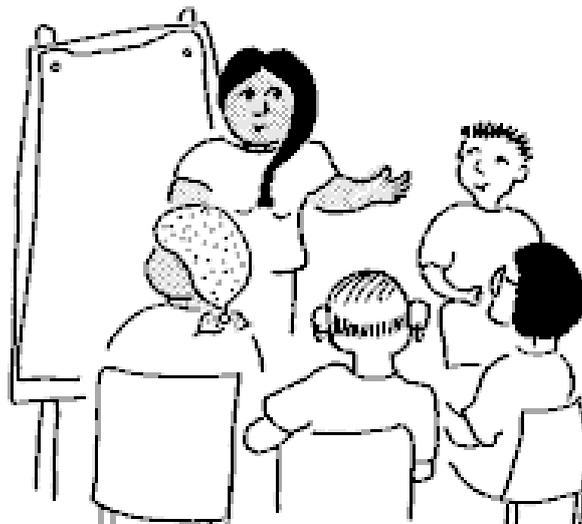


Sharing Expectations

discussion summary



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

1. Main themes of discussions

The research for the Sharing Expectations project involved consultations with a range of young Londoners with learning disabilities, families, commissioners and service providers about their experiences and what they see as the barriers to young people with learning disabilities leading good lives in their communities. We also asked young people, families and professionals about how we could ensure that young people with learning disabilities could expect a future where they had the same opportunities as everyone else despite the economic climate.

It is clear that everybody has a different experience, even when circumstances are very similar and that the impact of austerity on each of the 33 London boroughs varies widely. Many of the themes have less to do with budget cuts and just as much to do with ongoing problems that young people, families, service providers and commissioners have been facing for some years. The following is a synopsis of the main themes discussed and the conclusions we have drawn from these discussions;

1.1 *'There is only enough money to provide the bare minimum...'*

There is a fundamental question over the role of public services and whether funding should be used to address all the aspirations for young disabled people in times of austerity. Is it the duty of the state to support equality for disabled people or is it simply to keep vulnerable people safe and well?

There is a lack of clarity and knowledge around the following 3 issues;

- What is the legal requirement of the local authority to support young people with learning disabilities to achieve equal lives?
- How can resources and money be deployed more creatively (alternatives to traditional services) to achieve good results for young people?
- How can investing in preventative approaches be more cost effective, even in the short to medium term?
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1.2 *'Families are still fighting for places in specialist services outside of London..'*

Young people with more complex support needs often end up in services outside London and at significant distances from their families and communities. Families often fight to get their child a place in a residential college or facility. These are often at high cost and there is little evidence that this represents value for money even if the service is good quality.

This results in significant investment from London boroughs not just financially but also in developing expertise, services and jobs outside London instead of investing

in local services. Boroughs struggle to monitor residential placements and this can place a greater burden on stretched social workers.

Young and vulnerable people live further from their families, friends and loved ones and lose connections with their communities and this becomes a self fulfilling prophecy. Unless the cycle is broken with the development of good local alternatives families will continue to battle for what is best wherever it is located.

There are a number of reasons young people are continuing to move out of London.

- Specialist services offer (or appear to offer) all the social, health, education and behavioural support a young person needs within one service and at one location
- There are very little appropriate further education opportunities for young people with more complex support needs in London.
- There is little equality in the offer if a young person attends college outside London to what is included at home.

“If I send my some away to residential college I know he will get access to speech and language therapists, physio, sensory rooms, hydro pools, riding and all kinds of specialists. If he stays at home I have been told these things don't exist.”

- There are very few housing and care opportunities that can meet more complex needs in London and individual boroughs sometimes do not have sufficient numbers to justify the investment in commissioning local services
- There are not enough specialist respite/short break places and where there are, there are not enough 'nights' being offered to give the family a real break.
- Families are exhausted from juggling intensive caring responsibilities with other family commitments, work and life so the out of borough option offers an 'off the peg' solution that gives a good result for the young person and the family.
- It is an easy solution for the commissioner where there are no local options.
- Some people just want to move out of London and it is an informed choice

1.3 'Young people with mild to moderate learning disabilities not eligible for adult social care support are falling through the net...'

