



WILL WE LISTEN?

LEARNING, RECOMMENDATIONS AND RESOURCES FROM THE EAST LONDON TRANSFORMING CARE PROJECT

OCTOBER 2020



Havering
LONDON BOROUGH

ABOUT THE PROJECT

This briefing sets out the key learning and recommendations from the East London Transforming Care Project. The Project was designed to deliver better family and community-based support for a small group of children and young people who are autistic, some with intellectual disabilities, and/or mental health support needs.

The project worked in depth with three young people; two of whom were placed in hospital/residential institutions and one living at home, deemed at risk of being placed away from their family home. It aimed to develop and deliver improved family and community-based support services for children and young people and identify early intervention activities to prevent family separation and institutionalisation.

This briefing draws on 12 months of work – including detailed case audits, financial mapping and developing support plans – with the three young people, their families and local services. **It provides six simple and actionable recommendations, drawn from the learning from the project:**

- ✓ Focus on the 'whole family'
- ✓ Listen early
- ✓ Focus on safeguarding, not just diagnoses
- ✓ An integrated approach to support
- ✓ Undertake a sample case audit
- ✓ 'Whole life' support planning

Local areas wanting to transform the future lives of children and young people with very complicated lives and support needs are encouraged to take forward these recommendations, to draw up their own action plan and deliver the much-needed change.

ABOUT THE PARTNERSHIP

This project set out as a partnership between Havering Borough Council, Waltham Forest Borough Council and Lumos.

It was overseen by a Steering Committee bringing together key local representation, with NHS England Transforming Care team members, expert research advisors (SQW) and a Parent Representative. The initiative was steered and delivered by a Lumos Consultant and Practice Support Adviser (a seconded social worker from Havering).

This briefing has benefitted from advice from NHS England Transforming care team in London and nationally, the input of parent carers at all levels of activity and a strong partnership between Lumos and Havering Borough Council.

LUMOS

Lumos Foundation is an international non-governmental organisation, founded by author J.K. Rowling, working to end the institutionalisation of children.

To achieve this aim, Lumos works in partnership with governments, United Nations agencies, European Union institutions, civil society, communities, families, children, and caregivers to transform outdated and ineffective systems that separate families. Together with partners, Lumos replaces institutions with family and community-based services that provide children with access to health, education, and social care tailored to their needs. This support enables families to provide the care their children need to develop to their potential.

Lumos delivers a combination of country programmes; sharing expertise and provision of technical assistance; research and documentation of best practices; advocacy and policy influencing at the highest levels of government, funders and the international community to change attitudes and drive positive change.

In 2017, we began our first piece of work in the United Kingdom with early discussions that resulted in what became the East London Transforming Care Project.

HAVERING

Havering is situated in North East London, centred around the large town of Romford. The Borough Council works in partnership with Havering Clinical Commissioning Group and North East London Foundation Trust to support children and young people with learning disabilities and/or autism. There is an active parent carer network called Positive Parents.

WALTHAM FOREST

Situated in North East London, the Borough is in partnership with Waltham Forest CCG and health services provided by North East London Foundation Trust.

BACKGROUND

This project set out to deliver on changes headlined in Dame Christine Lenehan's report *'These are our children'* (2017) and more recently the report from the Children's Commissioner in England *'Far less than they deserve'* (2019). Both highlight significant failures of the system in supporting children and young people with learning disabilities and/or autism and their families. These two reports follow on the work of NHS England's Transforming Care Programme and the 2015 report *'Building the Right Support'*.

The work of the NHS England Personalised Care Directorate provided strong policy and guidance to support the development of the project. The Directorate promotes a child and family-centred approach and the development of integrated family and community-based support. The Children and Families Act (2014) and the Code of Practice for Special Educational Needs and Disabilities (2014) provide the legislative framework within which all the work of the project was carried out.

The practical work of the project; life stories, planning and developing support were shaped by the Department for Education funded project *'Me, My Family, My Home'* (In Control 2016) and established good practice in the use of person-centred approaches to supporting people of all ages with complicated lives and support needs.

All these reports and practice highlight a common set of recommendations and action to be taken to improve support to children and young people with learning disabilities and/or autism. The work of this project evidences that there has been slow progress in implementing these changes and adds further weight to the need for radical change.

