



**Hackney Independent Forum for
Parents/Carers of Children with Disabilities**
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Parent-carers' experiences of services for disabled children and young people in Hackney

April 2015

About HiP

HiP is Hackney's independent forum for parent-carers of disabled children and young people. The forum was set up six years ago by a group of parents who wanted to help families of disabled children have a bigger say in how services for their children were commissioned and run. From small beginnings, the forum has expanded beyond expectations.

HiP now has an established and experienced steering committee comprising 15 parent-carers from a range of community backgrounds with a variety of experiences of disability in the family. The forum supports parent representatives to sit on committees and boards across education, health and social care services in Hackney. We are engaged in co-production of some areas of the SEN reforms.

Our parent-carer representatives make sure the views of parent-carers are heard whenever services are planned and commissioned. We also provide feedback on the quality of, and barriers to accessing, existing services.

HiP aims to improve outcomes for families of disabled children in Hackney by:

- Representing the views and experiences of parent-carers
- Holding services to account
- Empowering and supporting parents through events and signposting
- Communicating information on local services to families with disabled children

About this report

This report sets out findings from a four month project to test and establish a new way of capturing the views of parent-carers of disabled children in Hackney.

HiP has always worked hard to reflect and represent the views and experiences of all parent-carers in Hackney, regardless of background, ethnicity, child's age or disability. We have actively encouraged parent-carers to share their views and experiences at workshops, training events and focus groups arranged by HiP or at events organised by other services/agencies. HiP representatives always aim to reflect the views of local parent-carers across education, health and social care.

In December 2014, HiP embarked on an unfunded trial project to test a systematic way of capturing parent-carers' views in various settings. The aim of the project was to:

- Capture parent-carers' voices, especially those seldom heard
- Identify emerging themes/issues about services for disabled children
- Highlight areas of excellence/poor practice
- Provide commissioners/operational services with useful qualitative data
- Help HiP set priorities and focus energies where need is greatest
- Identify gaps in provision (services) and activity (HiP)
- Track improvements/services over time

Method – not a conventional survey

HiP has developed a two-page comment collection sheet for use with parent-carers of disabled children and young people in Hackney. The sheet was designed for ease of use and to be flexible enough to use in range of settings. The form requires parent-carers to provide consent for HiP to use and process the anonymous data. The form collects equalities data. The comment collection form was adapted from a similar form routinely used by Healthwatch Hackney to collect feedback from residents on health and social care services.

Respondents are asked to tell us about their experience of services they use and rate them on a scale of 1 and 10. A sample comment sheet can be found in Appendix 3 at the end of this report. The form was revised slightly shortly after the start of the project following feedback from our comment-collection volunteers.

The form is not designed to be completed by the parent-carers themselves. Instead, HiP volunteers start by engaging in conversation with parent-carers before the form is produced. The aim is to allow the parent-carer time to relax and focus on the main service/s they use and their experience of using them.

Our comment-collectors use semi-structured prompting such as: 'Which school does your child go to?' 'What type of additional needs does your child have?' 'Are you happy with the support he/she gets?' 'Do you use short breaks?' 'What support do you get as a carer?' This approach provides greater experiential insight and reduces the risk of just 'listing' services on the form. It also allows time for the volunteer to identify the key issues that matter most to the parent-carer.

Feedback conversations typically take place during breaks/lunch at events and workshops or at the school gate. Some data and feedback is gathered via email and phone conversations with parent-carers who contact HiP for advice or signposting.

Where and when we collected comments

Comment collectors used the form in the following settings:

- HiP Spring Lunch *27 February 2015*
- Planning Together for my Teenager's Future (HLT event) *21 March 2015*
- HiP SEN legal training with IPSEA *24 March 2015*
- Via email contact *various*
- Face to face with parent-carers: school gate, on bus etc *various*
- Over the phone *various*

65 comments were collected from Hackney parent-carers of disabled children between 1 December 2014 and 31 March 2015.

Scope and limitations

This method of collecting parent-carer feedback has many advantages. The feedback sheet is short, flexible and promotes 'community conversations' with parent-carers around services for disabled children. However, it is not a 'scientific' survey and therefore it should be treated as a useful snapshot of parent-carers views/experiences about local services for use by HiP and commissioners alongside other established feedback channels.

We would stress that regular ongoing comment-collection should not remove the need for services to conduct more formal surveys on specific services or borough wide issues such as EHC planning and transfers.

Findings

Summary of key findings:

- Short Breaks are highly valued/rated by parent-carers
- Hackney Ark and CAMHS are also well regarded (with some exceptions)
- Parent-carers can have widely different experiences of the same service
- Evidence of poor SEN practice persists in some schools/nurseries
- 54% rated services as above average, good or very good
- 31% reported poor, unsatisfactory or below average experience of services
- The average score/rating across all services was 6/10
- Education services scored 4.8/10
- Health services (including mental health) scored 7.5/10
- Social care services scored 7.1/10
- Hackney's Local Offer is not meeting parent-carers'/YPs' needs
- Support around transition (18-25) continues to be a major concern
- More feedback is needed from Turkish, Asian and Vietnamese parent-carers
- More feedback is needed from a wider range of disability areas

Recommendations for HiP

- Further develop comment collecting
- Share findings and data with EHC managers and commissioners
- Secure funding to support comment collection work
- Produce three reports a year and case studies
- Produce an annual report
- Scope feasibility of using electronic devices for comment collection
- Share data with all HiP reps to inform representation
- Aim to collect up to 400 comments a year (with funding)
- Arrange specific training for volunteers on how to comment collect
- Ensure a wider range of disabilities is represented
- Target Turkish, Asian and other communities underrepresented in findings
- Create an electronic form for use alongside face to face collections

How do parent-carers rate services in Hackney?

