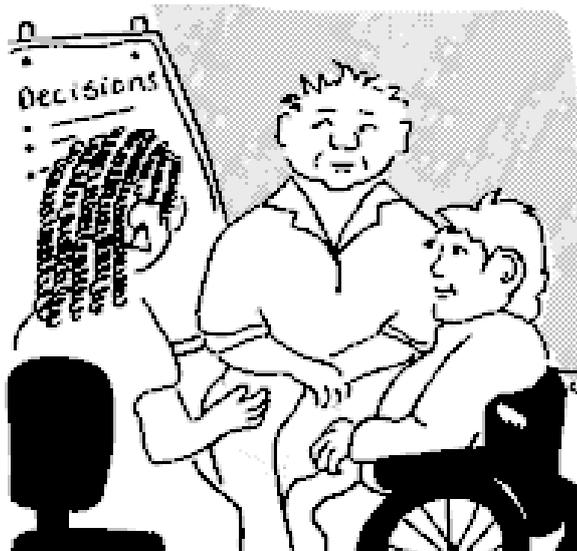


Sharing Expectations

for young Londoners with learning disabilities



This paper is one of a series of resources produced for the London JIP Transition Project . Written by Alicia Wood & Linnet Macintyre, Housing & Support Alliance

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1. Introduction

This paper outlines how young people with learning disabilities, families, professionals and services can together define their shared expectations for the future and share a commitment to equal lives for young people with learning disabilities. The focus is on how this can be achieved within the context of the current economic climate and threats to budgets for care and support.

We outline how young people can achieve good lives in fair and cost effective ways by thinking differently about support and communities and working together so that better value is achieved with the money and resources that we have. A major factor in sharing expectations is developing more open and honest relationships between commissioners, providers, young people and families and therefore more honest conversations about money and resources so that we can share decision making about how best to use these resources.

This report draws on a series of discussions with young people, families and professionals from across London and summarises their views of how we can adopt positive approaches to sharing expectations for good outcomes in their lives.

2. Background

The Valuing People White Paper from 2001 and Valuing People Now 2009 have done much to raise our aspirations for the lives of young people with learning disabilities. Our everyday language is of person centredness, choice, rights and control and on the whole, the intentions of professionals and organisations also reflect these aspirations for young people.

We have seen a shift in service provision and attitude over the last 10 years which is to be welcomed. It should be the case, and likely is, that if we asked most young people with learning disabilities, families and professionals in London in 2012 what they want happening in the lives of young people, they will all say similar things such as;

- A good place to live
- Help to get a job, a decent education, meaningful activity and lead a valued life within communities
- Good, respectful support
- To be safe and well

- To have good friends and relationships

Despite the good beliefs and intentions of most people involved in supporting young people with learning disabilities, the reality for many young people with learning disabilities is that these basic aspirations are not always being met even though they are mostly basic rights in today's society.

This is not just a reflection of reduced budgets. This experience has been a reality for young people with learning disabilities and families during periods of relative wealth in NHS and Local Authority commissioning budgets where a great deal of money has been spent without achieving good outcomes. There is no doubt that austerity is having an impact, however, there are also a range of systemic, organisational and cultural factors that impact on whether or not a young person with a learning disability will get what they need to live equal lives.

Despite the economic climate, there are examples of how commissioners, service providers, young people with learning disabilities and families are doing things that are enabling good lives and are finding new and cost effective ways to enable young people to live ordinary lives with their families and/or communities. London is a diverse, unique and remarkable city that is a world leader in business, education, the arts and culture. London also has the potential to lead in enabling equal lives for young people with learning disabilities and use the richness of its resources and people to achieve this.

3. Developing relationships between young people, families and professionals that are based on honesty, openness and trust

Most professionals want the best for young people with learning disabilities and most young people and families have reasonable expectations for the support and funding they get to lead equal lives.

We are however, caught up in a relationship with each other that is far from open, honest and trustful and this is at the root of so many of the unnecessary battles and flawed decision making that take place between families and professionals.

Now more than ever, professionals are encouraged to reduce public spending and to ration resources yet there is often confusion over the criteria for rationing, the rights of the individual, and what is a fair way to spend money on any individual. Within this context, professionals can end up being 'protectors' of the public pot rather than enablers of equal lives and are often making decisions based on a mix of protecting budgets and a lack of knowledge about rights and the law. This is often combined with a lack of confidence or knowledge in designing cost effective solutions and brings professionals, families and young people into conflict.