There are more children and young people with autism in residential provision than five years ago. The costs to the taxpayer are significant.

For one young person involved in the project the last year has cost £270,000. Residential accommodation rarely lasts for one year, so this becomes a long-term commitment. This results in precious resource directed to residential care, away from family and community-based support solutions.

The removal from home, the change in family relationships, the new community, the new people in the young person's life, can build need and a dependency for longer-term support.

WILL WE LISTEN?

The title of this briefing is both a question and a challenge to those of us who deliver support and services. Will we actually listen? Will we genuinely change? Will we make a real difference and a radical transformation to the future lives of children and young people?

This project has challenged everyone in the partnership to ask whether we are truly listening to those we seek to serve. We have to learn to listen to children, young people and their families. We have to listen to their requests for help, however early these may be in their child's life. We have to take those requests seriously and have a full and appropriate response. We have to listen carefully to take note of the key details that they share, as these will be the building blocks for support that works well for them.

The findings from this project are clear – at present, we do not listen enough to children and young people or their families, and it has to change.

If we listen, there is no argument about the need for change. The stories families tell us illustrate how the system has and will continue to fail them. If we listen, we will hear the solutions, and the ways services need to change.



**“YOU HAVE LISTENED
TO ME. NO-ONE ELSE
LISTENS LIKE YOU DO.”**

Participating young person, June 2020

THE APPROACH

Participants: Three young people and their families were selected from a group named on the local 'Enhanced Support Register'. Each young person and their family was invited to participate, and was provided with easy read information and the opportunity to talk to their social worker about taking part and what it would mean for them. They all agreed and gave their consent to participate. Two of the young people were placed away from home with one on an adolescent ward and the other in a full-time residential placement. The third young person had just started a residential school placement for 38 weeks a year, spending weekends and holidays with their family. The focus of the project was to set out plans for the two placed away full time to return home, and for the third to plan to be back with their family in the following year.

Information gathering: The project set out to structure work with the young people and their families based on their own testimony. Work began with collating family stories, hearing from young people about their memories, important people in their lives, their gifts and strengths and their hopes and dreams for their future. It was essential for the project to step away from simply revising statutory assessments, information and plans, these had, to date, failed to prevent the young people being placed away; the project provided an opportunity to start again from a different base.

Planning: This work fed into individual planning sessions with the young people, family members and those involved and supporting them. These plans started to identify ways that support could be offered that may work well, enabling young people to have discussions about good and difficult days and how best to support them when they were finding things challenging. **The immediate effect of this work was that young people felt listened to and respected**, this had not been their experience, or their families' experience, to date.

Case audits: Audits of all statutory information held about the three young people were completed, chronologies of interaction with services were constructed and set alongside young person and family testimony. This provided a strong foundation for building a very 'young-person-centred plan' for the future. The process also provided much learning to the project team and to local services.

Completed support plans: The completed 'whole life support plans' were signed off by the young people, their families and local services in June 2020, and have since shaped support.

Capacity: The work of the project was led by a Project Consultant and Practice Support Adviser. The Consultant focused early effort in bringing momentum to the project and beginning to collect information from families and the first planning sessions with the young people. The Practice Support Adviser, a social worker seconded from the Havering Children with Disabilities team, took forward the case audits and as the project progressed built stronger relationships with the family and young person that have gone on to be invaluable. This capacity from the Project Consultant and Practice Support Adviser enabled much greater effort to be invested in information collection, young person centred working and communication with families. The Practice Support Adviser has since returned to working as a social worker taking with them all their experience; this is now being used to inform redesign of planning and information gathering, with the social worker delivering training to their team and, in the near future, as part of NHS England Transforming Care work in North East London.

Oversight: The two local Project Steering groups provided a forum to share the work of the project, issues that were identified and to seek support and advice from the multi-agency representation, including local parent carer representation. The Steering Committee hosted by Lumos provided an interface between those delivering the project, local representatives, a parent/carer adviser and national organisations, in particular the NHS England Transforming Care programme. Support from NHS England Transforming care team (London) has been invaluable and discussions are ongoing about how the work and learning from the project can feed in to national work to develop key-working, the work of Health Education England and also into London-wide work on Looked After Children and Young People with autism and safeguarding.

