



An exploration of parents/carers and young people's experiences of going through transition from children to adult services in Bexley.

August 2016

Acknowledgements

Healthwatch Bexley would like to thank the parents, carers, young people and personal assistants for participating in this survey, as well as the community organisations: Bexley Mencap, Ken Boyce day centre, Bridging the Gap and Bexley voice, for facilitating access to their members. Healthwatch Bexley would also like to thank Adult social services for their input to this process and for facilitating access to Local college first students.

1. Executive Summary

The transition from adolescence to adulthood is challenging for all young adults irrespective of background and circumstances. It is further exacerbated for young adults with health and social care needs as they move from children's services to adult services. The transition process is a central aspect of preparing young people with health and social care needs for adulthood and should have a positive impact on the young person's outcomes in terms of education, employment and health.

Improving outcomes for this cohort is vital, as young adults with special needs commonly experience poorer outcomes and inequalities. Poor transition in health and social care may further lead to disengagement with services and poor relationships with health professional. As a result, young people may become marginalised (National Institute for Health and Care Excellence (NICE), 2014; Transition Research Programme (TRP), 2014).

National reports and studies suggest there are wide variations in the experiences of young adults and their families going through transition. Many families are left without a dedicated support worker within a fragmented system where there is little information and gaps in service provision (Care Quality Commission, (CQC), 2014; Royal College of Nursing (RCN), 2013; Sloper *et al.* 2010). Locally, there are anecdotal reports of similar problems, particularly with discontinuity of services

and especially in mental health services. At a critical time in young adults' lives this may have an adverse effect on outcomes.

A review of existing local practices for transition took place in 2012/2013 by the London Borough of Bexley (Transitions Scrutiny Review (LBB), 2014). The review identified a number of key issues within current practice, such as transition planning frequently starting late and insufficient communication for families. The review subsequently outlined a number of recommendations, taking into account recent policy changes, such as the increased age to which the Local Authorities (LAs) retain responsibility for children in transition.

This report presents the findings from a number of engagement events in Bexley between February 2015 and June 2016. The primary purpose of the engagements was to explore respondents perception and experiences of going through transition from children's to adult services and the effects it has had on the young person's outcomes.

The findings suggest there are aspects of the transition process that may be improved. The engagements identified how participants, especially parents, feel isolated in navigating the health and social care system, particularly through lack of communication and information sharing from health and social care. Participants expressed feeling frustrated by budget restrictions and lack of suitable options locally. There were also accounts of gaps in provision of services when transferring from children's to adult services, especially within health. Some participants voiced concerns over how their child has regressed physically, socially and emotionally as a result of a fragmented system and unsuitable provision, and expressed frustration over a perceived limited understanding of young adult's needs, which participants believe differs substantially from older adults. There was general consensus that services within the borough take a 'one size fits all' approach, and has yet to develop a fully person-centred approach. Crucially, the findings demonstrate the marginalisation and isolation experienced by young adults with special needs within the community. Once education and all the support they received whilst at school or college terminates, young adults are left with very little support to progress into adulthood, on equal terms as their peers without additional health and social care needs.

This report will be communicated to the Local Authority, Healthwatch England, the Clinical Commissioning Group and the CQC, in addition to the community organisations and participants in the study.

1. Introduction

A good transition requires adequate and timely planning, supported by a joined-up approach by all relevant agencies, who actively work together to meet the young adult's needs. A good transition needs to be person-centred, with the young person and the carer/family at the centre at all times. It requires timely access to appropriate information and advice, whilst keeping the

family actively involved in every decision about their young adult (Department of Health (DoH) 2008; NICE, 2014, London Borough of Bexley (LBB) 2014).

Local studies have identified problems in transition in Bexley. (LBB, 2012, 2014). There are accounts of needs being re-defined and subsequently met in alternative ways, along with gaps in service provision and a lack of understanding of young adults needs (LBB, 2012).

