

Merton Autism Strategy 2018-2023

Public Engagement Feedback Report

Introduction

The London Borough of Merton and Merton NHS Clinical Commissioning Group (CCG) have developed a draft Autism Strategy working in collaboration with a range of partners. The draft strategy encompasses children, young people and adults, taking into account the needs of families and carers. The draft strategy set out plans to work in partnership towards an autism-friendly borough and address the wide range of areas to improve the lives of residents with autism. The draft strategy was developed in response to increasing numbers of children and adults with autism in the borough and awareness that there is a need to make improvements in support and services currently provided. National policy and statutory guidance has also informed development of the strategy.

The strategy sets out a framework for action over the next 5 years and identifies priorities for commissioning and service re-design and improvement for people with autism in Merton.

This report analyses responses to recent public engagement on the draft strategy and provides a detailed overview of the respondents' comments and suggestions.

The report is split into 3 main sections:

1. Methods
2. Findings
3. Conclusions

Section 1: Methods

A public engagement period took place from the 5th of February to the 19th March 2018 (6 weeks).

The engagement was comprised of 2 main strands:

- written engagement via a structured on-line survey and paper easy-read survey
- verbal engagement through facilitated feedback sessions with stakeholders including people with autism; parents and carers; and professionals.

Engagement questionnaire

The on-line questionnaire was made up of 21 questions and focused on the 6 main themes within the strategy. There was a mix of closed, ranking questions and free-text questions. The intention of the questionnaire was to ascertain stakeholders' priorities for actions and identify any issues which have not been addressed.

The engagement questionnaire was available online, either to be filled in via the council's consultation website or downloaded and emailed to a member of the public health team. It was also available as a hard copy on request. An easy-read survey was also available to download. The questionnaire was disseminated via stakeholders and networks from the

Local Authority, NHS partners, MVSC and local voluntary sector organisations, schools and individuals on the Merton Autism Strategy reference group (see appendix 1).

Engagement sessions

Engagement sessions were organised for a range of groups to enable individuals to offer their views on the strategy. Sessions were facilitated by members of the autism strategy steering group in collaboration with local group leaders. A total of 7 sessions were held over the 6 week period and were attended by stakeholders including young people and adults with autism, parents/ carers and professionals working in health, education, social care and voluntary sector organisations (see appendix 2).

Additional feedback

A small number of respondents emailed their comments directly to the public health team. These responses were logged and analysed alongside those from the questionnaire and engagement sessions.

Responses

A total of 146 participants were engaged in the feedback process as individuals and/or part of group feedback. 42 respondents completed the online questionnaire and a further 5 questionnaires were received by post. Engagement sessions were attended by a total of 90 individuals across 7 sessions. 9 respondents submitted individual feedback via email.

Additionally, the draft strategy was presented at two GP locality meetings which were attended by a total of 35 health professionals across east and west Merton.

Not all respondents provided demographic data, but of those who did we have categorised respondents as per table 1 below.

Table 1. Respondents by category

| Category | Number of respondents |
|--|------------------------------|
| People with autism | 19 |
| Parents/carers | 45 |
| Health professional | 4 |
| Education professional | 56 |
| Local authority employee (non-education) | 3 |

Analysis

Following the closing date, all responses were collated and analysed. Responses from the online questionnaire were downloaded into an excel spreadsheet. Paper copy responses were input into the spreadsheet as well as information from engagement sessions which responded to specific questions. For example, where stakeholders had ranked priorities in a feedback session this data was included in the spreadsheet. Where groups of individuals had responded e.g. in group work through engagement sessions this was logged as an individual response on the spreadsheet.

Additional comments and suggestions were analysed and grouped into themes; the 6 priority themes within the strategy and cross-cutting themes.

This report reflects the views of those who responded to the engagement but may not necessarily be representative of all views across the Borough.

Acknowledgments

Many thanks to all those who responded to the public engagement and to partners who contributed and co-ordinated feedback sessions including: Talk Autism/Merton Mencap and the Hearts and Minds Group; LBM CSF engagement team; LBM Adult social care; Merton NHS CCG Patient and Public engagement team.

Section 2: Findings

Vision and aims

1. The vast majority of respondents to the questionnaire (78%) agreed with the vision and aims set out in the draft strategy. A number of people commented that the aims were positive and comprehensive.
2. However, there was significant feedback that the language used in the strategy did not give strong enough commitment to achieving the aims of the strategy and there was a risk that the strategy would be aspirational and not result in tangible improvements for people with autism and their families.
3. It was noted that the proposals within the strategy are to be delivered within existing resources, however many respondents commented that without additional resources it would be very difficult to achieve the aims set out in the strategy.

