friends. I like to be with people of my own age and I like to make people laugh.

Great support while I'm in hospital

- Please talk to me when you are discussing my health. I get really upset if you don't include me in discussions about ME!
- I will try really hard to be independent, sometimes I will not let staff know that I can't practically do something and this may mean I will get into difficulty (such as carrying lunch tray) Please support me as much as you can to feel independent.
- I know that I will need help and support with personal care but I get really embarrassed about this. Please try and find ways to help me but maintain my dignity.
- If I need a wheel chair please make sure that it is self propelling. It will amaze you that I will be able to manage- but hate being pushed around.
- Please remind my mum that she can have some time away from me – but remind me I will need her to be back for night time. I will need her then!

Important decisions in my life	How I must be involved	Who makes the final decision
Having bloods taken	Talk to me! • I will remind you to use EMLA cream and will tell you what arm hurts the least. • I really don't mind watching what is happening too. I am not squeamish	I understand that the doctors and nurses sometimes will make decisions in my best interest. Tell me about this. I will understand if you explain it to me
Changing medication	Talk to me! Tell me what you are planning to do. I will tell you what has been tried and how this has made me feel in the past	I understand that the doctors and nurses will make decisions in my best interest.

Chris, who has Sydenham's chorea, has created a health one-page profile to use when he goes into hospital. The one-page profile summarises all the information that people in the hospital will need to know about Chris and who he is as a person.

The profile includes what people like and admire about Chris, for example, "he's a comedian!" It sets out what is important to him, including playing with his Nintendo, listening to talking books, eating Sunday dinners and being around other young people his age.

The one-page profile is useful for the people who will be supporting Chris and gives some ideas about what could help keep him busy and more relaxed when he is in hospital. It provides a summary of his health history, as well as what great support looks like when in hospital: for example using a self-propelling wheelchair rather than being pushed around, and having his mum staying with him at night.

Chris also has a Decision Making Agreement to highlight how he wants to be involved in decisions about his health. For example, he understands that doctors and nurses need to make some decision in his best interests but the agreement makes it clear that it is important that they talk to him and explain what they are planning to do.

Mitchell's Story

Mitchell is 17 and has complex needs. In 2001, after a medical crisis, Mitchell was discharged from hospital after a with a support package delivered by a team of healthcare assistants and nurses, and mainly funded (92%) by the PCT.



Although the support provided enabled Mitchell to remain at home with his family, the family had little control over the choice of carers and how the care was provided, and Mitchell's parents said they "felt frustrated and disempowered by an inflexible and bureaucratic service informed by the same policies and procedures as the hospital. The support Mitchell received was overly clinical; he was "in hospital, at home".

Despite anxieties about rocking the boat, the family achieved change by meeting with the people who had the power to make decisions, and becoming active in the decision-making process to take control of Mitchell's budget for care and support.

Since 2007, Mitchell has had a personal health budget. This has been achieved by using a local community interest company to hold the budget whilst the family manage the package on a day-to-day basis. He has a person-centred plan, and his staff are chosen for their personal qualities and attitude to supporting Mitchell and responding to his changing needs. Mitchell hasn't had a hospital admission since 2007, and his support team have enabled him to access education – they have been going with him to school for the last few years and now he is going to college, his team will go with him.

Mitchell's mum says,
"After many years of frustration, we are back in the driving seat. It took a huge leap of faith to get where we are now but we know we've made the right choice. Mitchell is enjoying life and is clearly more settled."

DEVELOPING FRIENDS, RELATIONSHIPS & COMMUNITY



YEAR 9

Person-centred transition plan

Set up a Circle of Friends: include best friend & other people from the neighbourhood or school

Support me to keep and develop friendships
Include family support

Take part in extended school & out of school activities

Take part in the same things as other young people
Go out with friends

YEAR 10

Person-centred transition plan + support plan

What is important to me about friends and having a social life now? In the future? Is the Circle meeting?

Use Direct Payments/ Personal Budgets

Am I going out often enough?
Am I part of my community?
(Use Inclusion Web)

YEAR 11

Person-centred transition plan + support plan

Do a PATH with your Circle of Friends
Find P.A.s
Have a support group?
Connect Circle of Friends with Circle of Support

How do we make sure friendships are maintained after school ends?
How best to stay in touch?

Move on to new things with friends

CURRICULUM:

Personalised to you so you get the learning you need for your life
How will your Year 10 options help you work towards your hopes & dreams?

THINGS THAT NEED TO BE IN PLACE & QUESTIONS TO ANSWER (STRATEGY):

Do youth parliaments/councils include young people with learning disabilities?

What reasonable adjustments do the youth service in order to include young people with learning disabilities? Are extended/after school activities inclusive? Are special/mainstream schools working together to provide inclusion?