In 2012/2013, the London Borough of Bexley undertook a Transitions Scrutiny review (LBB, 2014). The review outlines a number of key findings and recommendations for transition within the borough. The findings primarily relate to:

- a) The transition process, including planning, which often started late
- b) Communication issues, such as access to information on transition for families
- c) The provision of local services and the introduction of Local College First to reduce out of borough provision
- d) The need for timely planning for resources for future needs to ensure needs are met

The report demonstrated a clear recognition of the anxiety and stress that individuals and their families may be subject to as a consequence of transition not working well and the impact it may have on outcomes and wellbeing.

The recommendations set out in the review primarily relate to:

- e) Timely planning for transition
- f) Increased access to information
- g) Clear communication for all parties involved, particularly the young person and their family
- h) Active involvement by young people and their families at all stages through transition

These recommendations will be reflected in the Transition Strategy for Bexley (LBB, 2012), which sets out key principles for the transition process. Transition is further supported by the new SEN Code of Practice, in which LAs are responsible for young people aged 19-25 and the continuing access to ongoing education. The review demonstrates a commitment by the LA to improve how transition is executed and experienced by young people and their families. This will be reinforced by the ongoing monitoring of the recommendations set out within the Scrutiny review (LBB, 2014).

The local evidence arising from the Scrutiny review is further reflected in national research and publications, which demonstrate that similar concerns regarding the transition process occurs on a national level (All Party Parliamentary Group (APPG) 2009); CQC, 2014; NICE, 2014; RCN, 2013; Transition Information Network (TIN) 2009). There is considerable evidence available from research which demonstrate that insufficient and untimely planning, in addition to a lack of joined-up working amongst relevant agencies and the absence of a named key worker are common themes within the transition process. There are accounts of fragmented services,

coupled with a lack of accountability and engagement amongst health and care professionals, which has an adverse effect on transition and subsequently impacts on young adult's outcomes (APPG, 2009; CQC, 2014; NICE, 2014, RCN, 2013; Sloper *et al.* 2010; TIN, 2009).

A review of the literature further illustrates that there is an abundance of guidelines and best practice recommendations available for transition, with some dating back almost 10 years (DoH, 2006, 2007, 2008). The principles and key messages outlined within these publications remain the same, but with seemingly little change within the system over the past decade. In February 2016, NICE published new guidelines for transition and identifies a number of overarching principles, which includes:

- Involving young people and their carers in service design, delivery and evaluation for transition
- Ensure transition support is developmentally appropriate
- Ensure transition support is strengths based
- Use a person-centred approach
- Joined-up health and social care in children and adults services
- All agencies take responsibility for sharing safeguarding information
- Check that the young person is registered with a GP
- Consider ensuring the young person has a named GP

The guidelines further identifies the importance of a named key worker to support transition and for transition planning to be timely and ongoing.

There is however limited evidence of what 'best practice' actually looks like but the RCN (2013) have identified some good local examples for transition arising from case studies in London (location not specified) and in Salford (the paediatric and young person's diabetes team) undertaken as part of their recommendations for transition. Many of the recommendations are reflected in national guidelines, as well as in the CQC's report (2014) but some are worth highlighting as they arise from direct observation of what works in practice:

1. *Transition roles/responsibility form part of job descriptions & the appointment of key-coordinator for transition*

Ensuring transition is key part of health professional's job descriptions enables them to allocate time and resources for this task. This also provides consistency for families.

2. *Early planning and developing of pathways with the young adult*

The pathways recognises that young people are a vulnerable group and will undergo many transitions during this phase and that they need a service which continues to meet their needs.

3. *Collaborative approach and adolescent clinics*

Transition is a joint responsibility supported by a dedicated transition service with key professionals within children's and adolescents/adult services establishing formal links and working across teams.

4. Communication and Information

Providing good and timely access to information as well as recognising the importance of preparing the young adult and their parents/carer for transition so they know what to expect.

These recommendations are supported by the Children and Families Act (2014), which outlines a number of key principles aimed at improving outcomes for children and young adults with special needs, with a particular emphasis on education, health care and social services working together. The Act further highlights the significance of effective planning of transition, and incorporates provisions to specifically support transitions for young people. Adopting a person-centred approach when planning for transition, coupled with the involvement by young people and their families throughout the process is highlighted as fundamental to ensure needs are met. The Care Act 2014 further incorporates employment as a measurable outcome, by recognising the significance of young adults to engage in meaningful activities to improve health and wellbeing.