Many young people and families feel they need to manipulate, cajole or create a crisis in order to get what they need without really knowing what their rights are, what is possible or how much money or resources are available. Sometimes to be told that they are asking for too much or that if they get what they need, then others will miss out. They hear the language of inclusion, person centredness and choice and control but if the reality of their lives is very different then all they believe they are hearing is hollow words and false promises.

It is unsurprising that so many decisions made by professionals and families are flawed when they are made in situations where neither party can be open, honest or trust each other.

How can we build openness, honesty and trust?

“They say a lot of things but why do they say it and not do what they promise.” A young person with learning disabilities

- **Being honest about the position we are in without taking away power and control away from young people and families**

To simply say ‘we can’t afford this’ or using other less transparent means to deny services or funding is frustrating and disempowering to young people and their families. Most families of young people with learning disabilities are at least vaguely aware that the young person has rights to care and support and will fight on that basis.

Young people and families are likely to be more committed to developing cost effective services if they have more awareness and control over how money is spent. The messages we need to be able to communicate effectively to young people and families are;

- We want young people with learning disabilities to have equal opportunities to their non-disabled peers
- There is restricted funding for care and support but we will allocate it in a fair and transparent way so that you are able to make real choices about your life.
- We want you to help us spend the money we have more effectively.
- These are your rights to support and this is our statutory duty to you...
- We will support you (or ensure you get support) to plan your life in the way you choose
- We will help you connect with other people and share services if you want to make your money go further

- We will advise you about options such as assistive technology, homeshare, community networks and live in carers if you want to look at more affordable solutions to 24 hour care
- If you are not eligible for funding or services, we will proactively work with you and other agencies to build your independence and avoid needing care services in the future so that you do not fall through the net.

“My investment in my son’s life is in the fight against the system. I would rather be investing in my son’s life in a more positive way.” A mother of a young man with learning disabilities

- **Clarity about what the law says**

Young people and families know that we do not live in a perfect world and can accept when things are not perfect if they are in control of their lives and can make the changes that are important to them. What is not acceptable to young people and families is when decisions are made about funding or services that are not fair or in some cases, unlawful.

We need an open dialogue between professionals and families about how they should expect to be treated to support equality, what adjustments should be made by law and what is the role of health, social care, education and housing in helping them to achieve equal lives.

The law is clear in some areas and less in others about the rights of young people and families in transition and the duty on public bodies to provide funding and/or services. We need to make sure that young people, families and the professionals supporting them understand their rights and have clarity around the process of getting support

If young people and families know exactly what they are entitled to in terms of services and funding, then this goes a long way to avoiding the unnecessary battles and enabling people to make real choices about their lives. In this series of resources, there is a paper that outlines these legal requirements.

- **Fair and transparent mechanisms for getting support and allocating resources**

In theory, the FACS eligibility criteria and resource allocation systems create a fair and transparent system for rationing resources but neither are perfect systems and need to be used with transparency and common sense in order to work. There have been concerns that some resource allocation systems have been used simply to reduce funding for care rather than to meet identified need. Resource allocation calculations need to be transparent and show how they meet need as highlighted in the recent case *KM v Cambridgeshire*¹.

- **We need to find ways to share difficult decisions about money with young people and families and enable them to prioritise how it is spent.**

When decisions are being made about efficiencies and service and budgets cuts, we need to be able to engage young people and families in the process of making these decisions. Using processes such as voting or collaborative decision making processes for Community Budgeting can give people real power and choice in shaping how best to use the resources we do have.

4. Developing services that keep our young people in London

- **London needs to become a hub of excellence in supporting young people with learning disabilities to remain in their communities**

London has rich cultural diversity, high student population, amazing arts including theatres, music colleges, art galleries, museums, concert halls and venues, large workforce, excellent sports facilities and an abundance of creative thinking. This coupled with significant numbers of large charitable trusts and wealthy individuals should provide a platform to create something aspirational, but not exclusive for young people with learning disabilities including those with PMLD and challenging behaviour.

As we have already examined, people choose to go to residential settings for a variety of reasons. There has to be a positive alternative to stay in London, a good enough solution will not suffice because outside London parents and young people are finding places of real excellence.