HiP comment collectors asked parent-carers to tell them about services they or their child had used. They asked them to score the particular service they had told us about using a scale of 0-10 where 10 is 'very good' and 0 is 'poor'. 19 out of 65 comments were unscored, 46 were scored.

25 out of 46 (54%) parent-carers rated services as above average, good or very good while 16 out of 46 (35%) rated services below average, unsatisfactory or poor. The average score across all services was 6/10. Parent-carers particularly valued Short Breaks, Hackney Ark and CAMHS although the same three services also featured among the lowest rated.

Two primary schools and one school nursery were among the lowest scorers while a local secondary academy featured among the highest and lowest rated. The Local Offer appears three times among the lowest scores.

These scores suggest many parent-carers experience excellent services for their children in Hackney but there are pockets of poor quality provision that need to be addressed. An indicator of overall improvement across services would be an increase in the average overall score over time.

Score out of ten	No	Satisfaction
Ten (very happy)	13	Very good
Nine	5	Very good
Eight	4	Good
Seven	2	Above average
Six	1	Average/OK
Five	5	Average/OK
Four	3	Below average
Three	3	Unsatisfactory
Two	2	Unsatisfactory
One	3	Poor
Zero (very unhappy)	5	Poor

Highest rated (7-10) Short Breaks x 10, Hackney Ark x 7, CAMHS x 5, HiP x 2, HPPS x 2; xxx Academy x 2, Carers Centre Advocacy Service x 1, primary ARP x 1, out of borough Academy x 1; Young Hackney x 1, Transition Health Outreach x 1, Homerton Hospital x 1, GP x 1, SEN Support x 1

Lowest rated (0-4) Local Offer x 3, secondary Academy x 1; HLT SEN team x 1, HLT x 1, Police/CAMHS x 1, HPPS x 1, school nursery x 1, primary school x 1, Short Breaks x 1, Primary School x 1, ASC post 18 x 1, Specialist Dental Service x 1, CAMHS x 1, Transition to adult services x 1

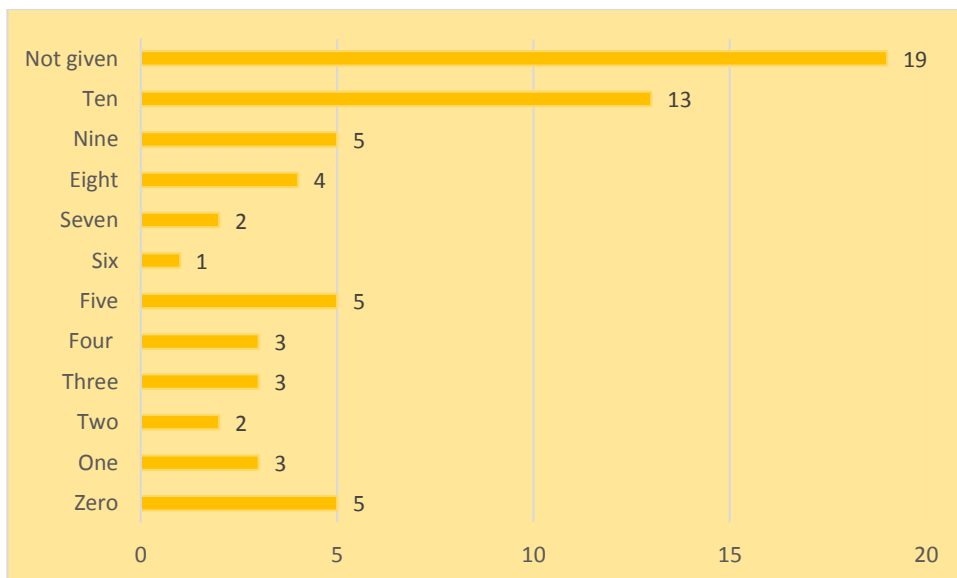


Figure 1 parent-carer satisfaction with services 31 Dec 2014-31 March 2015 (total: 65)

Parent-carer satisfaction with education services

Twenty-three parent-carers commented on their experiences of education services in Hackney. Comments related to Hackney Learning Trust, particular academies and primary schools, one nursery, the Local Offer and the SEN process. Four comments did not include a score. Four comments/scores spanned more than one service (Education/Health/Social Care). See the summary of comments in Appendix 1 for more details. The average score for education services in Hackney was 4.8/10.