Current services and access to support

4. This question relates to the section on 'our current services and access to support' (p.16 in the draft strategy). The questionnaire asked respondents if there were any other local services or support that was not included. Respondents listed the following services which were not included in the draft strategy.
 - ACES youth club for high functioning autism (Merton Mencap)
 - Merton Sensory Support Service
 - Mencap 0-5 supporting families team

Additional comments relating to services and support will be detailed in the analysis of theme 2.

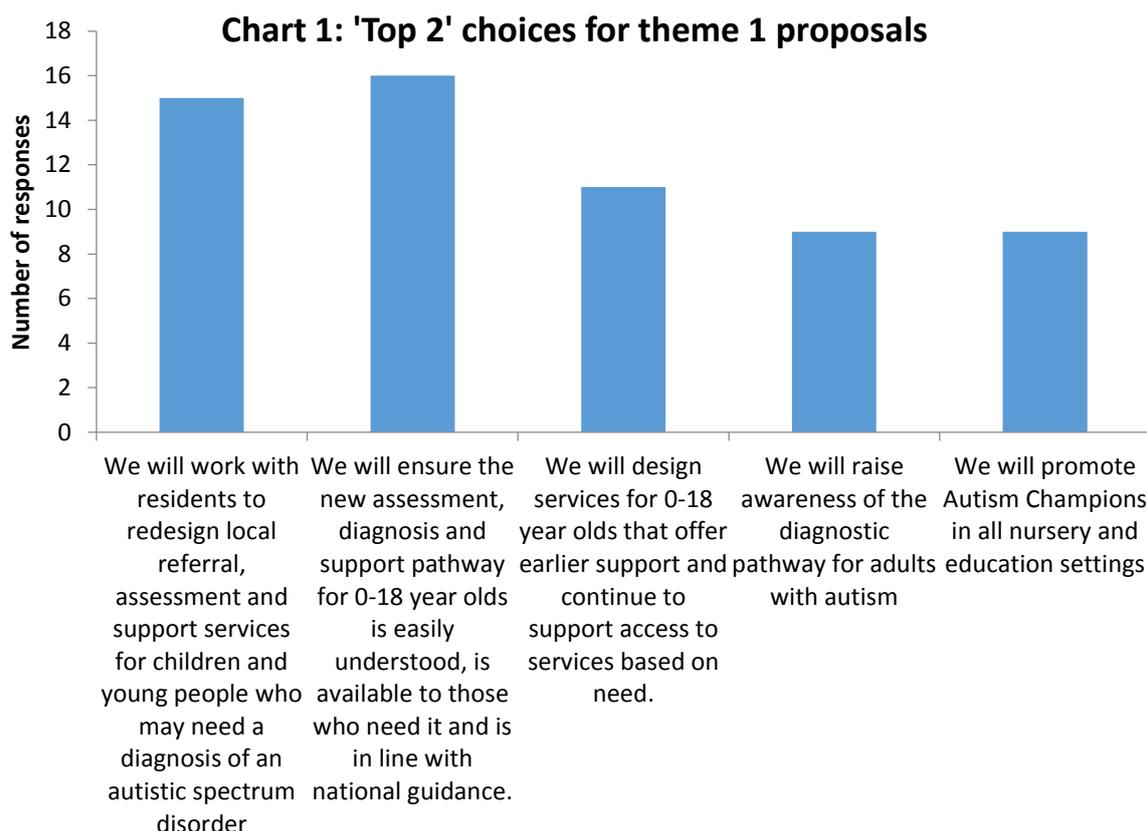
Priority themes

5. Most respondents to the questionnaire (81%) agreed with the 6 key themes around which the strategy is framed. It was suggested that education could be a separate theme. It was also suggested that there could be separate themes for children and adults as this would make the strategy easier to navigate. Another suggestion was that theme 6 (awareness training and support for staff and services) should be earlier

on in the strategy as this was thought to be one of the most important areas to address.

Theme 1: Recognition, support, referral and assessment.