2. Methodology

The findings within this report are based on a number of engagements, including focus groups, interviews and questionnaires. The four focus groups consisted of 23 participants, of which 21 were parents/carers and two were young adults. In addition, 12 questionnaires were completed, primarily by parents/carers. Interviews with five LCF students and their PAs were also held, bringing the total number of contributors to 40 (45 including the PAs). The average age of the young adults discussed was 19. The majority of the young adults have complex health needs and fall within the criteria of receiving education, health and social care support, with a small number of participants (n=6) falling below the threshold for statutory support.

The sample was recruited through focus groups invitations, which were circulated by the community organisations to their members, and which explained the purpose of the discussions. A minimum number of participants were confirmed prior to each session (n=5), although one session was so well attended it was subsequently divided into two groups. The participants at each group were as follows: Bexley Mencap (n=5), Ken Boyce Day Centre (n=5), Bridging the Gap (n=5) and (n=8). The limitation of the sample is that participants were a self-selected group, motivated by their experience of going through transition and their experiences are therefore not representative of the wider population. It may be noted that the self-selecting sample may have been motivated to participate due to not having achieved desired outcomes. Access to the LCF students was facilitated by LBB and LCF.

Informed consent was obtained through a written consent form, which clearly outlined the purpose of the focus groups and how the information would be recorded. The consent form further obtained permission for verbatim quotes to be used whilst assuring participants of

anonymity. The focus groups were audio recorded, manually transcribed, analysed and thematically coded.

The discussions centred on questions such as having a dedicated key worker during transition, how information was shared between agencies and health professionals, how effective agencies worked together and how families were involved and kept informed during transition. The discussions concluded by asking what worked particularly well and how transition may be improved in the future.

Limitations

It is important to note that the use of focus groups has limitations. Although the use of focus groups enables in depth information to be explored and captured in a relaxed environment, the findings cannot be generalised and are not necessarily representative of the wider population. A limitation of the use of focus groups refers to the possibility of individuals dominating group discussions, thus making their opinion the central point to be explored, which may subsequently alter the data and further limits the extent to which data can be reproduced through each focus group and thus compared (Smithson, 2000; University of Surrey, 1997). Additional limitations refers to group dynamics, in which dialogues and discussions may be constrained by the group setting, subsequently leading to the reproduction of normative discourses and the avoidance of controversial view-points (Smithson, 2000).

The limitation of the interviews primarily relates to the cognitive abilities and communication needs of the LCF student in relation to the transition process. These interviews primarily enabled Healthwatch to gain an insight into the students experience and thoughts of attending LCF and not how they have experienced transition as a process.

Acknowledgements

During the process, Healthwatch attended four meetings with health professionals and the local authority to gain insight into transition in Bexley and would like to thank them for their time.

3. Findings

3.1 Support and communication

Transition is an ongoing phase in a young person's life, spanning from 14 years of age when transition planning should start through to a person's 25th birthday where there is eligibility for support. This requires a long term perspective, with an adequate identification of individual needs to ensure support is available as and when the next phase of transition is taking place.

Participants were asked if they had a named key worker to support them through transition. The majority of respondents said they did not have a named key worker specifically for transition and parents identified themselves as the main coordinator of the young person's care. Many participants expressed feeling isolated in their pursuit of a smooth transition for their young adult and would welcome a named key worker to support them, with some expecting the social worker to perform this role. Parents further perceived there to be a shortfall in support from the local authority and largely attributed this to the frequency in which social workers changed, with three young people saying they had had 2-3 social workers in the past 18 months. Concerns with change of social workers generally related to information not being passed on and information being misunderstood, or acted on at all, which resulted in duplicate conversations and delays in cases going to Panel. One participant stated:

"We are going through exactly the same thing (again), where all the paperwork has now been done but the social worker has now left and we are now waiting for another social worker and my son's case cannot go to Panel, it has already been cancelled once, because of the lack of social workers".