Evaluation: Expert Research Advice was provided to the project by SQW. This additional resource enabled the team to develop a set of simple evaluation tools that aided information gathering and would inform learning through measuring impact and experience. The expert advisers also took part in the case audits and advised on the final internal and external reports.

Coronavirus: With the pandemic impacting all our lives in March 2020, decisions had to be taken about the future of the project given the pressures local services were facing and the challenges of having to reorient the project to work remotely. Work continued to the end of June 2020 with Whole Life Support Plans in place for each of the young people and an internal report produced sharing learning and making recommendations for action with the Havering Project Steering Group. All parties were informed of this decision, and a review meeting was held in September 2020.

WHAT WE LEARNED

Experiences of the three young people:

The experiences of the three young people have been positive, given that each has traumatic life experience, autism and, for some, mental health support needs.

The planning process and whole life support plans piloted in this project provided **a very strong base on which to start moving forwards and supporting the young people** to move towards their dreams and hopes for the future.

The planning process **deepened the relationship between social worker and young person**, facilitated difficult discussions and continues to underpin positive direct social work and communication.

Concrete evaluation information has been difficult to gather from all three young people; in simplest terms due to the clash between formal research and the everyday life of young people and competing priorities. Second, the project has drawn to a close earlier than originally envisaged and not enough time has elapsed to fully gather robust data about change. For one of the young people and their family, they are very clear of the positive changes the project has helped make to their support, the relationship with their social worker and their summer together as a family. For a second young person, they are becoming more independent, attending local college and genuinely feeling like they are moving towards their goal of an independent adult life. For the third, the project has greatly improved communication and the relationship established with the social worker has proved vital and beneficial.

All three children shared a number of common challenges in their lives, which we now better understand and recognise **the need to better respond to their families when they ask for help**. Each young person has experienced numerous failures; in relationships, at school and in their daily life. The

project work acknowledged the fact that they had rarely been listened to, an experience common to their families as well. Using simple open-ended conversations each young person was supported to feel listened to.

For each of the young people, a key short-term goal for the plans became 'stability'. Far from planning moves on from their current situations, it became very clear that a period of stability and routine was most important. This would foster relationships, mean more 'good days' could be had and a platform on which to then start thinking about the future that could be put in place. 'Stability' was not something any of the three young people had in their lives until very recently, if at all.

Change can be stressful for us all, for these young people it was really important to remove fears of change in home, relationships and in life and enable them to grow, talk, and live. This has not always been without challenge, however it is very clear that this focus has provided a strong base on which to build.

Observations from case histories:

Early in the lives of all three young people they, and their family, sought support (10 or more years ago). Families reported seeking support from health professionals early in their child's life but without any marked success. Two families also came to the notice of safeguarding services early in their child's life. If there had been, at the time, an early intervention offer with links across different teams and services, then there were numerous opportunities for the young children and their families to have support that may have changed their lives for the better.

Schools often identify difficulties being experienced by children and are well placed to seek expert support. **Any future early intervention offer needs to include links into all schools, provision of expert advice when needed and better communication with other agencies and services.**

At the time that each of the young people were accommodated away from home part or full-time

Experiences of participating young people and families

"You have listened to me, no-one else listens like you do."

Participating young person, June 2020

"I think [the young person] has confidence in this and that people are going to help now. [The young person] is starting to trust people now."

Participating family member, June 2020

"[The young person] has been really involved and has been listened to, [their] voice has been heard – even the silly things have been recorded as an action and has contributed to it."

Participating family member, June 2020

"I know my social worker much better now, this is different. We can talk 'straight' – this is good and is definitely better since the planning work."

Young person, September 2020

"For me it wasn't as stressful as I thought it might be, it really helped me feel more adult and to be treated as an adult. It helped me feel more independent and take steps into the outside adult world."

Young person, September 2020

there were **no local community-based support services available**. Long-term work on the provision of personalised support for children and young people with complicated lives and support needs is an action within the future focused plan of work.

In June 2020, an internal project report was presented to the local Project Steering Group in Havering, which made a number of recommendations for actions both short and long term. **Havering are now taking forward the development of a detailed action plan** and consulting with key people including parent/carer representatives on its content.