6. There was consistent feedback that the current referral and assessment process takes too long and there is no support available to those who are awaiting assessment. Ensuring the new diagnostic pathway is NICE compliant was highlighted as an essential priority, in particular the points around a 3 month minimum waiting time and assignation of a key-worker.
7. Most respondents agreed with the proposal that support should begin as soon as a need is identified and should not be dependent on having a diagnosis. However, some respondents were sceptical about how this could be implemented, believing that many services require a diagnosis in order to access them at present. Many respondents also felt strongly that whilst a diagnosis should not be a requirement for support, this does not mean that receiving a diagnosis is less important to people with autism or their families and carers, and certainly should not be a reason for limiting access to diagnosis.
8. Some respondents felt that there should be more emphasis on early intervention in the strategy; they felt that currently many front line staff are not properly trained to recognise the signs of autism and therefore the opportunity for early intervention is being missed. There was also a view that more should be done to address the under-diagnosis of autism in girls.
9. Strong feedback was received that establishing autism champions in schools should be a priority. It was suggested by some respondents that the autism champions could be people with autism themselves, or that people with autism were involved in the training of autism champions.
10. A lack of recognition of co-morbidities associated with autism e.g. ADHD, anxiety and depression was highlighted. Some respondents felt that at present these co-morbidities are often ignored or 'bundled together' with autism and therefore not treated appropriately by health professionals. In addition, it was noted that some people are only diagnosed with autism when being assessed for co-morbid mental health problems i.e they have to wait until they require intervention or assessment from mental health services in order for autism to be recognised. Furthermore, if the autism was recognised and managed at an earlier stage they may not have gone on to develop these problems e.g. anxiety, depression etc.
11. There was significant feedback that the diagnostic pathway for adults is unclear and this prevents many adults from accessing assessments.
12. For both children and adults, there was a consistent feedback that there is a lack of support following diagnosis. In particular, where to go for help/advice in the future and counselling on how to come to terms with a diagnosis (especially for adults) were identified as priorities.