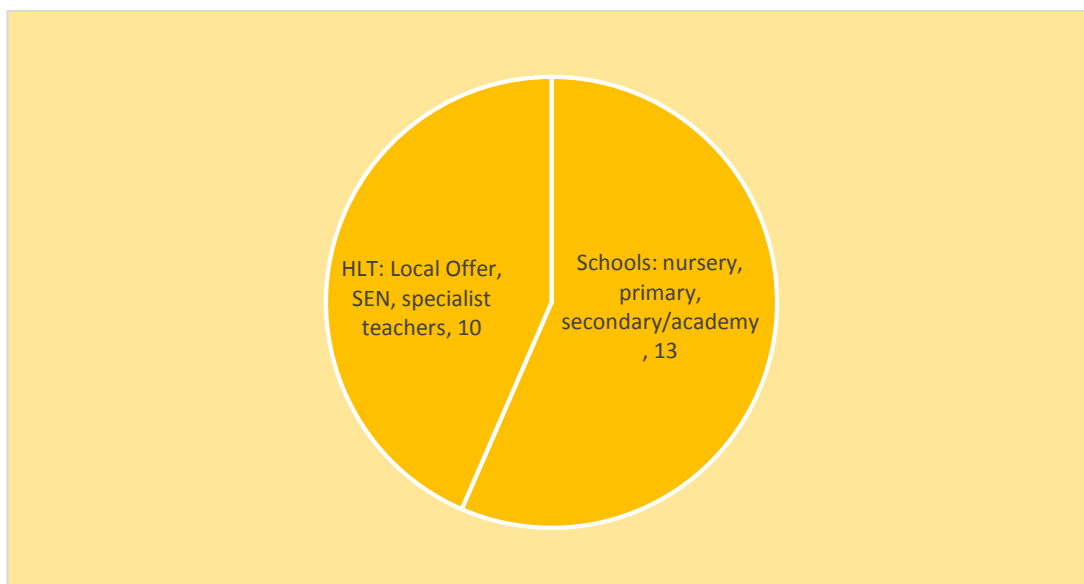


Figure 2 Parent-carer comments by education service type

Some comments about schools/early years' services highlighted particular cause for concern. A parent-carer of a nursery age child undergoing assessment for ASD and learning disabilities was extremely worried about the school nursery's approach to her child.

'I don't think school staff know what they are doing. They do not pay attention to my child. They say they cannot give 1:1 because he doesn't have a statement. My son comes home with bruises and my mum has to check his body at school because I am scared of social services. Son gets bullied but because he does not say anything the school does not believe this. Son acts out actions of the day at home – this gives evidence of what goes on at school. My son gets shouted at and told sit down on the cushion.'

Another parent-carer of a nine-year-old with ADHD told us her child's primary school regularly excluded their son because the school couldn't manage him but she had *'no-one to talk to about this'*.

Hackney Parent Partnership (HPPS) was rated as 10 by two parent-carers, however another parent-carer gave the service a zero rating because she felt staff were 'rude' and lacked knowledge. This suggests parents can have widely differing experience of the same service. It also suggests excellent service exists alongside poorer quality service/communication.

Parent-carer satisfaction with health services (including mental health)

Thirty parent-carers provided feedback on various health services they had used for their child or themselves. 13 of the comments were unscored. Some parent-carers fed back on more than one health service and on education and social cares in the same comment. The chart below is based on 36 comments on health services provided by 30 parents. The average score for health services in Hackney (based on 17 scores) was 7.5/10. See the summary of comments in Appendix 1 at the end of this report for more detail.

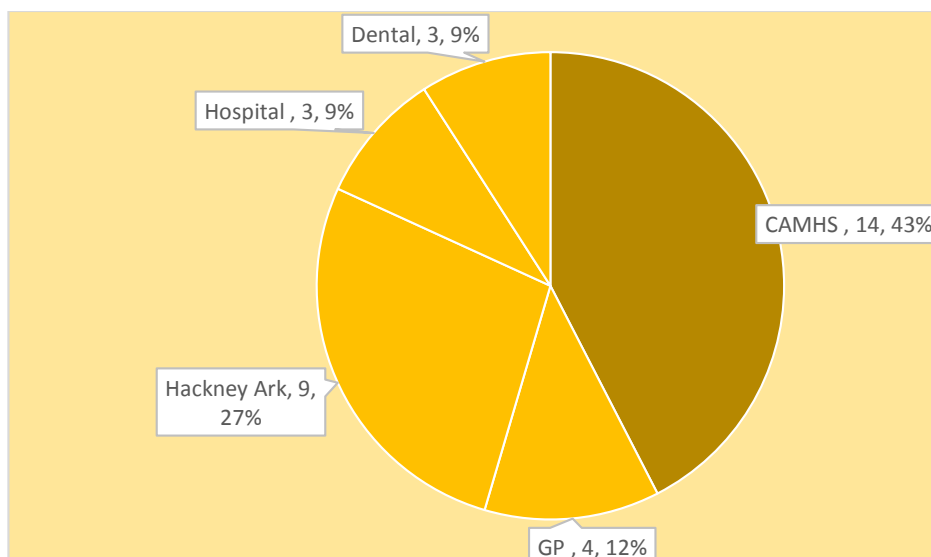


Figure 3 Parent-carer feedback by health service type

CAMHS was rated highly by parent-carers and clearly operates well for some families although waiting times remain an issue. One parent-carer of a child with autism said of the CAMHS services at Homerton Row:

'All worked very well. They listened to my child and us. Gave us parent support while on five month waiting list. They understood the complexity of the issues and gave excellent, non-patronising and sensitive support.'

However often the quality of the service depends on the experience and approach of the professionals who work with the child and family.

Another parent-carer of three children with long-term health conditions had a mixed experience of using CAMHS:

'The first psychologist was excellent with my son. She was professional, pleasant and friendly and talked with him not to him and helped him open up. The second was not child friendly. She never listened to both of us so we stopped going as it was time-wasting.'

The same parent-carer provided some useful insight into the specific mental health needs of parents caring for more than one sick child.