Ten participants reported that the first transition from children to adult services went well, especially when there was a continuation of education, including college and travel arrangements, with many relying heavily on the schools for support. Participants were further asked how they were kept informed during transition and the majority of respondent's perceived communication and information sharing to be limited, with 75% of stating not knowing if a transition plan had been put in place. Two parents said:

"My son is 16 (years old) and we haven't got anything in place....Not aware of anything happening to support transition".

"There has been no planning put in place for my daughters future. As stated I have received no direct help or advice about her post sixteen placement".

Participants spoke of expectations of working *with* social services to get the best for their young adults but 80% said they did not feel sufficiently informed and involved, or what to expect about

the next stages in transition. Participants frequently attempted to organise care and support for their young adult but did not feel sufficiently informed if plans fell through. One parent said:

“Perhaps that was naïve of me, but I did expect that basic communication to be in place and to be notified if there was a problem, so that the parent/carer can do the necessary action to support whatever the problem might be”.

Lack of communication and information was further identified as a concern during the interviews with the Local College First students and their PAs. The PAs expressed concern and anxiety, on behalf of the students, about the next stage of transition, as the LCF students at the time of the interviews were unaware of their time at LCF coming to an end. This limited conversations about the next stage of transition and their experiences associated with it. The PAs expressed concerns over the lack of information about whether the PAs would remain with their allocated student in a new setting or if the relationship would come to an end. All PAs felt it was important to be able to prepare their students for the forthcoming changes but felt unable to do so in the current situation.

Discussions frequently centred on the provision of services within the Borough. 55% of participants expressed concerns over the lack of suitable services to meet their child’s needs in addition to the frustration of not being able to secure funding for out of borough services. There were examples of young adults requiring services which are not available in Bexley, such as specialist services for epilepsy. Crucially, 80% of participants felt they have to ‘fight the system’ to get the support their child needs, with 35% of participants voiced feeling depressed at some time during transition and expressed a lack of support for carers.

3.2 Continuity of health services

Respondents perceived that whilst in education, their young person continued to progress physically, socially and emotionally. Significantly, the majority of participants (65%) felt that whilst their child is in education, their physical, social and emotional needs were met. Participants expressed a desire for their young person to remain in education for as long as possible and participants often negotiated with schools and colleges to have courses extended for this specific reason. This includes access to physiotherapy, speech and language therapy, epilepsy services and hydro therapy in addition to taking part in social events with their peer groups. However, 45% of the participants expressed frustration that once their child came out of education or changed setting, some services appeared to stop and the investment that has gone into their child’s development is lost as there is no continuation. One participant stated:

““My son has definitely regressed since July last year physically and socially.... As parents, you get worn out after a while as he is very active and needs to be engaged all the time”.

Two young people reported having had access to hydro therapy and speech therapy at their past school, but they were no longer able to access this as there is no provision in Bexley. One respondent said that their IPAD, with a speech programme to help with communication, had been broken for almost 12 months without being repaired or replaced, and this had a significant impact on the respondent's ability to communicate with peers and social networks.

There were also reports of services ceasing when children turned 18 and one participant told of her son being discharged from the dietician they had used when her son was 18. Subsequently the family had to go privately. Similar comments were made about mental health services, whereby Children and Adolescent Mental Health Services (CAMHS) would cease when children turn 18 only to be put on a waiting list for the adult services. This left a big void of support in a young person's life who at the time may be going through turbulent times of finishing education and moving onto new things. One young adult spoke of the long waiting time, nine to 10 months, to move onto adult mental health services during a time when he had just finished school. He was spending a lot of time at home not engaging in any meaningful activity at all and said this had a negative impact on his mental health. This was echoed by five participants who spoke of the long waiting list for mental health services and highlighted the vast differences in approaches within CAMHS and adults mental health services. Young adults move from supported children's services to adult services, which took a much more clinical and diagnostic approach with no allowances made for young adults in transition:

"The adult services have a very clinical/hostile environment compared to CAMHS; the obsessive need to 'tick boxes' and follow procedures is very daunting for young adults".