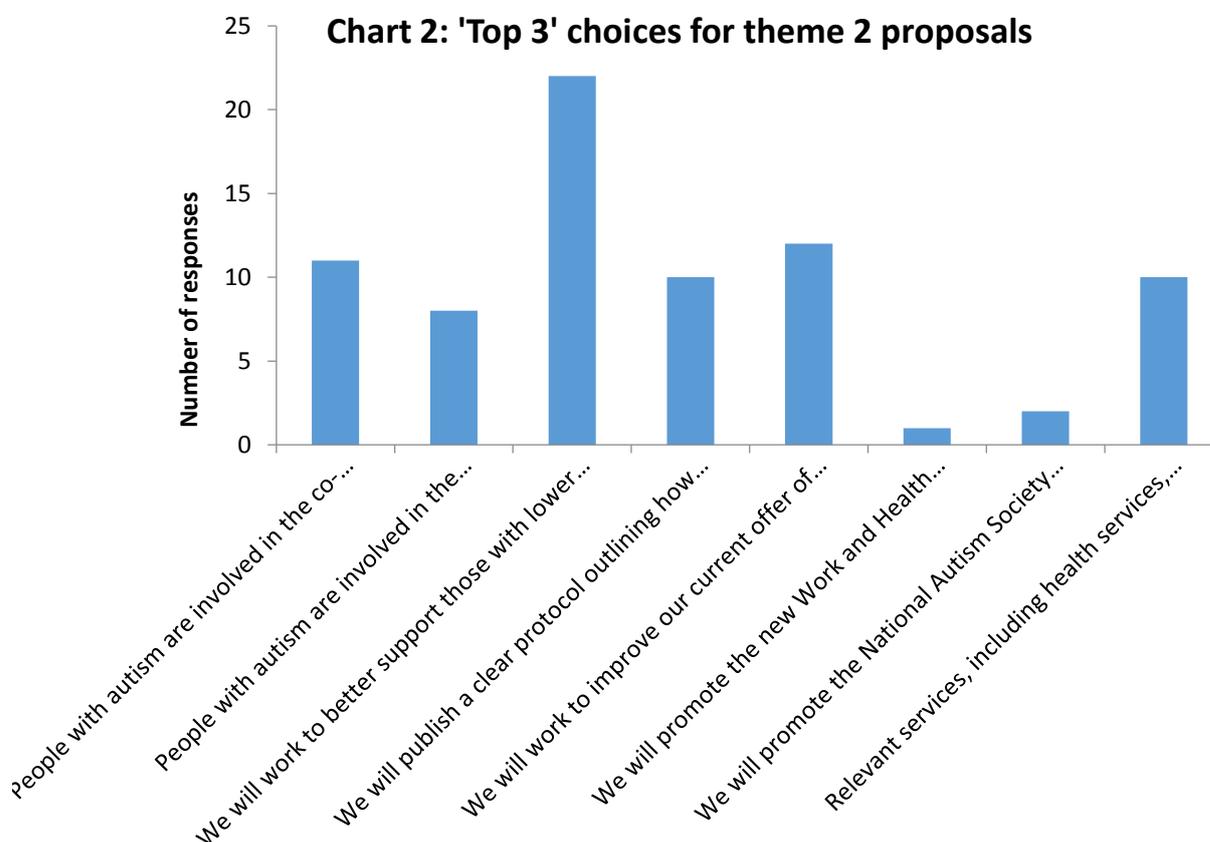


Theme 2: Involving and supporting people with autism

13. It was highlighted that there is currently no register for people with autism in Merton, and a lack of data on adults with autism (diagnosed or undiagnosed). As a result, services are planned on estimates rather than true figures. To overcome this it was suggested that the voluntary disability register, which currently exists for children aged up to 19 years old should be extended to include adults. In addition, the M-Card scheme which you can apply for through the disability register should be extended to include adults.
14. There was wide feedback that there is a lack of social activities for both children and adults with autism in the borough. In particular, the young people with autism who participated in the engagement felt there was a particular lack of social activities for teenagers. They suggested well organised, small group activities, i.e. in the same place, at the same time each week/month would be a good start. They were in agreement that activities should be autism-friendly, but not necessarily autism-specific.
15. There was feedback that services need to be better co-ordinated, and it was suggested that an autism team within London Borough of Merton be established to address this. This team should include representatives from housing, benefits, social care and education who are trained in autism, and there should be a named 'autism lead' to oversee the team.
16. There was a consensus that support needs to be individualised, and available throughout a persons life i.e.it should be accessible on an ad-hoc basis. By providing

a better continuum of support this would lead to a reduction in crisis intervention whereby people are only accessing support at a critical point.

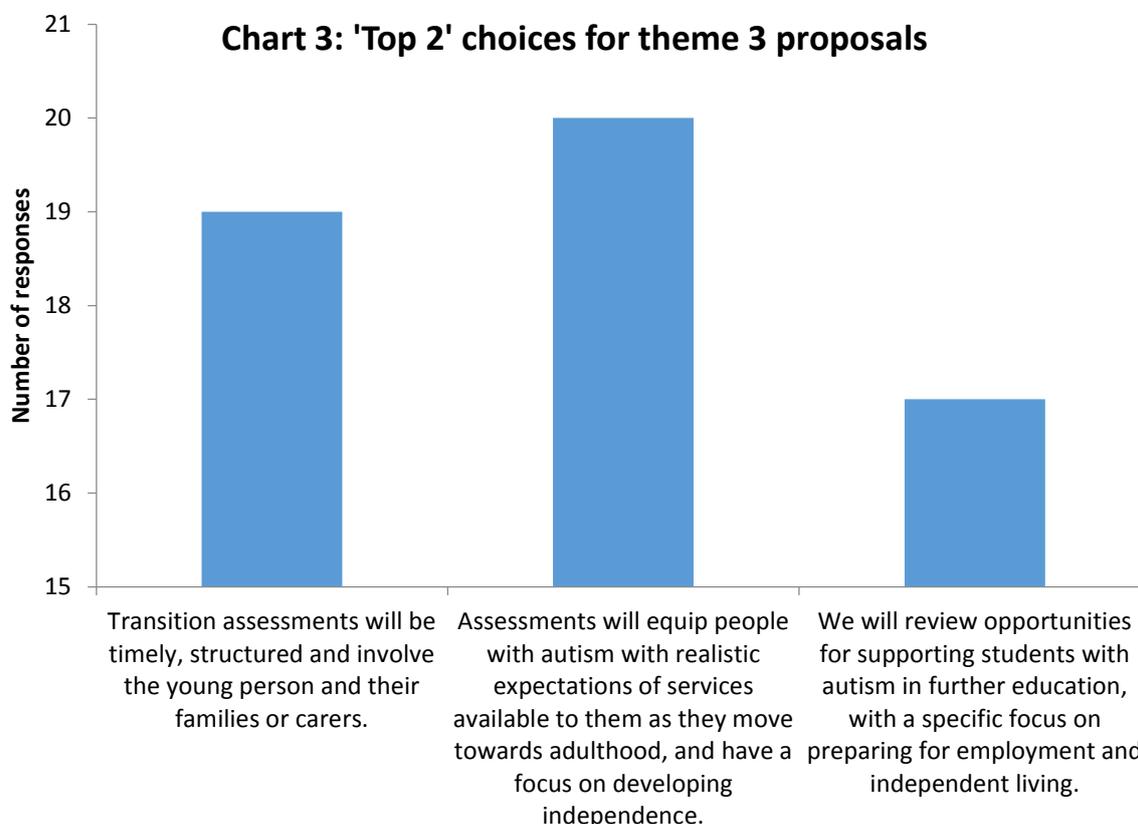
17. Young people passionately expressed the importance of involving people with autism in the design of services and in particular the recruitment and selection of staff who will work with those with autism.



Theme 3: Preparing for adulthood

18. There was widespread feedback that the proposal to focus on developing independence as young people move towards adulthood was important.
19. Young people felt that there should be more opportunities for apprenticeships and training e.g. extended work experience and interview training. One respondent had recently completed travel training and valued this extremely highly as a means of increasing independence.
20. Young people felt that it is easy to pigeon-hole young people with autism into specific courses or programs designed for SEND and this is sometimes limited in its offer. They felt more should be done to either increase the offer of subjects available in SEND provisions or further enable inclusion into mainstream courses.
21. Young people felt more should be done to support the basic independent living skills including financial management, understanding employment, transport and living skills such as using kitchen appliances, cooking, planning their own timetables etc.