'When one child is sick or has a disability, this can have an impact on the emotional, behavioural, and physical well-being and health of the whole family but in my case I have three kids with medical conditions which I find very changeling and difficult. As the main carer it would be nice if we could get some kind of counselling or respite to help and cope better with the situation.'

Parent-carers were largely positive about services at Hackney Ark although one parent-carer felt the OT service had not adequately addressed her son's ASD-related sensory integration needs.

Three parents also raised concerns about difficulties accessing Hackney's specialist dental service and the fact it is no longer provided at Hackney Ark.

Parent-carer satisfaction with social care services

A total of 20 parent-carers provided feedback on social care services including Short Breaks, Disabled Children's Services (DCS) and Adult Social Care (ASC). Short Breaks scored highly except among parent-carers of young people in their later teens about to go, or just completing, transition to adulthood. Support for disabled young people through transition and up to the age of 25 remains an area in need of significant improvement. Five comments out of 20 were unscored.

One parent-carer of two children with autism said her 18 year old with Asperger Syndrome was reclusive and 'doesn't go out for months'. She got 'little help from services.'

'Social services don't provide enough information and support. I wish there was more support for getting him out of the house and to get more 'integrated.' She said he son had refused to co-operate with an application for DLA. She added that she spends most of her money on food and things for him. *'I sometimes steal food.'*

The average score for social care services was 7.1/10.

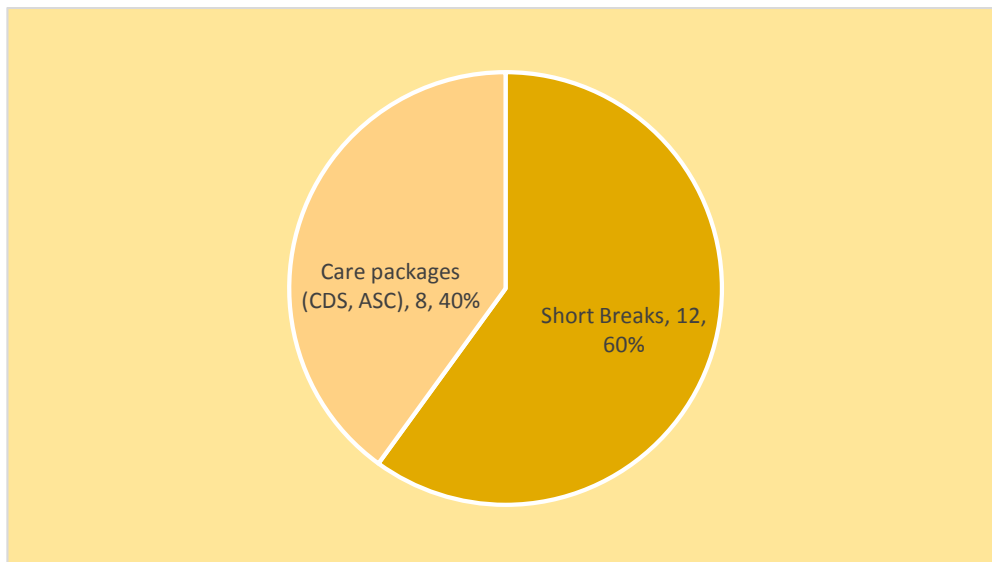


Figure 4 parent-carer comments by social care type

Equality data

HiP's comment collectors collected equality data on the child's disability /additional needs, the gender and age of the parent-carer and their ethnic or cultural background.

Child/young person's disability or additional needs

More than half (53%) of parent-carers who provided feedback had a child or young person on the autistic spectrum. It is unclear how many of these children/young people also had a learning disability. 12% had a child with speech and language needs and/or dyspraxia. 8% had a child with a learning disability, rare syndrome or global developmental delay. 6% had a child with Down's syndrome and 6% with a long term health condition.

The large number of ASD parents providing feedback to HiP is likely to reflect the high prevalence of ASD compared with most other childhood disabilities. It may be possible that this group of parent-carers feel a greater need to comment on services because historically they have found it harder to find the right type of autism-specific support for their child and their related behavioural issues. Service pathways for autism are also less clear.

It is not possible to say whether parent-carers of children with ASD are over-represented in this survey as there is no reliable local data on the number of children with autism living in Hackney. Hackney's key register data, for example, fails to collect separate data on children with an autism diagnosis.

Any future HiP comment collection should seek to widen the range of parent-carers interviewed to gain insights into the experience of children with disabilities under-represented in this feedback.

Disability/additional need	No.
ASD (including ASD with ADHD)	35
Speech and language needs, dyspraxia	8
Down's syndrome	4
LD, rare syndromes, GDD	5
Long term health conditions	4
Cerebral Palsy	2
Other – hearing loss, ADHD, behaviour	3
Not given	4
Total	65