The question for London providers is how can they compete in a residential school and college market that has built up years of experience, knowledge and trust with families. Many families will make the choice to educate their children outside London at an earlier age, at the first point of transition, when children leave their primary schools and move to secondary schools. At this point families may already have reached breaking point with little available local respite, and very little truly

¹ <http://www.bailii.org/ew/cases/EWCA/Civ/2011/682.html>

specialised education. In order to stem the flow outside London at transition age families could be offered adequate respite and support from an earlier age. A larger investment at this stage may seem in the short term economically suicidal but in the longer term should reap benefits, both socially and in terms of driving the market to accommodate the particular needs of this highly complex group.

Planning enough services for young people with learning disabilities is not simply about having enough 'places' in services. This generation of young people have changing expectations for their lives and the range of services available needs to reflect an investment in a variety of services, funding mechanisms and partnerships.

- **Having less money means we need to try harder and achieve more for less**

High quality and high cost do not necessarily have a direct correlation. Some young people with learning disabilities, particularly those with more complex needs, will always require higher cost support packages. Some young people need more investment in support at an earlier stage in their lives so that they can go on to be more independent and less reliant on formal support. Other young people simply need low levels of support to sustain them in their communities. A default position for supporting young people with learning disabilities is to put in high levels of paid support in services that do not differentiate individual need. One size does not fit all and this needs to change and take account of individual need.

We need to take a preventative approach and invest in good quality, lower level services to keep people with their families and communities and not wait for crises to provide more expensive and often unnecessary levels of support.

We need to commission a range of low cost, high quality services and interventions such as assistive technology, Supported Living Networks, Homeshare schemes and Local Area Co-ordination that have proven results.

We need to enable families and communities to input their resources into supporting young people with learning disabilities.

"I would be happy to put my own money into my son's home and support but the way services are set up, I can't do this." A mother of a young man with learning disabilities

- **More cross borough work needs to happen, particularly around specialist and preventative services**

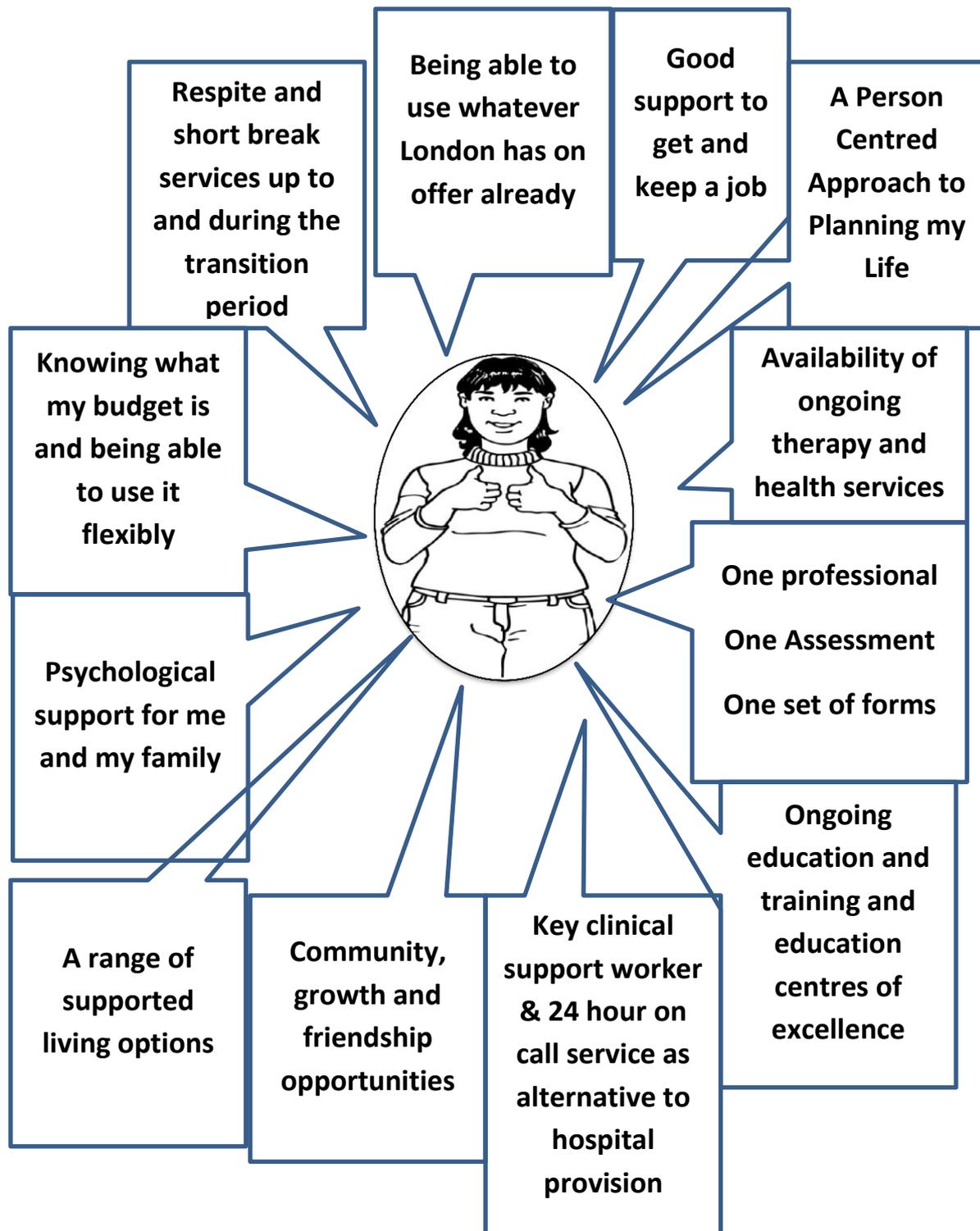
There are fewer specialist commissioners in London as social care departments merge and create efficiencies. We need to ensure that the expertise we have built over the last 10 years is not lost. Boroughs are moving to more collaborative approaches in other areas and it makes sense to explore how these collaborative approaches can enable better and more cost effective services, particularly when it