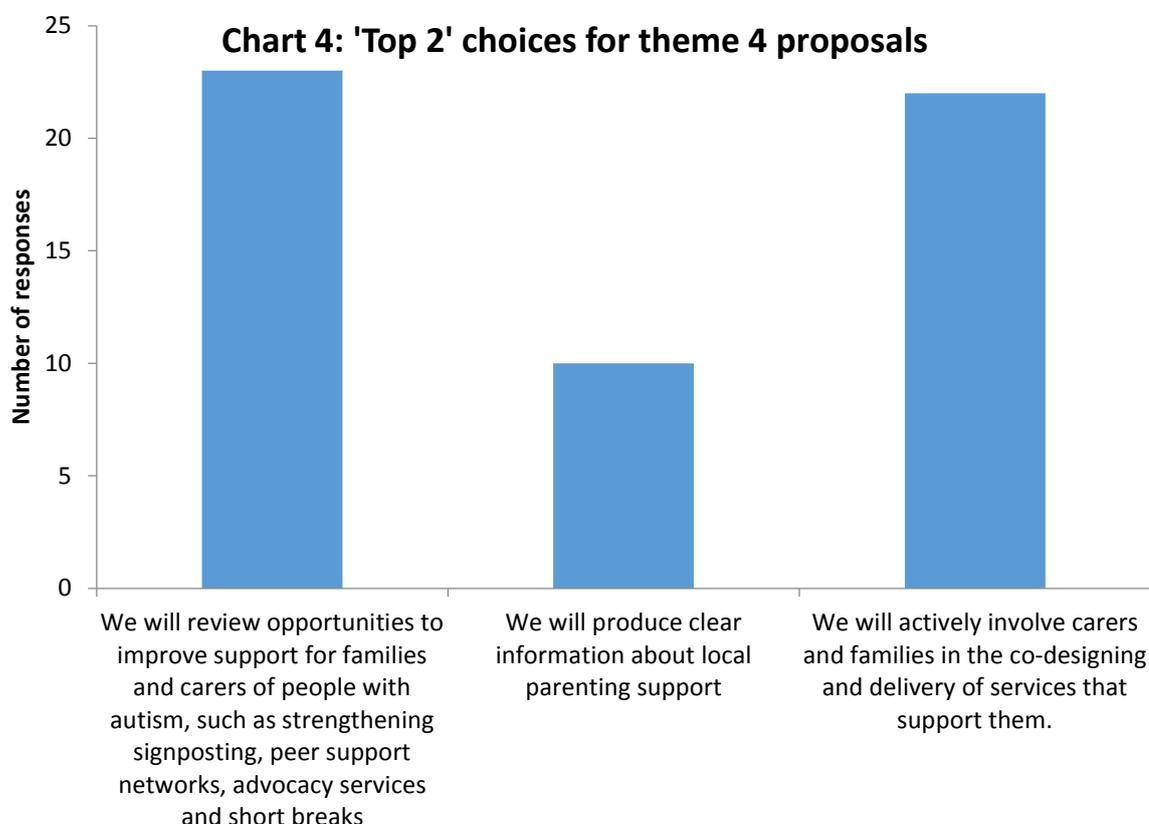
22. It was suggested that an event such as an ‘autism fair’, which advertises opportunities for young adults with autism in education/work/social activities would be beneficial.