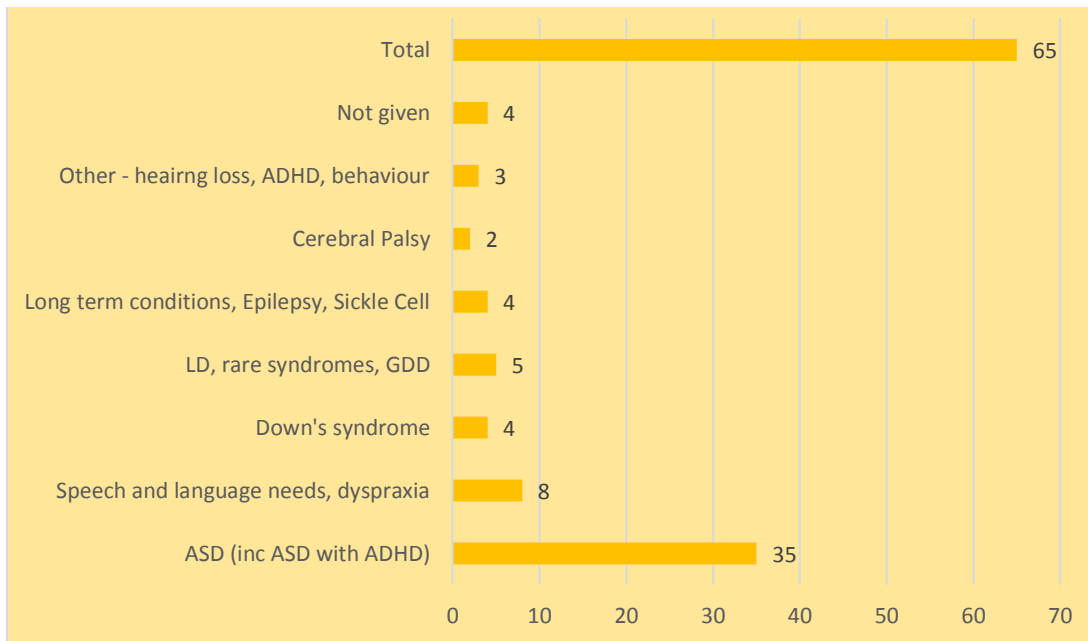


Figure 5 Child/young person's' disability/additional need

Ethnicity/cultural background of parent-carers

31% of parent carers described themselves as White British including Irish, European, East European and Jewish. 29% of parent-carers described themselves as African including Nigerian, Ghanaian, Congolese, East African, West African and South Sudanese. 17% described themselves as Caribbean/African Caribbean or British Caribbean while 6% were Turkish.

Future comment collection should focus on collecting comments from underrepresented communities including Turkish/Kurdish, Asian (Pakistani, Indian, Bengali) and Vietnamese parent-carers

Ethnicity	Number
African – all	19
Caribbean/African Caribbean	11
British Chinese	4
White British/European/Jewish	20
South American	3
Turkish	2
Asian (Pakistani)	1
Not given	5
Total	65

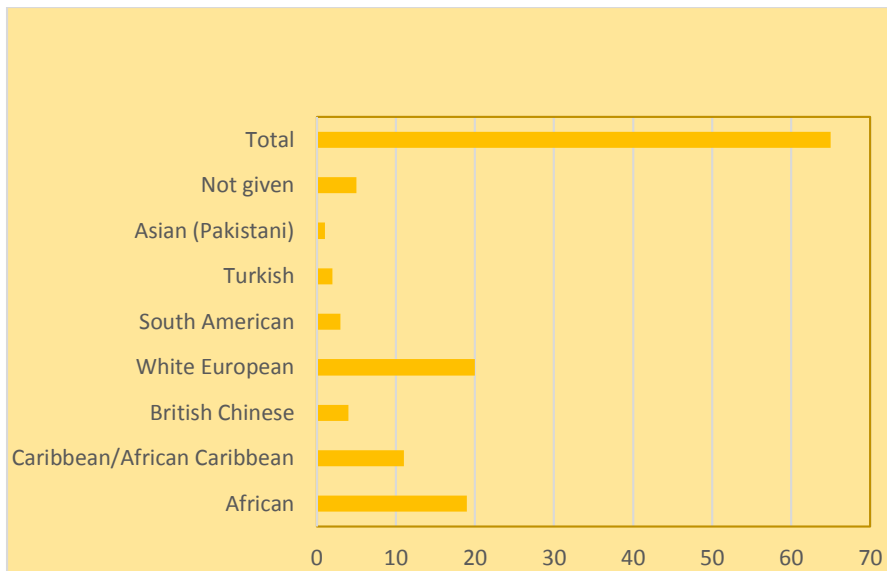


Figure 6 Ethnicity/cultural background of parent-carers

Age of parent-carers

Most parents-carers providing feedback were aged 30-60. The largest group of parent-carers were in their 40s. Only one parent-carer was in their 20s. HiP could improve the comment collecting by seeking out younger parent-carers to provide feedback.

Age group	Number
20+	1
30+	15
40+	25
50+	10
60+	4
Not recorded	10
Total	65

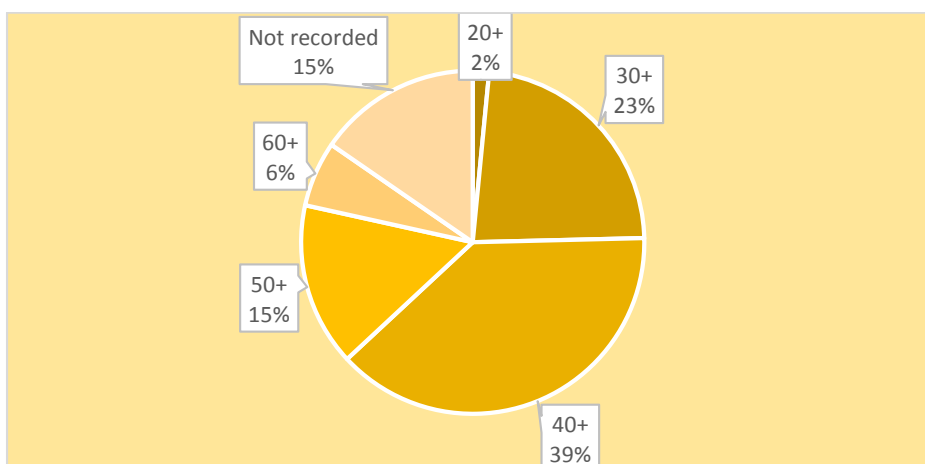


Figure 7 parent-carers by age group

Breakdown by gender

The vast majority of parent-carers were women. Five men provided feedback to HiP. These figures are unsurprising but efforts should be made to seek out the views of more fathers/male carers in future.