comes to delivering highly specialised services and/or innovating and working in radically different ways. Clinical Commissioning Groups will have new powers to work with other CCGS to commission services together.

- **We need to invest in leadership and innovation**

Achieving excellence and cost effectiveness requires staff with the vision, confidence, knowledge and skills to make it happen. During the initial stages of this project, we met with staff in local authorities and provider services who have achieved radical change and excellent services. What stands out consistently as success factors are the qualities of the individuals who are in leadership roles. We also visited services that have great potential and come from good ideas and values but lack the leadership to turn these ideas into reality. These are the type of services that many of the young people with learning disabilities and families describe as 'not good enough' and is likely to be one of the main reasons that so many young Londoners with learning disabilities leave their communities.

5. What does 'Good' look like for young Londoners with learning disabilities and families?



- In practice, what does 'GOOD' look like?

A GOOD scenario -Group A

Being with people you choose to spend time with

Group A have known each other since they were 11 and started attending a small dance group in their area. They are a diverse group of 4 young women all now aged between 17 and 21. To see them together it would not be immediately obvious what they have in common, but they all share a common love of music and drama. Two of the young women would be described as having profound and multiple needs, Lorna additionally has a tracheostomy and requires a gastrostomy for night feeds while Julie has very complex epilepsy, never sleeps through the night and communicates non verbally. Their friends Zeenat and Alex are both lively complex individuals who seem to thrive in helping with Lorna and Julie's care however neither could live independently as Lorna is overly trusting and Julie can sometimes find it difficult making herself understood.

Staying in their communities, near friends and families

The 4 young women had chosen to stay near their families and to stage their transition from home by using the local respite service before they made their move from home. The girls book in for the same weekends and try and make sure it is when there are good local bands playing in the pub nearby.

Being person centred and creative when planning the move

The young women are working with the same support planner to not only draw up their individual plans but to look at what resources they might pool.

The families work with a charitable landlord who buys a house to adapt and rent to them. The first thing they had identified was that they wanted their house to be accessible to all of them, nothing should be off limits to any one of them. They share 2 accessible bathrooms between them and have overhead tracking throughout. They decided to have one room available for the PA's. This doubles as an office for the extensive paperwork required and as a bedroom/ rest room for both the PA's to take short breaks during the day and for the sleeping night staff to use at night.

Additionally in place of another bathroom there is a sensory room which is equipped and funded through a specialist charitable grant.

Being in control of who supports you and how you are supported

The PA's are funded through their personal budgets and all the young women are helped to recruit and train their PA's. They pool their budgets to fund 1 team leader who will have overall responsibility for the house although each PA in addition to working 1-1 is allocated responsibility for specific tasks relating to their identified strengths. There is 1 waking night staff on duty and some contingency has been put aside to accommodate supporting nights when any of the young women choose to return to their family home.