How does the local system support Circles of Friends/Support & peer mentoring?

POST 16

I have some close friends
I know lots of people
I am part of a social group

I know how to stay in touch with people
People stay in touch with me

I meet friends regularly
Direct Payments/ Personal Budgets support this

I get out and have a good time!
My PA helps me use public transport
I travel with friends or on my own
or my P.A. can drive my mobility car
could I learn to drive?

BUS STOP
NIGHTCLUB

How does the local system develop an ethos that enables welcoming, accessible, inclusive environments & the development of positive social relationships? Do anti-bullying policies include specific behaviour that indicates positive attitudes to learning disabled young people? How are friendships monitored? Do they go out?
Tools: Community Mapping / Capacity Building / Inclusion Web

4. Developing friends, relationships and community Pathway

When Valuing People was published in 2001, young people said during consultation that they want to be treated like their sisters and brothers. This has been reinforced by the young people involved in Getting a Life, who have said that employment, independent living and housing are very important, but having friends and good social lives is at the top of the list.

Valuing People Now says that people with learning disabilities have the right to choose to have relationships, to marry and to become parents: “They also have the right to be included in community spaces and social groups. Often people are lonely and the evidence is that many people with learning disabilities have few relationships. They are often excluded from the kinds of places where other people form and maintain relationships such as work, college, clubs, places of worship, leisure centres. They also often find it difficult to use local services such as sports centres, libraries, cinemas, restaurants and shopping centres, because of physical inaccessibility, a lack of accessible information and because they face unwelcoming attitudes”.

The Pathway identifies the following outcomes for young people leaving school:

- I have some close friends.
- I know lots of people.
- I am part of a social group.
- I know how to stay in touch with people.
- People stay in touch with me.
- I meet my friends regularly.
- Direct payments/personal budget support my social life.
- I get out and have a good time; my PA helps me use public transport, I travel on my own or with friends, my PA can drive my mobility car, could I learn to drive?

Most people develop friends when they are young, usually with people who live close to them or who they go to school with. We often have lifelong relationships with a small number of people we met when we were young. It is important therefore that young people with learning disabilities are supported to follow a pathway into adulthood similar to that of other young people. They face a number of barriers. It is important that these are understood, and that strategies are put in place both at the individual and organisational level to overcome them.

The Developing Friends, Relationships and Community Pathway has been produced to support local systems, young people and their families to tackle barriers. It sets out some suggestions and ideas about what has worked for many young people over the years. Supporting young people with learning disabilities to be part of their communities and to be citizens should be something that everybody has a part in. It may not be in anybody’s job description, but we need to remember that it is the most important thing for many young people.

Making it Happen School year 9

It is important to include friends, relationships and community as part of person-centred transition plan. It is at this age that most young people start to develop independent lives through their relationships with friends at school and in their communities. Often this does not happen for young people with learning disabilities, making it necessary to support them to do this. The year 9 transition review meeting should explore what is important to the young person. Families often express sadness that the son or daughter is or might become socially isolated, and it is valuable to enable them to express these views at the meeting. One of the most effective ways of supporting young people is to develop a Circle of Friends.¹² This can happen at any age and in many ways the earlier the better. But at this age it is vital. A Circle of Friends can include classmates, young people who live in the neighbourhood or young people in neighbouring schools.

Local strategy and commissioning should be informed by young people’s person-centred transition plans. In order to check whether every opportunity is available for young people with learning disabilities to have friends, good social lives and be part of their communities, the following questions will help:

- Are extended school, after-school and summer activities inclusive of young people with learning disabilities, and is support available to make sure that they can participate?
- Are young people with learning disabilities taking part in all local activities alongside non-disabled ones?
- Are they going out with friends?
- Are they fully supported in the youth service?
- Are schools supported to develop Circles of Friends?
- Are young people with learning disabilities properly represented on the local youth parliament or council?

Young people and their families need good accessible information about how they can be supported to take part in sports, arts, faith and youth activities. If the young person has a direct payment or personal budget, it is important that they think about how this could be used to see friends and go out with them. Actions need to be set at the review meeting, so that the young person and their family know who will be making sure that things happen.

¹²*Creating Circles of Friends, Newton and Wilson, Inclusive Solutions, 2008*

School year 10

The plan will be reviewed, including any actions that were set around friends and community participation. Again, the young person should be enabled to express what is important to them now and for the future, and what is working and not working in their life in terms of friends, relationships and community. One of the useful tools for ensuring that people are developing strong social networks is the Inclusion Web.¹³ This helps to identify where more effort is needed to ensure that people are active citizens.