Gender	Number
Female	55
Male	5
Not recorded	5
Total	65

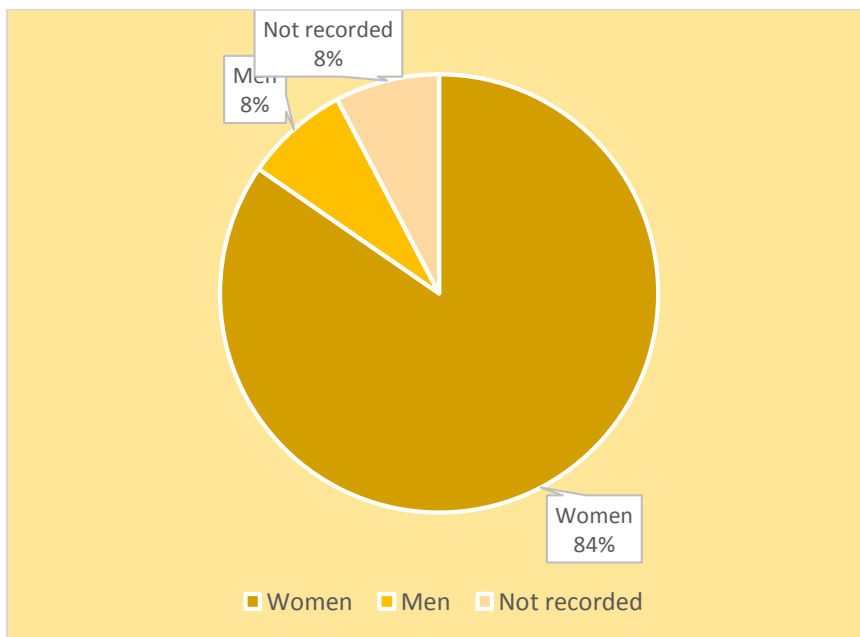


Figure 8 parent-carers by gender

Appendix 1 – parent-carer comments*

*More detailed comments along with equality data is available on the source spreadsheet and these are available to managers on request

There is no involvement [for my son] due to uncertainty between School and Specialist teacher service [school not providing specialist teacher time in statement but resolved after parent sought advice from ISPEA]	Primary School and HLT specialist teacher service
Long delay by CAMHS identifying child's atypical autism presentation	CAMHS
Waiting times to be seen by CAMHS for possible ASD	CAMHS
CAHMS able to provide my daughter (now 19) with appropriate assessments and referrals	CAMHS
Inconsistent quality of staff at CAMHS. First psychologist excellent with son, 2nd not child friendly and never listened so we stopped going. New person was not child friendly and never listened to both of us and for that reason we stop going as it was time wasting. First CAMHS psychologist (for one of three disabled children) was amazing. She was professional and pleasant and friendly, talked with him not to him and it helped him open up.	CAMHS
Everyone should be able to access family therapy and individual support if they want it. Family therapy with the Ark therapist was helpful for us	CAMHS
We need an autism-informed and friendly support for the parents in terms of meeting their mental health and isolation. Not a good experience of family therapy in Hackney	CAMHS - family therapy
All worked very well. Listened to my child and us. Gave us parent support while on waiting list. Understood Complexity of issues and gave excellent, non-patronising and sensitive support	CAMHS - Homerton Row
Loss of HFA/ASD expertise at CAMHS following redundancy of key Consultant Psychologist	CAMHS - Homerton Row and John Scott
Better mental health support for parent-carers please	CAMHS - therapy
Services are disjointed. They should be joined up	CAMHS, Short Breaks, Hackney Ark
Comprehensive service - good referrals	CAMHS; Short Breaks
Advocacy service worked very well. It was very supportive and liaised with organisations on my behalf	Carers Centre - advocacy