Getting the right health care

The house has excellent links with not only the community nursing team and their local GP practice, but also with the psychology service and the excellent local neurologist. With their help the young women have drawn up excellent health and well being plans with back up from their local hospice where necessary. Additionally the young women have decided to purchase the services of a physiotherapist one morning a week and also buy in input from a therapist specialising in intensive interaction. As they all love music they have pooled their resources to set up a small music group at their local college with volunteers from the Royal College of Music.

Enjoying what their community has to offer

Two of the young women have chosen to access their local health and well being college 5 mornings a week where they attend classes in yoga, dance, drumming, drama and cooking. Additionally they are part of a new project run by IBK initiatives that access their LLDD specialist placement budget and provides them with ongoing education addressing in particular their communication and therapy needs. The other 2 continue their diploma course at the local education college 2 days a week where they are enrolled on a drama course. They are all involved in setting up a small business with their local charity shops. Additionally they have block booked the hydro pool at the local special needs school 2 afternoons a week. They have deliberately left some time unplanned so they can do lots of the things they enjoy including walks, cafes, shopping, cinema and theatre trips.

Monitoring and reviewing with a person centred approach

In addition to all their paid support two of the young women have very active family members who sit on a supportive panel that meets once a month. This panel also includes a key worker (who represents all the young women), the community nurse (who has a background in learning disabilities) and a representative from the local authority and the team leader. Any issues can be raised at this meeting and prompt action is taken.

Using volunteers

The young women are also supported by an excellent team of volunteers recruited from many of the colleges nearby, ranging from medical students, to musicians, to physio and massage therapists. They are also providing work experience to 2 young people with learning difficulties who are enrolled on a hospitality course at their college.

Being resourceful & pushing the boundaries of what ordinary services achieve

The young women are linked to another very similar setup in Cornwall and during the holidays they have agree to houseswap. Rather than being reliant on the local council for transport two of the young women have purchased vehicles using their mobility allowance and can accommodate the others or they can use public transport.

6. What does GOOD mean for commissioners & providers?

The previous scenario presents an example that is far from typical, yet it shows how 4 young women with high support needs can create an ordinary lifestyle, get the support they need and use public money and resources more effectively with better outcomes.

This scenario is based on real young women and their families that want exactly what has been described. As yet they are struggling to make this happen. The local system is geared towards placing young people with the most complex needs in specialist services away from their communities. It would have been easier to place all the young women in specialist services but their parents have persevered as they are determined to keep them living close by. The council is actively working on getting them the right housing. Equally they are taking a proactive approach to education and in a cross boundary initiative they have identified 6 young people who

have commissioned one fulltime teacher and 3 skilled PA's to support their education both at a hub and in an ongoing way in their community. Commissioners need to ask themselves how easy it would be to achieve this type of scenario where they work. What would stop it from happening and how can that be changed? This will be the key to unlocking current systems and resources and invest in local services and supports.

- **Having a clear shared vision for the lives of young people with learning disabilities and a shared set of expectations between young people, families and professionals.**

Developing a local shared vision and set of shared expectations in real terms- moving away from simply using the language of choice and inclusion towards defining what this actually looks like in the real world in 2012.

The vision needs to be shared by young people, families and professionals to have any impact. One of the common themes in conversations with families was the disparity between the promises of professionals and the reality of how young people live their lives. We need to move away from promoting social care as a magic pill towards a more honest dialogue about what social and health care can really offer and that it is only one part of young people's lives.

It is a requirement of the proposed Children's and Families Bill that each local authority develops a local offer showing the support available to disabled young people (0-25) and their families. This should facilitate a move to greater transparency and honesty about local opportunities.

- **Being upfront and transparent about what councils can and cannot provide for young people with learning disabilities and families**

Setting out an 'offer' for young Londoners with learning disabilities and their families **that includes;** (see appendix 1)

What young Londoners with learning disabilities can expect from education, health, social care, housing and help to get a job.

How councils have to help by law- what the rights are to education, social care, health care and housing.

What universal/mainstream services should be offering young people under the Equality Duty.

How the various agencies work together to make sure that young people get the help they need.

How young people and families can get information, advice, support and guidance.

How do we ensure that assessment and reviews are not duplicated by various organisations?

What are young people and their families expected to input into their care, education and support.

How will young people get support to connect with other young people and families.