3.3 Recognition of adolescence and young adulthood as a distinct stage/phase

The majority of participants (65%) felt that there was an assumption that when their child turned 18, their needs had changed, as re-assessment and form filling would take place. Participants frequently said it felt like their child had been 're-born at 18' and they had to start the whole process again, including needs assessment, when in fact, their needs have not changed. This caused a lot of frustration and anxiety amongst the participants, as they did not know how it would affect the support they had come to rely on. While criteria for adult social care are different from those for children's services, it is difficult to reconcile this with a person-centred approach. Managing expectations, through clear communication channels, is therefore fundamental to avoid misunderstandings and pre-conceptions.

The majority of participants (75%) perceived that the transition process lacks a person-centred approach and felt that services were not designed or tailor made for young people with complex needs. Concerns were made in relation to supported living and care homes, where participants voiced their frustration about their young person being placed in unsuitable accommodation,

including being grouped together with much older adults in their 50s, 60s and 70s, or in mixed housing. One participant said:

“It is Bexley’s inability to understand what young adults require. They block them in from 18 (years) to death. Bexley don’t accept that the requirements of a young person is different than to an older person. Older people don’t want to go to discos and have extra activities and go to sport centres and concerts, they (Bexley) are not interested in funding additional needs”.

Additional concerns relates to the services and activities available locally, which participants did not always feel met the young person’s need. These includes some activities provided at LCF and by Twofold, which some participants felt would not translate into skills that can be used by the young person independently, although this varies greatly from person to person. However, all of the students from LCF expressed great satisfaction attending LCF and highlighted some of the classes, including Zumba, art and cookery lessons to be of great value and benefit to them. Social networks and friendships were also highlighted as key benefits from attending LCF.

3.4 Young people with SEN without statutory support

A small number of participants (n=6) had young people with special needs, particularly with Autism Spectrum Disorder (ASD), who fall below the threshold of receiving statutory care services. Participants expressed concerns particularly relating to employment issues, such as applying for jobs and the interview process in addition to maintaining suitable employment. Respondents felt there is very little support within job centres and employers to accommodate for the very specific traits that people with ASD display. All of the participants spoke of their young adults being unable to find and maintain employment, subsequently spending most of their time at home, socially isolated and with very little to do. Two participants stated:

“They (young adults) need special needs work experience, same routine every day. You can’t make them better, just making life easier for them as they are capable of making a living”.

“He (my son) has not been able to get into the adult system and falls under the criteria and he does not get any help, but he does need help. And I don’t know where to go. He is currently unemployed, at home, in his bedroom, bored”.

Meaningful occupation was expressed as a concern for *all* participants in this survey, as although many young adults attend day centres there is little variety and not always sufficient amount of hours allocated. There were also gaps in between services being allocated, often for months and up to a year, which left young adults isolated and under stimulated. Participants expressed a wish for more volunteering opportunities and support in the work place for young adults with special needs.

3.5 Recommendations from service users and carers to support transition

The respondents were asked to identify how transition can be improved and five main issues were identified:

1. Person-centred approach

Participants would like Bexley council to implement a person-centred approach, which is fundamentally based upon joined-up working amongst different agencies, to clearly identify a young person's needs from a holistic point of view. This should include having a short, medium and long term plan through transition, thus reducing the need to start the process again when one service stops. This is crucial to ensure support remains in place so that young people can continue to develop physically and socially, particularly following education when some services appear to stop.

2. Information and communication

Participants want to be listened to. They want to be actively involved and regularly kept informed throughout transition. Participants would like to be informed of all the options available regarding education, health and care support within the borough so they can make informed choices. However, participants would also like increased choice and flexibility for support arrangements, as young people with special needs, particularly complex needs, have very different needs. Crucially, participants want to have the opportunity to look outside of the Borough when needs cannot be met locally.

3. Named key worker

Participants would like to have a named key worker, independent of education, health and care professionals, to support them through all stages of transition at regular intervals. This would help to identify carers needs and wellbeing in addition to providing ongoing feedback from a service users and carers perspective about services and transition.