Insufficient means to help 12 year old son access the curriculum. He does like school though	Academy
Turned away from free swim although had Hackney Carers Card	City and Hackney Carers Centre
Unsure if parent/carer could ask for revision of core assessment form after assessment	DCS
Not enough direct payment; son gets 1:1 but carer refuses to take out sisters as well. I need service that involve family/siblings	Direct Payments
Son (9) with ADHD constantly excluded because school couldn't manage him - parent had no-one to talk to	Primary School
Poor quality GP referral to CAMHS and Paediatric services	GP
Finds it really difficult waiting at GP with son	GP
All services working well for five year old with hearing loss	GP, CAMHS, Hackney Ark, Homerton Hospital, Short Breaks, SEN Support
Lack of autism awareness and training among Hackney GPs	GPs
Son (3 1/2) bullied and bruised at school but staff do not notice or act on it. Mum has to check his body at school Son acts out what happens at school. Son does not speak so not believed.	Grazebrook - nursery
Info from Hackney Ark works and instruction work well with my child - also uses GP, HPPS, National Autistic Society. A local website would improve service	Hackney Ark
Hackney Ark is helpful for my eight year old who has behavioural [issues] I would change nothing. Service is OK	Hackney Ark
All services (GP, CAMHS, Homerton Hospital, Short Breaks are all good. Good to have all services in one place	Hackney Ark
ASD son's (11) sensory issues not addressed by OT who says issues are behavioural. Not enough time spent. Son was given useful activities but parent would prefer sessions with OT	Hackney Ark - OT
Praised physio at Hackney Ark, support at school and short breaks. 'Everything works well.'	Hackney Ark; out of borough Academy; Young Hackney
HiP very informative and supportive	HiP
Likes spending time with other parents in the same situation (peer support) strategies and techniques and liaison with schools	HiP events
Phone HLT at 4:40pm and it went straight to ansaphone message (Xmas message)	HLT

Useless information on Local Offer	HLT - Local Offer
Parent-carer and parent adviser unable to find what they need on Local Offer	HLT - Local Offer
Son's revised statement very late and missing key information	HLT SEN Team
Worked well in all areas. Helped by coming to school meetings to help put strategies in place for 13 year old son's ASD behaviours	HLT/Inclusion Team
Lack of local support groups for parents of children and teens with epilepsy	Homerton Hospital, community services
Found HPPS staff rude and unhelpful. Did not know what they were doing Will not use them again	HPPS
HPPS good providing info and running informative groups	HPPS
Parent partnership is very supportive attending school meeting for 15 year old son. Events eg behaviour, adolescence etc very useful	HPPS
Delay in getting DP. Assessment was difficult. DP is good and choice.	Learning Disabilities Team - direct payment
Difficult to find out of borough provision on Local Offer Website	Local Offer
Respite provision and mental health/counselling support for parent-carers especially those coping alone or with more than one disabled child	Mental Health Services, CAMHS
Excellent AR report - autistic son finally making progress academically	Academy
School 'no mobile phone' rule barrier to pupils with LD or SEN learning more independent home-school travel	Academy
Punishing ASD child for lateness caused by ASD anxiety& school refusing to listen to parent-carer	Academy
Took child with dyspraxia to Hackney Ark and found the service was very fast and good	OT - Hackney Ark
Inappropriate treatment of ASD teens who meltdown. Shocked to witness police bring ASD Asian 15 year old to Homerton Hospital A& E in back of police van. Clearly she had been handcuffed as was rubbing her wrists. Made point of listening in to conversation between police and A&E staff as my teen son has ASD. Meltdowns can be tough but this is not the way to manage disabled children	Police, Homerton Hospital. CAMHS
Struggle finding schools before formal ASD diagnosis	Primary schools
Struggle finding and changing schools for ASD child without statement/EHC plan in place	Primary schools

Lack of information on school and educational provision for ASD CYP in Hackney	Schools
Failure to properly join up home/school support for ASD children	Schools
Happy with provision for 17 year old ASD daughter but needs more travel training. Having English is a second language has been a barrier to understanding and accessing services for her	Short Breaks
Sat short breaks stopped. Now only gets Thurs and Mon at Huddleston after school. 17 year old son depressed because he has no social life. Sits at home and watches TV	Short Breaks
Short Breaks good at first but worker left. Service went on claiming though son not using it.	Short Breaks
Short Breaks service is very good. Gives carer a break and 12 year old son fun things to do	Short Breaks
Worried where children (14 & 12) can go now they are bigger & needs help to a place	Short Breaks
Short Breaks with personal budget, we can use as we want, works well for eight year old with learning disability and ASD but this does not work well with direct payments	Short Breaks - IB and DP
Tone & content of Short Breaks letter seeking proof of DLA entitlement	Short Breaks Team
Mum to reclusive AS 18 year old who 'doesn't go out for months' little help from services. Social services don't provide enough information and support. Also has 8 year old with autism	Social Care 18+
Severely autistic son gets excellent care at Royal London but there is a six month wait	Specialist dental service
Specialist dental service stopped at The Ark - nowhere to take five year old with sensory needs. Referred to St Leonards but six week wait	Specialist dental service
Specialist service Ok when you get to see someone. High staff turnover at St Leonards. With 18 week treatment target, too easy to fall out of system. Happened to us four times due to dentists moving. Sometime dentist didn't turn up or were late. Son needs specialist service as has enamel problems. He is 13. Have been using since he was 5. Some dentists only work one day a week	Specialist dental service
Really impressed with Transition Health Outreach staff at Ark - doing travel training with 16 year old ASD son in holidays. They 'get' autism	Transition Health Outreach
Change over to adulthood poor & communication lacking - fund for his 100 hours carers time stopped at 18. OT is great but finishes in four weeks and we are not sure what is happening. Live planning really helpful - now have clear plan	Transition/ASC
Very happy with school ARP but struggled to get school to accept IB for after school club	Primary ARP; Short Breaks IB