Where does the council stand if the young person or family chooses services outside of London.

What the council can't do

A commitment to developing real solutions not just pathways and protocols

- **Having a good balance of local provision**

A key issue that came up over and over again when talking with young people and families in London was the lack of local desirable respite, education and support services for young people and this triggering the need for specialist residential placements. The local market needs to reflect the needs and aspirations of young people coming through the system if we are to be successful in keeping young people local. Key areas to address are;

Using demographic data and information from person centred plans to inform and manage the market.

Investing in more flexible and sustainable forms of provision that fit well with personal budgets and individual service funds such as supported living networks, homeshare and community enterprises (see case studies)

Ensuring there is investment in a range of respite and short break opportunities – particularly for those with the highest support needs- with boroughs working together to provide specialist respite facilities if necessary. A leading palliative care consultant noted that for parents with children with neurodisabilities transition is the most difficult time. The time when families come closest to buckling as they can see no future for their children and the respite and assurance given by children's hospices disappears in adult life.

Ensuring that there is a range of support to enable young people to live more independently including support that can be flexible and taper off as the young person develops more skills.

Ensuring that young people with learning disabilities can access a wide range of assistive technology to support independence, privacy and dignity.

Ensuring that there is a range of housing opportunities – both specialist and ordinary.

Working with other services to ensure that there are a range of good quality education, employment and leisure supports and opportunities that can replicate the high quality services that some of the residential colleges provide

Mechanisms to support local young people to come together and pool resources and personal budgets.

Mechanisms that help young people find flatmates to share with, meet others and have a full social life

Ensuring that mainstream services know how to support young people with learning disabilities.

Increasing educational opportunities that reflect the needs of young people with the most challenging and complex difficulties and recognising that for many these will be life long needs , particularly around therapy and communication.

Working with local PCT/CCG's to ensure a knowledgeable transition from paediatricians to a relevant specialist in adult care supported where necessary with excellent community support.

7. Maximising current opportunities

- **Health & Wellbeing Boards**

Health & Wellbeing Boards are a statutory requirement from April 2013. Their main aim is to join up local services and worked to a shared set of outcomes for people in the community. They are responsible for producing Joint strategic Needs assessments (JSNA) and Health & Wellbeing Strategies. They will give local authorities and enhanced role in the planning of local health services and has great potential to influence how services for people with learning disabilities are funded and developed.

It will be important to ensure that the voices of people with learning disabilities and families are influencing local plans both through the representation of commissioners, and just as importantly, engagement with people with learning disabilities and families directly.

London HWBs are ideally placed to address the issues around young people with learning disabilities being places out of London. There is also a good opportunity for HWBs to tackle some of the issues surrounding the disjointed provision of housing, health and social care and education and work on creating communities that welcome people with learning disabilities.

- **The Localism Act**

Understanding the Localism Act and how this is played out locally will be crucial in maximising opportunities for young people and families to use the new powers to develop, take over or improve local services.

Under the Localism Act, the government have brought in new powers for communities that may be helpful in helping get housing for people with learning disabilities.

- The 'Community right to challenge' gives local community groups, parish councils and local authority employees the right to express an interest in taking over existing council services. The local authority must consider and respond to this challenge and run a procurement exercise where the challenging organisation can bid.
- The 'Community right to buy' assets of community value. This will include the right for community groups to buy council services that come up for sale or change of ownership.
- The 'Community Right to Build' gives groups of local people the power to deliver the development that their local community wants, with minimal bureaucracy.

There is potential in all of these mechanisms to change the way services are planned and delivered. It is important for health and social care commissioners to be thinking about how they can ensure that young people with learning disabilities, families and local groups can maximise opportunities under the Localism Act.

- **Clinical Commissioning Groups (CCG)**

Under the Health and Social Care Act, CCGs will have the responsibility for commissioning healthcare services for people with learning disabilities including continuing healthcare in out of area placements. The CCGs have a duty to co-operate with relevant local authorities and participate in their Health and Wellbeing Boards. CCGs will have powers that will present opportunities for working in more effective and collaborative ways including;;

- Powers to enter into partnership arrangements (e.g. pooled budgets, lead commissioning) with local authorities, including power, in conjunction with a local authority, to be designated as a Care Trust.