4. Meaningful occupation

Participants would like support to increase employment opportunities, both paid and volunteering opportunities, to develop social skills and to encourage independence. Participants said there needs to be greater understanding of special needs within the community (both within job centres and amongst employers) so that people who require help to access employment and to maintain it, can get help to do so.

5. Resource Centre

During the initial engagements, participants expressed concerns over a lack of access to information about services available within the borough, such as day centres and supported living accommodation, along with general information about where to access help and support for employment and education. Participants told Healthwatch they would like a 'resource centre' where they can access all the information they may need. The Local Offer was at that time in its development stages. Its implementation should help families to access information.

4. Discussion

Transition and its associated challenges have been on the agenda for some time in Bexley and there are several principles in place which states what a good transition looks like. There is however inconsistent evidence these principles are followed in practice.

The results from this engagement demonstrate that participants often experience challenges during transition and perceive it lacks a person-centred approach. Shortfall in communication and information sharing are identified as key contributors to this, as the majority of participants did not feel involved in transition at all. Managing expectations, through open and transparent communication channels, is an important aspect to ensuring parents/carers and young people feel informed and involved at all stages and will further contribute to realistic expectations of provision of services. This is reflected in the SEND code of practice, in which active and effective participation with families is recognised as fundamental to achieving higher satisfaction with services, thus improving outcomes (Department of Education, 2014).

Putting young adults and their families at the heart of the planning for transition is fundamental to ensure that support arrangements meet the needs of the individual. Five participants spoke of their young people being placed in unsuitable accommodation, such as being offered places in supported living which failed to meet standards or being grouped predominately with much older residents. Suitable accommodation for young adults can meet their social needs as well as their physical needs. It can help to promote good mental health by providing peer interaction and social events suitable for this group. In this way, independence and resilience can be promoted with a positive impact on their overall wellbeing. The recognition of adolescent and young adulthood as a distinct phase, separate from older adults, is noted in the CQC report "From the pond into the sea", in which the CQC identifies the differing needs 16-25 year olds have and that these needs may be very different and constantly changing. This approach is further supported by NICE transition guidelines, who emphasises the need for joined-up service provision, with the young person supported to play an active part in their care and support (NICE, 2016).

For young people without special needs, becoming an adult is about achieving personal autonomy, employment, independent living and social interaction (Social Care Institute for Excellence, SCIE, 2015). For the majority of young adults with special needs, becoming an adult is less marked and takes place gradually, sometimes over a lifetime (SCIE, 2015). However, research demonstrates that young people with special needs have the same key aspirations of having a job, to live independently and having friendships when moving into adulthood (SCIE, 2015). Participants generally spoke of the importance for their young adult to have social interactions and meaningful activities, even when these might not be in paid employment, as their young people have aspirations but are spending time at home, isolated and with little motivation. This requires the local authority to continuously plan ahead so that when young people leave education, there is continuity to ensure young people with special needs do not fall behind when it comes to physical, social and emotional development. The significance of employment

opportunities and engaging young adults with special needs in meaningful activities is now recognised as an outcome in the new Care Act 2014 and SEND code of practice. The emphasis is on social care professionals supporting young adults in their aspirations and working in partnership with agencies within the community to explore employment opportunities.

The feedback from participants suggest that health services, such as physiotherapy, hydro therapy and mental health services, sometimes cease to be provided when moving from one setting to another, particularly when the young person leave education or turn 18 years old. Parents/carers generally expressed a wish for their young person to remain in education as they felt their physical, emotional and social needs would continue to be met and 65% of participants felt that once education stops, services becomes fragmented and inconsistent. The Children and Families Act (2014) place particular focus on integrating education, health and care services to assess local needs and states that local authorities 'must have arrangements in place to plan and commission education, health and social care services jointly'.

The findings from this engagement suggests that parents are the main coordinator of transition for their young adults, with limited support from health and social care professionals. These findings are consistent with the CQCs report, in which parents are identified as the main coordinator of care and services, with little support to navigate the health and social care system (CQC, 2014). The NICE guidelines state that a named worker should be appointed to coordinate transition care and support. This will support families to access all relevant information in a timely manner, to ensure transition goes smoothly.