Appendix 2 – suggestions/actions based on individual comments

School needs to listen to parent and work in partnership not blaming the parent all the time
Make schools accept IB for after school clubs
Much more travel training and more support for families with ESL
Join up services better
More funding for peer support
More support and info from social services
Make sure HLT is answered during office hours
Lack of clear information around core assessment process in social care
Sent to Hackney paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway
Sent to Hackney paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway
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Sent to Hackney paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway
Where can HiP raise poor or discriminatory practice by schools? Parent has now successfully applied for school transport
Sent to Hackney Ark paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway
Parent said HPPS should call back when they said they would with the right information to tell parents or go and find out the info
Pass to SB and LO - websites need to be promoted better
More direct OT support and interventions for ASD children with sensory integration needs
More training for police and families on dealing with challenging behaviours especially YP with autism. Charter needed. Children should not be criminalised due to disability
Restore Sat SB offer. Need programme for older children to help socialise them.
Sent to Hackney paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway

Great if HLT could monitor outcomes & progress of SEN children - parents could use this after first meeting
N/A
Parent plans to raise with school.
Allow young people to access transition services like this for longer (till 25) as condition means it takes much, much longer to learn independence skills. A handful of sessions are not enough. They need to expand/resource team to do this.
Waiting list was five months but we understand reasons and were seen as soon as possible
Reduce waits for specialist dental appointments
More preventative mental health support for parent-carers
Sent to Hackney paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway
Raised via call to SB team and passed to HiP SB lead to raise with manager and at March SB Board. Email response received providing clearer information but had to chase response
Stop high dental staff turnover and make it easy to access and get back in the system
Communicate with parents every step of the way during transition esp 16+. More social clubs.
Make family therapists more aware of needs of families affected by autism
Sent to Hackney paediatrician to raise at Disabled Children's Board – ASD diagnostic pathway
Parent raised matter with SEN team.
Improve content on out of borough provision on local offer
N/A
N/A
Invest more in transition 18-25 and do not leave families or young people without support
HiP parent signposting family to IPSEA etc. Sent DM tweet to IPSEA to find out how accessible advice line is for ESL family. Issue resolved using IPSEA and IS
Keep funding HiP!
More info groups for parent-carers

N/A
Improve local offer using ongoing feedback form parent carers including focus groups for different conditions
N/A
Ensure all CAMHS staff/psychologists are child friendly and listen to child and family. Also more support for parent-carers of children with medical needs
Respite and better support for mental health needs of parent-carers of disabled children
N/A
Parents' needs need to be considered. They need to be listened to and involved in decision making and carers' assessment (adult services)
N/A
Would have benefited from extra help to get him used to his new school
Improve direct payments for children and families
Keep it going - everyone needs it (Short Breaks)
Feedback sent to LO team
More social activities and clubs for disabled/SEN teens
Not enough DP support. Should support whole family
Improve GP waiting/appt for children with special needs - waiting is difficult
Improve access to family therapy and individual support for parent-carers
Funding for Hackney epilepsy support group/education for parent-carers
Specialist dental service needed back at The Ark
Raised with CHCC and LBH Better Contract Manager
People not aware of Carers Centre services. They need to advertise more
With more funding could get help with activities
N/A
Home-school communication book needs to be 'SMART' - explains nothing. Better communication, reassurance and evidence son is getting support now. Less shouting at my child. Need to model behaviour to him.

Appendix 3 – comment collection form

Venue/Event	
Date	

1. Your child's/young person's need/condition/disability

2. Does your child have a statement or an Education Health and Care Plan or Learning Disability Assessment? (circle one)

Statement	EHC Plan	Learning Disability Assessment (16+)	Being assessed	Applied & waiting	None
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3. What type of local service for child or young person with additional needs would you like to tell HiP about (for example: CAMHS, nursery, primary school secondary school, Hackney Parent Partnership, Hackney Ark, Carers Centre Hackney Learning Trust, Transition Outreach, Short Breaks, Therapies, GP)




4. What is the name of the service? (eg name of school, GP practice, therapy service, hospital)

5. What is not working well for you about this service?

6. What works well about the service?

7. How could the service be improved?

8. Overall- how happy are you with the service? Please circle a number

	1	2	3	4	5		6	7	8	9	10	
Very Unhappy						It's Ok						Very Happy

9. Do you give consent for HIP to add this information to our comment database and share it with services (anonymously)?

Monitoring

Please provide details about yourself. We do not need your name or address. We are asking for some details because we want to make sure we have the full range of views of people from all sections of Hackney's community

Your gender (parent/carer)	M / F	Your age (please circle one)	18-24 31-40 51-60	25-30 41-50 60+
Do you have a first language that is not English?	Y / N	Do you (parent/carer) have a disability?	Y / N	
Has having English as second language prevented you from understanding or accessing this service?	Y / N	Age of child or young person		
		Child or young person's gender	M / F	

Ethnic Categories: Are you? (please circle one or provide own description)

White	Mixed	Black or Black British	Asian or Asian British
British	White and Black Caribbean	Caribbean	Bangladesh
English	White and Black African	African Somalia	Indian
Welsh	White and Asian	African- Congolese	Pakistani
Irish	Other please specify	African-Nigeria	Other, please specify
Greek/Greek Cypriot		African Ghanaian	Chinese or other ethnic group
Turkish Cypriot/ Turkish speaking		Other West African	Chinese
Kurdish		East African?	Vietnamese
White Eastern European		Other, please specify	East Asian (please specify)
Traveller of Irish heritage			South East Asian, please specify
Gypsy Roma			South East Asian please specify
Jewish			Other please specify
Charedi (orthodox Jewish)			
Other, please specify			