RECOMMENDATIONS

The central theme to all recommendations made is 'listening'; listening to children and young people, listening to their families when they first ask for help and when plans are being made about their child's support. We must listen, and listen carefully.



Recommendation 1: **Focus on the 'whole family'**

Those receiving a referral need access to expert support with the family early in the child's life. All work has to be **focused on the 'whole family'. Siblings' lives are profoundly impacted upon, as are parents when a family member has complicated support needs, diagnoses and challenges with the everyday world.** It is not enough to simply focus on the individual child; the long-term outcome of in-depth work has to be a resilient family, able to absorb difficulty and challenge and provided with skilled support and access to expert advice and guidance when needed.

For one family, the planning work led to a more flexible use of direct payments over the summer. Money was used to facilitate access to activities, some of which were very family centred, and equipment to aid participation in sport (alongside family members). The Whole Life Support Plan set out clearly the justification for using funding differently and decisions were swift and family centred. The feedback from the family was that the outcome was a better and more active summer for the whole family.

Thinking **'whole family' requires a joined-up approach from the experts, practitioners and support providers;** the response has to be co-ordinated and based on open lines of communication, easy access for families and practitioners alike and a single bank of information. This information needs to be centred on the actual input and life experiences of the family and child. Current statutory information often excludes this vital information, and can simply be a list of dates, referrals, names and actions without the real **human information from the family.**

Without family-centred information that requires 'good listening', any plan of action or support is likely to fail. The fact that so many children and young people with complicated support needs are finding themselves accommodated away from home, often in a hospital environment, indicates the ongoing failure of services to listen.

Recommendation 2: Listen early

The family's stories and the case audit evidence requests for help early on in a child's life. The development of an expert early intervention or prevention offer has to include a central theme of listening to families when they first approach a practitioner/professional or service for help. It must not simply be a case of signposting and managing demand, i.e. only focusing on those families nearing or already in crisis. Time invested in listening, recording the situation and the story to date, will provide a strong base for advice, expert guidance and whole family support. **Listening has to be the first response to any request for help.**

Recommendation 3: **Focus on safeguarding, not just diagnosing**

The work of the project strongly suggests that a much clearer focus on safeguarding is needed as opposed to diagnosis, labelling and individual service centred responses. Keeping the child, their loved ones and others safe should drive intervention and interaction; action to be taken should always have safeguarding at its heart. The project evidences the need for local partnerships to see safeguarding at the centre of their activity as a multi-agency support to families.

Recommendation 4: **An integrated approach to support**

Multi-agency information sharing:

Information sharing is at the core of good Safeguarding Practice; for this group of children and young people with so many different people involved it has to be a priority that all information is gathered in one place and kept up-to-date. Responsibility for ensuring this happens must be clearly identified.

Care Co-ordination:

Mirroring the role of Care Co-ordinator in adult services, there has to be a single point of reference/person with the responsibility for co-ordinating all support, being the contact for the family and child/young person and for ensuring that all information is up-to-date. Essential to this role is the building of a strong, honest and respectful relationship with the child and their family.

Monitoring and measuring impact:

A feedback cycle must be embedded in the system, where families, young people and associated practitioners can review progress, impact and experience. This evidence, using simple questions, will then provide a growing base upon which to amend, change or affirm practice and approach locally. In turn, this informs Commissioners about the outcomes of investment through the support plan in the child's life.

There has to be an overriding assumption that support and investment will improve a child and family's life, not simply maintain the status quo.



Having explain the importance of the sample case audit for them:

The case audits were essential as it enabled workers to understand the child's journey and interventions that have been used up until this point in time.

One of the strengths of this approach/work was that it allowed a review of the whole life experience of the child/young person with fresh eyes and a sense of objectivity.

The case audits have informed the action plan that is purposeful, planned and focused.

Head of Service, September 2020

Recommendation 5: **Undertake a local area case audit**

Local areas have to take responsibility for understanding exactly what is happening, has happened and the current approach to supporting this group of children and young people. National guidance and instruction will offer solutions, however, there needs to be local understanding and evidence gathering.