Young people need to be supported through the curriculum to develop some of the skills to help them make and maintain friends, relationships and community participation. The young people in Getting a Life have told us they want to learn how to use telephones, social networking sites, email, to use money and to travel independently. For many young people, especially in rural areas, not being able to travel is cited as the biggest barrier to getting out and about.

Many young people have found that creating a PATH¹⁴ for their social lives is really helpful.

School year 11

It is important to check that a number of things are in place. If the young person has a circle of friends, is it meeting and are new people joining as others move on? Are other people identified who know the young person, so that there is a constant source of new ideas for connecting with the community?

Ideally, the young person will be informed about their indicative personal budget so that they can develop their support plan, taking account of the social life they would like and the things they would like to do. Their circle of support should be helping them to think about other support available in the community or from among people in the circle.

If the young person is leaving school at the end of the year, thought needs to be given to how they will maintain their friendships and how they will meet up with friends. Some people who receive a motability car recruit a PA who can drive, so that they can visit friends and get out and about. Other young people want to learn to travel independently, and it is important that they are supported to do this. Some young people have the aspiration to learn to drive, and this needs to be explored.

Again, the school curriculum offers many opportunities to help young people develop the skills they need as they move into adulthood. By year 11 it is important that they have had opportunities to learn about sex and sexual health and about making adult relationships.

All the ideas and suggestions above continue to be relevant as young people move into adulthood and beyond. Some additional questions for local services and organisations to consider are:

- How does the local system ensure that it provides welcoming, accessible, inclusive environments and the development of positive social relationships?

¹³*Inclusion Web, National Development Team for Inclusion, 2010*

¹⁴*People, plans and possibilities: exploring person-centred planning, Sanderson et al, Edinburgh: Scottish Human Services Trust, 2002*

- Are anti-bullying policies explicit about developing positive attitudes to learning disabled young people?
- How are friendships and social relationships supported?
- Are we thinking about building the capacity of the local community to include people with learning disabilities?
- Are we mapping the local community and using the inclusion web or similar?

Feedback and ideas from Valuing People Now transition workshops on friends, relationships and community

General points

- Everyone should have a place in the community. Sometimes it takes real creativity to make this happen.
- Services need to work to support community building.
- Young people value friendships and we can help them build more.

Challenges

- Many young people with learning disabilities simply do not have the opportunity to spend time with other young people in their communities. This is worse when we separate young people into schools away from their neighbours. When people are isolated they don't build the skills needed to build new friendships.
- Among some families, schools and other services we have low expectations of young people making friends and what they will bring to friendships.
- When we commission and plan services for young people we often don't think about whether they will really help include them in their community or, in fact, further isolate them.
- We can be fearful of the community and the risks. This makes us over protective and averse to taking 'normal' risks.
- Some community members and organisations discriminate against young people with learning disabilities.
- People living in rural or socially isolated communities are even more at risk of exclusion.
- When young people begin to make friends, we often don't offer the support needed to maintain those friendships.

Opportunities

- We need to build aspirations of friendship among young people, their families, educators and services. Aspirations of friendships that are safe, ordinary, valued and valuing.

- Young people have to be in the same place as other young people from their community, at the same time and doing what they do. This may be youth clubs, Saturday jobs, play grounds or simply 'hanging out'.
- Building friendships and community needs to be a central part of person-centred plans. Planning also needs to have conversations, that include the young person, about risk – what we can put in place to minimise risk and what are the risks that all young people face.
- Start early. This may mean thinking about how we help very young people to connect with their neighbours and community and understanding how decisions we make about separate schools and services separate young people.
- Invest time in understanding how young people's social networks work and then ensure that our services support these.
- Identify and address those things that place additional barriers in the path of young people with learning disabilities like inaccessible or no public transport, a lack of personal care spaces in youth clubs and social centres.
- Ensure that strategies, service plans and services all work together, valuing friendships and community and making sure that new opportunities, such as personal budgets, are community focused.

Elsa's story

I can clearly remember the importance of friendship in my own teenage years. It is almost unbearable to think about living those years without friends, yet that is the reality for many young people with learning disabilities today. Thinking about friendship in the transition review is 14 years too late– it should have started when the young person was a baby.

From the very beginning I had a vision of my daughter Elsa (now 14), having an ordinary life, school, job, friends, relationship, a home of her own. I suspect 'mother in denial' is written all over the early notes about Elsa, who has Downs syndrome. I had this strength of conviction because I had grown up with a brother and cousins who have learning disabilities and had seen them as other children when adults saw only difference.

When your child is born or diagnosed, you are encouraged to attend special groups, and to send your child to special schools away from the community they live in. Then, as they approach adulthood, and you have lost the community connections you once had, you are asked to think about how your son or daughter can join that community.