As social care budgets have become tighter, those with more moderate learning disabilities are becoming ineligible for care and support unless they are in a crisis or there is significant risk. This leaves young people with mild to moderate learning disabilities and families with little support and guidance when formal education finishes. Universal services such as the Job Centre and Connexions do not always have the skills, resources and expertise to support young people with learning disabilities into work, further education and independent living and they slip between the net of universal services and social care services. Many local services feel that their only responsibility is a sign posting and information service.

Surely it is questionable whether young people with mild to moderate learning disabilities who are ineligible for social services funding need to wait until they enter a crisis situation before they become eligible for help and can this be an effective long term use of limited resources? It is important to define the local authorities' duty to young people not eligible for social care funding and recognise how they can be more pro-active and creative whilst cost effectively supporting young people in order to avert a crisis situation arising.

1.4 *'The transition process is still fragmented and disjointed for many young people...'*

The transition process remains a fragmented and disjointed process despite much investment in the last 10 years. There is still a great deal of fear in reaching adulthood from young people and families and a lack of sound forward planning to enable a smooth transition.

1.5 *'Personal budgets have great potential to make fair and transparent decisions about money but resource allocation is often not open and transparent...'*

Personal health and social care budgets are a mechanism for fairly allocating resources and enabling young people and families to have more choice and control over their lives and many of the people we spoke to reported a good experience with having a personal budget.

There were, however some negative experiences particularly relating to the lack of transparency in how they are calculated and therefore a suspicion that the budget was not fair or sufficient. There was often a feeling that there was one budget available if a young person was to attend an out of borough placement ostensibly meeting all their needs whilst the budget offered in borough was much more likely to reflect only subsistence and care needs. Another theme that came up is that personal budgets are not enough in themselves, there still needs to be initial investment and market development in order to fill local gaps.

1.6 *'Change has been too focused on systems / protocols & processes rather than people and outcomes'*

There has been investment from the government in the transformation of social care in recent years but some commissioners and many families felt that much of this investment has gone into systems and processes rather than investing in staff enabling young people with learning disabilities to achieve good outcomes in their lives.

1.7 *'Systems operate in different camps, health, social care, housing and education and can stop some of the most determined people from achieving good things'*

Most professionals recognise the benefits and need for partnership across organisations but the cultural differences and technical issues between the funding and organisation of social care, health, education and housing mean that there are many barriers to young people and families getting what they need simply because of the way the various agencies are organised.

It requires the most determined professionals to make these partnerships work and even then, in some cases, the technical issues surrounding pooled funding and resources make it nearly impossible to get the right outcomes.

1.8 *'There is no safety net for change and flexible, creative approaches..'*

For young people and families, it can often feel like that once they agree to a service or budget, that it is fixed. There is no scope for change and this can lead to decisions that lack flexibility and creativity. There is also a sense that it is 'all or nothing'. If you need a lot of help then you need to send your child off to a residential service but if you keep them at home, you get nothing. For many families, particularly those of young people with more complex support needs, that there are simply not enough good local services to enable the young person to stay in the family home and so they opt for the residential service outside London.

Families would like to see a more open and flexible approach so that they can try out arrangements such as shared care or get the help they need to adapt their own properties to enable the young person to be more independent. Families would prefer to see transition as a staged approach over a number of years being given time to try things out at a pace that works for themselves and their family.

1.9 *'Planning for the future is not robust enough because of the lack of understanding of need ...'*

There is a lack of robust information for commissioners to use to plan for the future and much provision is being made in crisis situations. Commissioners need not only to know numbers of young people coming through but also the types of service they require. They also need an understanding of the amount of money that is currently

being spent out of borough and a realistic forecast of what a comparable local service would cost both in the short and long term.