- Power to enter into contracts and to make arrangements for other individuals or bodies (including voluntary organisations and public authorities) to provide services, including the power to enter into NHS contracts with other health service bodies.
- Power to act jointly with another CCG in exercising commissioning functions or for one CCG to exercise such functions on behalf of another, or for the NHS CB (if it agrees) to exercise commissioning and any related functions on behalf of a CCG.
- Power to make grants or loans to voluntary organisations which provide or arrange for the provision of similar services to those in respect of which CCGs have functions.
- Power to conduct or commission or assist the conduct of research, including by providing funding or by making the services of any person or other resources available

- **Draft Legislation for Special Educational Needs & Learning Disabilities**

The draft provisions set out measures that will offer new statutory protections to young people over 16 and that will streamline the system to improve transition. Key proposals are;

- The introduction of the new single Education, Health and Care Plan as a better way of supporting children, young people and families than the current statement and learning difficulty assessment.
- Parents and young people will be entitled to the option of a personal budget in order to extend their choice and control over their support. (LB Bexley & LB Bromley have taken part in the SEND pathfinder to test the above proposals – see case study <http://www.preparingforadulthood.org.uk/news/news-2012/draft-sen-and-disability-provisions-published-as-part-of-the-children-and-families-bill>)
- Academies, Free Schools and Further Education colleges will have the same duties as maintained schools to safeguard the education of children and young people with SEN.
- To introduce a new requirement on all areas to provide transparent information to parents on the support available for all disabled children and young people and those with SEN through a local offer.
- Underpinning all the draft provisions is the new duty on joint commissioning which will require local authorities and health bodies to take joint responsibility for providing services.

The proposals for young people over 16 to have an integrated assessment and a single Education, Health and Care Plan presents an opportunity to align these processes in adult services. The proposals are currently going through pre-legislative scrutiny.

- **Caring for our Future White Paper & Draft Care & Support Bill**

The Care and Support Bill proposes to clarify the complex legal framework and give more flexibility, focussing on the needs of local people.

The purpose of care and support has now been defined as needing to promote peoples wellbeing and will have more of a focus on preventative work.

By April 2015 there will be a National Minimum Eligibility threshold for care and support in England and this will improve mobility.

By 2013 everyone needing state funded care should be offered a personal budget.

Each council needs to develop a market position statement that includes information about local services, health services, housing and leisure services as well as future commissioning plans.

Councils will have a legal responsibility to promote a range of high quality services that meet the needs of the community.

8. Rethinking commissioning & provision of services- radically different approaches for radically different times

Most of the changes proposed in the previous section will have a significant impact on the way services are commissioned and there are very real opportunities to radically rethink what can be done to achieve good outcomes. There is both the opportunity to address some on-going problems and also to think about how to be innovative and do things differently particularly;

- Reducing the duplication of assessment and contact when more than one service is involved in a young person's life.
- Identifying cross borough initiatives and future opportunities to work across boroughs Explore new approaches to pooling local funding, such as Total Place and Community Budget pilots, that could be a good model for pulling together and making sense of agencies and budgets that surround young people with learning disabilities

- Maximising social capital and commissioning for inclusion and good outcomes in the community.
- Exploring new ways to fund services for young people with learning disabilities including methods that make payments by results.

- **Developing leadership**

London has many great people leading on making lives better for young Londoners with learning disabilities. Much is achieved despite the current financial difficulties and the array of apparently conflicting systems that surround young people with learning disabilities. But for a city that competes with all the great cities of the world, it is not enough. There are still not enough excellent services, there are not enough opportunities for young people and families to grow up as equals to their non-disabled peers. There is a fundamental need for more and better people to lead the changes, innovate and do things differently. The North West region has invested in leadership through years of regional development in a way that London hasn't. It shows. In each of our successful case studies there is at least one dynamic and committed person leading the organisation or the process of change.

The London JIP needs to consider what can be done to develop, support and mentor leaders. Otherwise there is a risk that whatever opportunities are presented, there simply won't be the leaders with the skills and ability to follow through.

Appendix 1 The 'Offer' from local authorities to young people and families

This section outlines key considerations which should be addressed in an offer from councils to young people with learning disabilities and their families. It should presents a clear statement and intention of what the council can offer young people and their families whilst giving young people and families choice and control over what happens in their lives.