The report further identified shortfall in provision for young adults who fall below the threshold for statutory care. One participant spoke of the lack of support and understanding amongst employers for people with ASD, thus being unable to maintain employment. Many participants spoke of their young people not getting the support they need to fill in applications and prepare for interviews. This creates a barrier for many young people with special needs to access employment and to gain personal autonomy, income and independent living. Moreover, this cohort commonly does not possess a conventional social life, such as freely mixing with peer groups and participating in social events, which subsequently subjects them to social isolation to a larger extent than their peers without special needs.

The SEND code of practice states that with the right support, young adults with special needs 'can go onto to achieve successful long-term outcomes in adult life' through a collaborative approach by LAs, education and employment agencies. However, increasing awareness and support within the work place is fundamental, as statistics demonstrate that only 15% of adults with autism are in full-time employment, with the majority out of work adults with autism (79%) and in receipt of benefits would like to work, but require adequate support to do so (National Autistic Society, 2015). The lack of support to access employment for this group has far reaching consequences, extending beyond the individual costs, in terms of income, health, social interaction and

wellbeing, to wider economic costs in terms of societal spending from the fall out of adults unable to achieve their full potential.

Healthwatch acknowledge that LBB are aware of the issues identified in this report, which are similar to those identified in the Scrutiny review (LBB, 2014), and that LBB are in the process of implementing strategies to improve transition.

5. Recommendations

In light of the issues identified in this report, coupled with current guidelines on transition from the CQC, NICE and best practice examples, Healthwatch Bexley has identified a number of recommendations for transition in Bexley:

- 1. London Borough of Bexley should appoint a named key worker for all those in transition.*

Having a named key worker will facilitate a holistic and person-centred approach to the young person's needs. It will improve planning and communication, throughout all stages of transition, and help to manage families expectations.

- 2. Transition plans should be developed for each young person in transition, with the involvement of young people and their families.*

The transition plan should take into account health, employment and education as well as social care needs. The transition plan should be reviewed regularly between ages 14-25 to ensure needs are reviewed and continued to be met, particularly after a young person turns 18. This will ensure accurate and timely monitoring of young people's needs as they go through the various stages of transition and will further reduce the possibility of gaps in provision. Particular focus needs to be paid to health aspects for young people with complex health needs, as well as employment support following education.

- 3. The Clinical Commissioning Group (CCG) to review health services for transition. .*

The CCG should review provision of speech and language therapy, dietetics and physiotherapy for young adults in transition to ensure continuity of provision and phased withdrawal of support.

- 4. The CCG and Oxleas to review mental health provision for young adults.*

The CCG and Oxleas should review mental health provision for young adults to ensure continuity of provision for vulnerable young adults and phased withdrawal up to the age of 25.

6. Future Research

It was outside the scope of this engagement to explore the impact and needs of the carers for young adults in transition, but it was clear from the discussions that transition affects the whole family, in particular the main parent/carer. Additional research may therefore be beneficial to explore the effect transition has on wellbeing for carers, particularly as carers are supported by legislation and are entitled to support. Additional research may also be beneficial into the challenges experienced by young people who do not meet the criteria for statutory support, particularly post-education in terms of accessing employment, as these challenges prevents them from fully entering adulthood and participating in society on equal terms.

7. Conclusion

Transition is a complex, multi-agency process, which affects a variety of aspects of a young person's life including health, education and social needs. These needs are unique to each young adult going through transition, with some living with very complex physical needs, and it is of outmost importance that these needs are fully assessed, identified and subsequently met when moving into adult services. This report outlines a number of key issues within transition that are currently not working well. It also identifies a number of recommendation to address these issues.

Healthwatch Bexley Transition will remain a priority for Healthwatch Bexley and a review of the recommendations outlined within this report will be carried out in 12-18 months' time.

The report has been sent to commissioners for a check for any factual inaccuracies and London Borough of Bexley have stated they feel the report is balanced. An initial response to the recommendations will be expected following the presentation at the Health and Wellbeing board on September 7th 2016.