Theme 4: Supporting families and carers

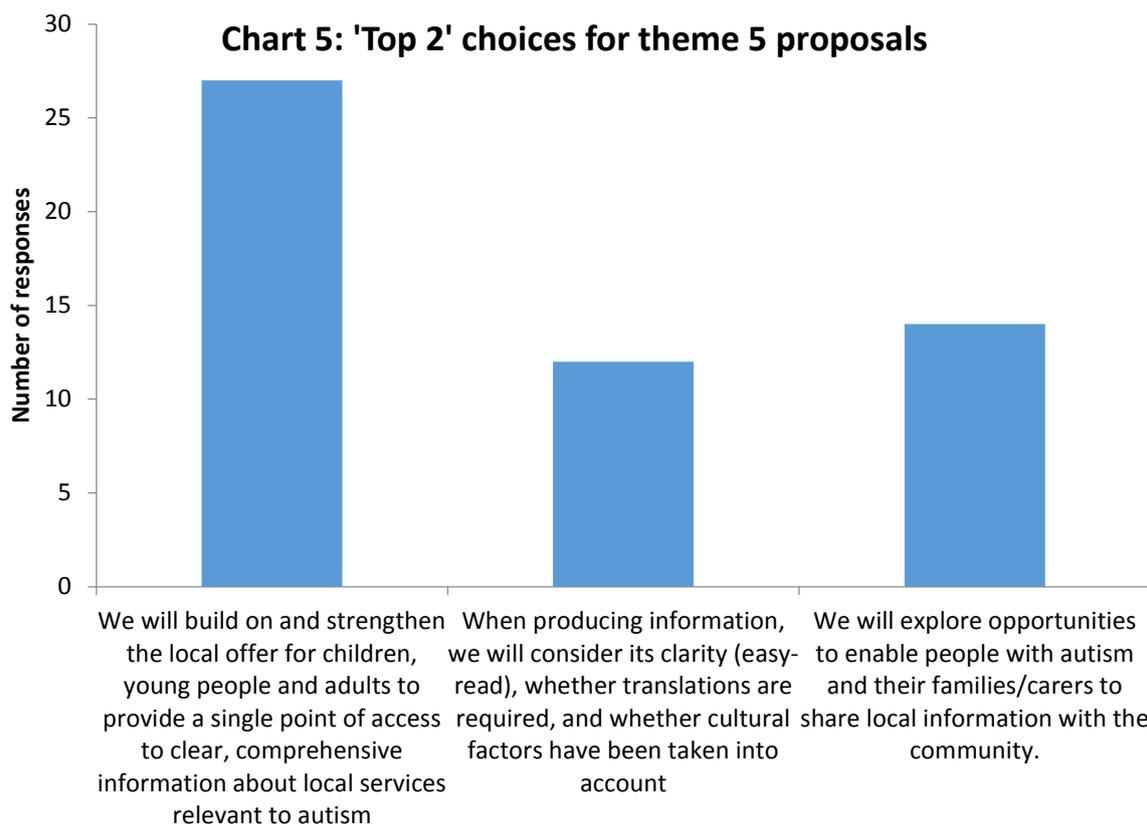
23. There was consistent feedback that there is currently a lack of support for parents of children and adults with autism in the borough. It was noted that parenting programmes are not available to those with children over 8 years and the current ‘Early Bird’ parenting programmes are only available to parents with children under 8.
24. It was acknowledged that parental understanding is key to improving outcomes for children with autism and that training for parents following a diagnosis of ASD should be a priority (see also theme 6).
25. In addition, it was highlighted that there was no recognition in the strategy that families and carers of people with ASD are often under extreme pressure which can lead to family breakdown and mental or physical health issues for the parents/carers themselves. It was suggested that post-diagnosis counselling is offered to parents/carers, and that GP’s and social workers need to be better trained in recognising, and acting on signs of stress or mental health issues amongst the families/carers of those with autism.
26. There was also feedback that there needs to be more training for parents and carers as children with autism grow up and their needs change, such as how to help their

children with issues related to puberty, friends and whether or not to disclose their diagnosis as they get older.