1. A clear statement of values & what the council wants young people with learning disabilities to achieve

- A clear statement should be about the council's vision for young people with learning disabilities. It needs to be grounded in practical terms and language that makes sense to everyone. Not just talking about the concepts of 'co-production' or 'personalisation' but , outcomes and future opportunities for young people across education, health, housing, support & employment .
- All staff, at different levels and in different departments should be involved in signing up to the vision in order to get much better buy in and understanding of what the council as a whole is trying to achieve.

2. Rights to care, housing and education

- It should include clarity about the law and rights to care, housing and education and health and the changes that occur when reaching adulthood.
- There should be clear accessible and written information on rights and the law, making clear what expectations young people and families should have for funding and services.
- There should be further clarity where the council chooses to provide funding and services that is in addition to their statutory duty

3. Sharing power & decision making with families

The roles and responsibilities of the young person, families and professionals should be clearly identified throughout the planning and decision making process.

Thought should be given to the following questions:

- Is power shared equally? Is there provision if the young person is not able to articulate their needs or wants? Is there a clear and fair appeals process if the

young person, family and/or professional do not agree with each other and is this supported by advocacy?

- Can the young person and family make a decision which a professional does not agree with and still be supported to achieve what they want?
- How is a step by step approach to planning supported? - if the young person and family only want a little help now, how do you assure them that you will continue to listen and act in the future?
- What is the plan for 'just enough support', where people have neither too much nor too little (both of which can be equally bad) <http://www.paradigm-uk.org/Resources/t/a/j/All%20Together%20NOW.pdf>
- Are young people and their families expected to input into their own care, education and support?

4. Assessment & Review

- Are there clear pathways for young people and families into social and health care, further education, housing and employment support?
- Are these pathways accessible and publicised to young people and families?
- Have you minimised duplication and simplified the assessment process, particularly between health, housing, social services and education?
- Does the assessment process put the young person and family in control and leading on determining their needs?
- Identify the circumstances where a professional may need to take control of the assessment away from the young person and family, or to arbitrate where the young person's views may differ from that of their families?
- Is there clarity around follow up reviews
- Have you considered a key working role and how this will be determined for complex plans?

5. Providing Funding & Services

- Have you calculated funding or offered services in a fair and transparent way?
- Many of the young people with the most complex needs will be eligible for Continuing Health Care. Are you offering Personal Health Budgets to cover all health and social care needs?
- How do Personal Budgets work and how do you support people to use a variety of mechanisms to manage them, DP's, ISF's, Independent Living Trusts, Managed Budgets , third party agencies etc?
- Is there honesty and transparency about what is and isn't affordable, meeting legal requirements and identifying where current local services /funding do not meet the aspirations of local young people. Have you addressed how you will address any gaps in local service provision?
- Is there clarity and honesty in relation to your position on young people with learning disabilities using services and residential colleges outside London. If you want to reduce their USE have you fully explained your reasons and identified as good or improved local choice? Do you have a policy on people using services across borough boundaries?
- Has there been local consultation if local funding is being prioritised for use in other ways that reduces or restricts budgets to meet aspirations for young people with learning disabilities- this will give local young people and families the transparency they need to take part in local democracy.
- Are you supporting young people and families to pool budgets and get more for their money? Or supporting young people and families to take the lead in developing local services and social enterprise?
- How do you work with young people and families to plan local services that are provided or commissioned by the council?
- Do funding models allow for the young person or family to use their own resources, trust funds or housing?

- How will the council seek other funding streams or support families/organisations to bring more funding in to the borough for young people with learning disabilities?

6. How do you support needs that do not come under social care eligibility criteria?

- Will you fund advocacy for young people with learning disabilities and who are eligible to use advocacy services and will you ensure there are appropriate advocacy services
- How will you work with other agencies to prevent young people from going into crises?
- How will you work with other agencies and universal services to ensure that they are meeting their duty to provide services your young people?
- How do you work within financial realities, to develop additional and alternative support through communities, families, technology and other solutions?

7. Developing high quality local services

- Is there a commitment to developing aspirational local services in order to avoid placing young people away from their communities?
- Is there a commitment to move away from short term pragmatism to long term solutions
- Is there a commitment to working with families to develop solutions in their own community that offer respite when it is needed?
- How do you work within financial realities, to develop additional and alternative support through communities, families, technology and other solutions?
- How do you work alongside other councils/areas to develop specialist services?

- How do you work with providers and strive to achieve excellent services, and involve young people and their families in this process?
- How do you constantly monitor quality?
- Have you committed to dealing with underperforming services?