We recommend that each local area partnership identify a sample of cases (3-5) from this group of children and young people. The local area then undertakes a case audit and provides space for the families and the child/young person to share their experiences, history and stories of important people, things that happened and memorable days.

We make this recommendation as this exercise became one of the two most valuable parts of the East London Transforming Care Project. Not only did we learn so much from the families and build much better relationships, but we identified issues, some historic, that have greatly informed our plans to improve our offer of support to this group of children going forward.

We suggest that there are a key set of questions to have in mind and to answer on completion of the case audit:

- Q.** Do the family/child life story and case notes provide a detailed understanding of the current situation and support need?
- Q.** What gaps in information, records and notes exist?
- Q.** What evidence is there that the child/young person and their loved ones have participated in and agreed with the final plan of support in place?
- Q.** What issues are identified by the family/child/young person that are not within the statutory case records?
- Q.** Is there evidence of ongoing and proactive information sharing between statutory agencies (health/education and social care)?



Elements of the case audit:

1 Family history and young person's life – open-ended conversations about memories, important people, when first asking for help, contact with services, things that worked/didn't work, things that happened good or bad, difficulties at school etc.

This is the opportunity to set aside the statutory held information and actually listen and value the family's experience and life story. It will prove a rich learning resource for building a whole offer of support to the young person and their family.

2 Audit of case notes; set alongside family/young person life story – set out a timeline from the first time services are contacted by or on behalf of the family, construct a timeline of all records of interactions, plans, and outcomes.

Note the gaps, or differences, note professionals making judgements and see how much attention has been paid to what the family have been saying. When complete, cross reference with the family story, check dates, and also see if the family are telling you information that better explains some of the interactions noted in the case notes/records.

3 Review findings and identify areas needing attention – action plan. Review with a multi-agency team. Avoid blame and finger pointing, see this as an opportunity to change things.

Check through funding available, ensure that all eligible funding/resources are already in use, for example S117 Aftercare funding. Create an action plan together.

4 Oversight, multi-agency responsibility – all partners taking action. Action Plan is owned by senior leadership of the multi-agency working group.



Recommendation 6: 'Whole life' support planning

Whole life planning: Good plans will come from comprehensive information gathering that in turn will be based on good respectful communication and relationship building between the lead practitioner and the child/young person and their family. Current approaches, relying on one or two long meetings, do not offer a young person who may be experiencing many challenges the opportunity to contribute in a way that works for them. Services are still expecting young people to fit within their structures as opposed to working around the child in a way that maximises their opportunities to have a say and share their thoughts.

A good plan should be the output, how it is completed should centre on relationship, and open and honest communication.

Children and young people, and their families, should have many opportunities to answer questions, comment and amend. The project evidenced the richness that such focus, using online video conferencing and graphic facilitation, that will be imperative to setting out what can be a successful plan.

Participant experience

"It was really good to be able to read it and see what we have said has been listened to. I feel with other reports you say things and when they send you the reports they half listened and put their own opinions in.

Everything we have said has been listened to and is in the plan. It is a warm feeling to know you are playing a part in the support plan and it is actually really taken on board."

(Parent, June 2020)

However, if an area chooses to build their own approach we recommend that planning with this group of children is viewed as 'whole life support' planning, and has three key approaches at its heart:

1 Child and family centred – listening to children and young people and those who love and care for them builds relationship. This relationship not only affirms, but will be crucial when talking through difficulties or trauma. For those in care of the local authority, those with complicated lives and support needs, this relationship will be essential. It is unlikely that this has been their experience of professionals and practitioners to date.

2 Whole life, including family – emphasis needs to be put on investment in the whole family – building strength, knowledge and ability instead of simply setting out to meet a child's identified 'needs'. Think home life, think family, think whole life.

We've created a Handbook to support the work of the project on developing Whole Life Support Plans. This includes a set of templates used during online planning discussions with young people and families – all available on request from Lumos.

3 Integrated funding and use of personal budgets: Whole life plans require whole life support. Funding (commissioning activity) has to be integrated. The funding must be centred on delivering the whole life support in the plan. There can be no argument about who funds what part of support once the funding has been integrated. Commissioning must take a similar whole life focus; agreements that underpin such integrated work will underpin the work of the commissioning officer(s). They have to be able to make decisions in the knowledge that those decisions may be challenged but will not become an argument about which service funds which part of the support; it has to be 'whole life'.