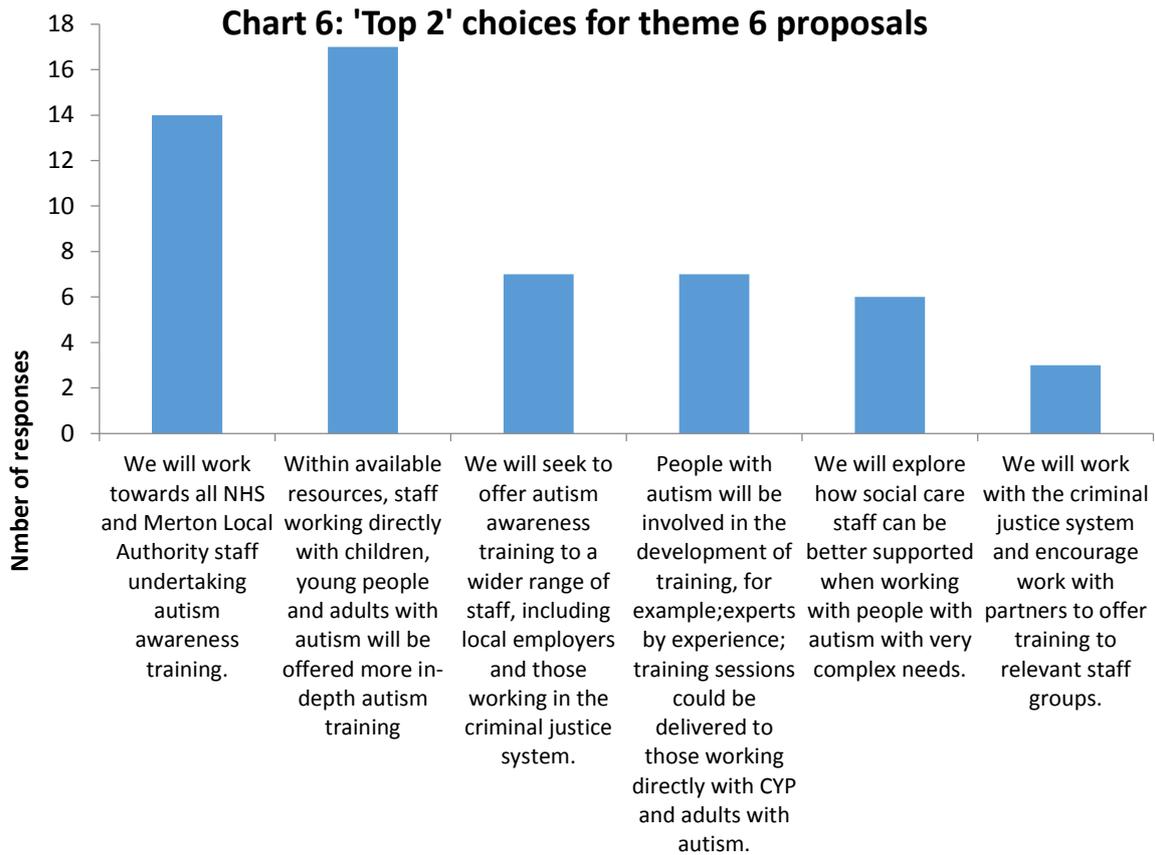
Theme 5: Information

27. There was a majority view that the 'local offer' which currently details information on services for people with autism needs to be improved in order to be useful. It was suggested that a role is created within the council for a local offer lead, who would ensure the information provided is comprehensive and up to date. It was stated that the council should be proactive in finding out about services available and should not be dependent on organisations or parents informing them about services. It was also suggested that the local offer be clearly laid out with headings of 'Childrens ASD' and 'Adults ASD' to make it easier to navigate.
28. Young people fed back that not enough was done to promote access to mainstream extra curricular activities such as youth clubs and that they don't always want to go to 'special clubs'. They felt staff running mainstream extra-curricular activities need to be autism aware. The lack of support available for young females with autism and how there are few opportunities to learn from positive female role models with autism was noted.



Theme 6: Awareness training and support for staff and services

29. There was an overwhelming consensus in the engagement feedback that training for staff and other residents is fundamental to achieving the strategy’s aims of making Merton an autism-friendly borough.
30. It was suggested that autism awareness training should be mandatory for all NHS and local authority staff, should include anxiety and sensory training and should be co-developed by people with autism.
31. People with autism who fed back views were mainly very enthusiastic about providing, or being involved in the development of, training for key staff groups. Similarly, respondents to the engagement (in particular those working in health services) were very positive about receiving training.
32. It was suggested in the feedback from people with autism that children need to be educated about autism as a priority, as well as teachers, employers and other professionals. They expressed that children and young people in school are one of the groups who understand autism the least, and this lack of understanding leads to bullying and people with autism feeling intimidated when out and about e.g. on public transport. It was proposed by young people with autism that older, non-autistic students could act as autism champions in school. They felt that this would help with acceptance and inclusion in schools.



Cross-cutting themes

- 33. Responses to the public engagement from people with autism, parents and carers in particular provided powerful feedback on the challenges facing individuals and families in the borough and many suggestions as to how these could be addressed.
- 34. There was a widespread agreement that strategy was comprehensive, the aims were endorsed and that it was a positive step towards making Merton a better place to live for people with autism.
- 35. There was also widespread feedback that whilst the proposals are generally positive and cover most of the important points, there was frustration that the language used in the strategy needed to give more positive commitment to delivering actions and offer more assurance that they will be achieved.
- 36. A recurrent theme across the feedback was that the strategy does not provide details of resources or costings that will be used to implement the proposals, which is needed to provide assurance.
- 37. It was noted that there is an emphasis on ‘support’ throughout the strategy but very little mention of ‘inclusion’ and removing barriers to participation, which would align with educational legislation. It was suggested that the language is revised to reflect this legislation more closely.
- 38. Feedback on the easy-read document was very positive, with respondents commenting that it is clear, well set out and of a high quality.

Section 3: Conclusions/recommendations

Priority Themes

39. It is proposed that the actions set out in the 'how we will get there' sections of the priority themes are prioritised in light of the public engagement feedback and aligned with the strategy action plan under the headings: 'In the first year we will..' and 'Over the life of the strategy we aim to..'
40. It has been agreed that the action plan is published alongside the final version of this strategy. It is proposed that this should identify priority actions for the first 1-2 years of the strategy, alongside priorities over the life of the strategy. This would offer assurance to stakeholders that progress is being made and accountability for delivery of the strategy.
41. It is proposed that theme 6 (awareness training and support for staff and services) is moved to Theme 1 to reflect the strength of feeling that training and awareness-raising is one of the most important themes in the strategy and fundamental to improving outcomes.

Theme 1: Recognition, support, referral and assessment.