8. References

All party parliamentary group (2009) *Transition into adulthood*. Available at: <http://www.appga.org.uk/resources/past-reports.aspx> (Accessed: 10 May 2015)

Care Quality Commission (2014) *From the pond into the sea*. Available at: https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf (Accessed: 10 May 2015):

Department for education (2014) *Young person's guide to the Children and Families act 2014*. Available at: <https://www.gov.uk/government/publications/young-persons-guide-to-the-children-and-families-act-2014> (Accessed: 12 May 2015)

Department for Education (2015) *Special educational needs and disability code of practice: 0-25 years*. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> (Accessed: 25 May 2015)

Department of Health (2006) *Transition: Getting it right for young people*. Available at: <https://www.bspar.org.uk/DocStore/FileLibrary/PDFs/Transition-%20getting%20it%20right%20for%20young%20people%20-%2023rd%20March%202006.pdf> (Accessed: 25 June 2015).

Department of Health (2007) *A transition guide for all services*. Available at: <http://webarchive.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/>

Department of Health (2008) *Transition: Moving on well*. Available at: http://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf (Accessed: 15 May 2008)

London Borough of Bexley (2011) *Bexley Children and young persons partnership plan*. Available at: <http://www.bexley.gov.uk/CHttpHandler.ashx?id=10251&p=0> (Accessed: 10 May 2015)

London Borough of Bexley (2012) *Strategy for the transition of young people who are vulnerable or disabled or who have special educational needs from children's services to adult services 2012-2013*. Available at: http://www.kent.gov.uk/_data/assets/pdf_file/0012/13323/Strategy-children-young-people-SEN-Disabilities.pdf (Accessed: 12 May 2015)

London Borough of Bexley (2014) *Transitions Scrutiny Review*. Available at: <http://www.bexley.gov.uk/CHttpHandler.ashx?id=13343&p=0> (Accessed: 12 May 2015)

National Autistic Society (2015) *Support for employers*. Available at: <http://www.autism.org.uk/Working-with/Support-for-employers.aspx> (Accessed: 1 June 2015).

National Institute for health and social care excellence (2014) *Health inequalities and population health*. Available at <https://www.nice.org.uk/advice/lgb4> (Accessed: 20 May 2015)

National Institute for health and social care excellence (2014) *Transition from children's to adult services*. Available at: <https://www.nice.org.uk/guidance/gid-scwv0714/documents/transition-from-childrens-to-adult-services-final-scope3> (Accessed: 10 May 2015)

Preparing for Adulthood (2014) *Fact sheet: The Children's and Families Act and the Care Act*. Available at: <http://www.preparingforadulthood.org.uk/resources/pfa-resources/factsheet-the-children-and-families-act-and-the-care-act> (Accessed: 20 May 2015).

Royal College of Nursing (2013) *Lost in transition*. Available at: https://www.rcn.org.uk/_data/assets/pdf_file/0010/157879/003227_WEB.pdf (Accessed: 10 May 2015)

Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N., Cusworth, L. (2010) *Models of multi-agency services for transition to adult services for disabled young people and those with complex health needs: Impact and costs*. Available at: <http://www.york.ac.uk/inst/spru/research/pdf/transitions.pdf> (Accessed: 25 June 2015)

Smithson, J. (2000) *Using and analysing focus groups: limitations and possibilities*. International Journal of Social Research Methodology: 3 (2) p.103-119.

Transition Information Network (2009) *Transmap: From theory to practice*. Available at: <http://www.transitioninfonetwork.org.uk/resources.aspx> (Accessed: 25 May 2015)

Transition Research programme (2014) *Transition*. Available at: <http://research.ncl.ac.uk/transition/> (Accessed: 10 May 2015)

University of Surrey (1997) *Social research*. Available at: <http://sru.soc.surrey.ac.uk/SRU19.html> (Accessed: 1 June, 2015).

World Health Organisation (2013) *10 facts on disability*. Available at: <http://www.who.int/features/factfiles/disability/en/> (Accessed: 15 June 2015)