Creating friendships for my daughter has been a deliberate and sometimes painful process. Women at the parent and baby groups



asked me why I did not test and terminate the pregnancy, or ignored me, embarrassed. It is not surprising that many parents retreat into the safety of 'special' groups where they do not have to justify the existence of their children. Until everyday prejudice is tackled, families will be forced away from the places that enable life-long friendships between mothers and children to develop.

Elsa went to mainstream nursery, where the small children were completely accepting of differences and only noticed them when adults drew attention to them. Each child had the space to develop his or her own relationships and interests.

Our local mainstream primary school was welcoming but was focused on the national curriculum not friendship and play. Reception class was easy, with big parties and parents automatically accompanying their children on play dates. By year 1, special friendships were forming and parents and older children I knew at the school began to report that Elsa was watching rather than joining in at playtime. It took me over a term to persuade the school that she was not too young for a circle of friends, but it made an enormous difference when it was finally set up.

Supporting friendships outside of school seemed to involve being some kind of "supermum". We baked and created all sorts of things – differentiating play activities became second nature. I made sure that children and parents knew me, and in the whole seven years of primary school, only one mum repeatedly turned down invitations.

The move to secondary school made friendships harder to maintain. Our local secondary school was not welcoming and although the mainstream school Elsa goes to is quite close, it does not have good public transport links and has different leisure activities. Without the school gate opportunities to meet other parents, it has been hard to support friendships to develop outside of school.

Elsa does however have good relationships within school, which were supported for the first two years by a circle of friends. We have just started using direct payments to pay a sixth form girl to co-ordinate some social activities and offer some low-key support to Elsa. It is clear from the girls' online communications that they would like to go out to town sometimes but they need a bit of help to organise dates and times. Elsa's best friend is the girl next door who comes on holiday with us, has sleepovers and they have been going to the cinema together for a few years now.

I realised about two years ago that my focus on inclusion had meant that Elsa had not developed close friendships with other disabled children, and she is now slowly developing friendships with a few other young people with learning disabilities.

Being Elsa's social secretary is a time consuming task and it does not always get the priority it needs to be successful. Nevertheless, seeing the girls giggling on the sofa as they watch the latest teenage heartthrob makes it all worthwhile.

Matthew

When Matthew went off to residential college he went with his best friend (from 12 year old) and there were two friends there from the year above them at school. This helped with the placement and the decision to go to that college. Unfortunately the college did not encourage the friendship to continue and later found out this was due to their funds.

Matthew was placed in accommodation with 4 other students and liked all but 1 person. The 5 were kept together for all of the leisure time and all spent weekend doing the same activities, no funds for freedom of choice.

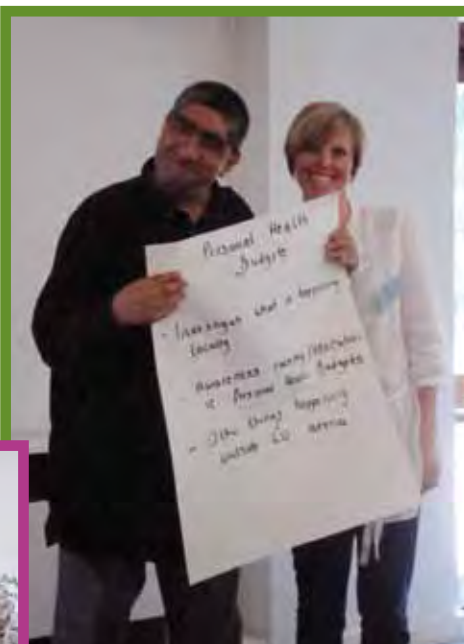
During the holidays when he came back into borough he always reconnected with his friends here, which we encouraged. We are lucky as our home town is small and easily accessed with good facilities which Matthew is comfortable with as there have been little changes on the high street whilst he was away and therefore he's familiar with the area. He was more than happy to meet up with school friends in our town whilst on Summer holiday and when he returned for good. He contacted his friends and arranged to meet up for coffee or for a meal.



Since Matthew moved into his own home his friendship base has widened considerably. His care providers are first class and are very knowledgeable of work in our area around issues for our youngsters. Within a few weeks, Matthew and housemate had a great social life and were included in lots more activities than they were used to, being out and about most nights. They found out which settings they felt most comfortable with and decided the rest were not for them.

Both boys are joining a "Friendship project" soon which is looking at expanding their circle, how to keep in contact and how to recontact those people who they have lost on the way. Also, as Matthew is working in DWP in his local area, he has met all new people at his office and classroom based setting and hopes to socialise with them in the near future. The future is looking bright and full of hope. Matthew had 250+ people at his 21st party, all of whom he knew and by his 22nd birthday he will know and be in touch with lots more. Matthew is on Facebook to keep in touch with his college friends and keep them up to speed with his ever changing and exciting life!

Valuing People Now Transition workshops



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