42. Merton NHS CCG, LB Merton and partners are currently working in partnership to re-design the diagnostic pathway for 0-19 year olds and are undertaking separate co-production engagement on this. Detailed responses which relate to the diagnostic pathway will be fed back to the relevant commissioners to ensure these views are taken into account.
43. It is recommended that the new diagnostic pathway for children and existing pathway for adults includes a post-diagnosis appointment. This appointment would allow people with autism and their parents/carers the opportunity to ask questions about the future and be referred to post-diagnostic counselling/training if needed.
44. We received strong feedback that establishing autism champions is a top priority for stakeholders. It is recommended that this action is prioritised for the first year of the strategy and that people with autism are involved in the training and/or selection of autism champions in schools.

Theme 2: Involving and supporting people with autism

45. It is recommended that increasing social activities for children and adults with autism is a priority in the action plan, with identified specific leads who will implement this action.
46. We received feedback that we should consider establishing an 'autism team' within the London Borough of Merton and that this should include trained representatives from housing, social care and education and be over-seen by a named autism lead. We recommend that this is considered going forward, but recognise that more information gathering is required around the function and feasibility of such a team.

Theme 3: Preparing for adulthood

47. It is recommended that schools, libraries and adult education explore their potential for providing more life skills training for young people with autism. This could include interview training, extended work experience opportunities, financial management, cooking etc.
48. It is recommended that further education providers consider how they can promote inclusion for people with autism in existing 'mainstream' programmes, or expand the variety of programmes on offer for SEND pupils.

Theme 4: Think family

49. It is recommended that LBM works with partners, including Merton NAS, to identify resources to increase the availability of parenting programmes on offer in the borough –particularly for those with children over 8 years.
50. It is suggested that LBM explores opportunities to offer counselling and peer support to parents/carers of people with autism. For example, ensuring that existing counselling services (e.g. new IAPT service) are promoted; trained professionals or autism champions are supported to facilitate peer support groups for parents.

Theme 5: Information

51. It is recommended that Merton holds an annual autism fair to promote autism friendly services and activities in the borough and increase wider awareness of autism.

Theme 6: Training and awareness

52. It is suggested the existing proposal on 'working towards all NHS and Local Authority staff undertaking autism awareness training as part of general equality and diversity training' should be made mandatory and include anxiety and sensory training.
53. For health care professionals, including GPs, it is strongly proposed that training is delivered which includes the importance of recognising and managing co-existing mental health issues in people with autism.
54. It is proposed that an action is included that people with autism are involved in the development of autism training in schools and that schools are encouraged to provide autism training to all pupils, as well as staff.

Next Steps

55. The findings from the public engagement have provided valuable insight into local challenges, priorities and solutions. Information will be used to update the draft Autism Strategy and Action Plan, and feed into the governance of strategy going forward.

Appendix 1. Questionnaire dissemination list

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|---|
| <p>London Borough of Merton</p> <ul style="list-style-type: none"> • Community and Housing: • Adult social care, Libraries and heritage, Housing needs, Public Health • Children, Schools and Families: • Education, Children's Social care, Youth offending team • Environment and Regeneration: • Public protection • Safer Merton • Elected Members |
| <p>Health services</p> <ul style="list-style-type: none"> • Merton NHS CCG • NHS Providers including South west London and St Georges NHS Trust • London Ambulance Service • Healthwatch |
| <p>Voluntary services</p> <ul style="list-style-type: none"> • KidsFirst • Talk Autism • Merton Mencap • NAS Merton • Carers Support Merton • Hearts and Minds • Citizens Advice Bureau • Merton Voluntary Service Council • Age UK Merton • Merton Centre for Independent Living |
| <p>Community services</p> <ul style="list-style-type: none"> • Schools: Head teachers and SENCOs • Lifeways • Ability Housing • United Response • Vibrance • Choice Support • Merton Fire brigade • Circle / Clarion Housing • Merton Job Centre Plus |
| <p>Other Individuals on the Merton Autism Strategy Reference Group</p> |

Appendix 2. Engagement sessions and meetings

i. Engagement Sessions with people with autism and parents/carers:

| Session | Date |
|---|-------------|
| TalkAutism/KidsFirst | 07/02/18 |
| NAS Merton | 08/03/18 |
| London Borough of Merton Learning Disability team | 12/03/18 |
| Hearts and Minds | 14/03/18 |
| Youth engagement team | March 2018 |

ii. Engagement sessions and meetings with professionals and partners:

| Session/meeting | Date |
|--|----------------------|
| Merton CCG Patient Engagement Group | 24/01/18 |
| Merton CCG Clinical Reference Group | 10/10/18 |
| London Borough of Merton Education Team | 05/02/18 |
| Merton SENCO Forum | 28/02/18 |
| Merton NHS CCG GP locality meetings (East and West Merton) | 21/03/18 22/03/18 |
| Merton Children's Trust Board | 21/02/18 |
| Merton Preparing for Adulthood partnership | 05/03/18 |