Having explained how the approach to whole life support planning is changing the way they do things:

The whole life plan was child focused and empowered the young people to use their voice and create – and be at the forefront in creating the plan.

Through video calls and the use of online templates and graphics, the relationship between the worker and young person significantly improved and made way for open and honest conversation. The young people have said they feel listened to and trust the worker.

Moving forward the team will:

- Review chronologies
- Be more child focused
- Ensure direct work is undertaken to gain the young person's wishes and feelings
- Ensure all intervention is planned, purposeful and focused
- Take time to listen to the parents/carers journey to build relationships and to gain an understanding of the parents journey/experiences.

Team Manager – 0-25 Children and Young People with Disabilities Team, September 2020

The Children and Families Act 2014, the Code of Practice for SEND and the NHS Personalised care programme all set out how this joining of investment is possible and provides a regulatory framework to underpin an integrated approach.

LISTENING TO YOUNG PEOPLE: KEY TRAINING RESOURCES AND TIPS

We have been asked to set out a number of key actions to assist working alongside young people. The plan is for these to be circulated as an accompanying 'e-card' that can be used by others. These top tips are already in use and informing training in Havering.

Listen to young people

Get to know the young person, not the diagnosis

You're not the expert on their life and experience. If you give them the chance, the young person will likely tell you the things you really need to know and how to help them.

Chat don't assess

Listen carefully for the little details they share – the key insights – these will help you understand what makes the young person tick.

Think positive cake support!

Find out what the young person's favourite snack or cake is, then take it along. Show them you care.

Make space for the family to tell you their story

Listen to those closest to them. People who love the young person can tell you so much.

Labels are for jars, not for people

It helps to remember how hard it can be as a young person and think about the challenges you experienced at a similar age. Don't make snap judgements.

Arrange more bitesize catch ups

Long meetings may be hard work for the young person. Meet them in their world, rather than yours, and arrange briefer chats over time. It's better for them than trying to cover everything in one meeting.

Take the time to really listen

By carefully listening, you're valuing and affirming that young person. It can help to create a more positive and beneficial relationship.

PEOPLE WHO KNOW ME SAY...				Date:
Who?	Gifts + strengths	Important to me	PEOPLE:	HOPES + DREAMS
		Important to know		
A good day:		A difficult day:		Today:
Notes				Next:

Graphic 1

One of a set of templates used during the COVID-19 pandemic to support online planning with young people and those who love and care for them.

SUMMARY AND CONCLUSION



What the partnership learned, the issues and challenges encountered, the gaps in service and the challenges in multi-agency working, are common across previous reviews into support for this group of children and young people.

This learning is, we are sure, pertinent to every local authority and their health partners across England and more than likely the UK.

Solutions can often seem like they will be expensive, and indeed early intervention/prevention expert advisory and support services will cost local partners. However, the solutions sought by young people and their families are not so expensive, if available early.

For one young person, joining the cadets has proved a great source of pride, a source of friendships, of normality and opened up life-long opportunities. For another, the local dance club is vitally important. The club leaders are in contact with the family often, enquiring after the young person, and at this club the young person felt valued. For the third young person, their family being supported to have a family membership at the local sports club which has contributed to this being one of the better summers for the whole family. They have shared laughter, discovered new skills and enjoyed themselves.

The long-term expenditure on out-of-area residential accommodation drains investment for the local area and prevents serving a much larger group of children and young people. There is not a quick fix, as it will take strong values-driven leadership with a core belief in the importance of family life for every child. It will take a local long-term vision of 'looking out for and looking after our children and young people'. And it will take brave decisions to change the current investment in out-of-area services to one centred on local solutions, good support, and ordinary lives for children and young people – whatever their complicated support needs.

This project would not have been possible without the participation of three extraordinary young people; a musician, an artist and an apprentice Lionel Messi, and their strong and loving families. We all thank you very much for your input, your time and your knowledge. We wish you the very best of futures, wherever that may take you.

Lumos and Havering Borough Council, September 2020

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