





A project exploring the feelings and experiences of families of children with additional needs.

A NEW DIRECTION



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Lambeth's mission to open up the creative and cultural sector to every young person in the borough



A brief history of Whippersnappers

Whippersnappers has 28 years of experience of providing accessible participatory arts to the local community. We have over 30 part time / freelance artists working with us as well as a bank of T.A staff who deliver our specialist playschemes. All in all, in the past year we have worked with 130 SEND* children.

In October 1994, Caroline Burghard, a professional actress, mime artist and musician, began running under-fives music workshops at Brockwell Lido, collecting donations in her orange hat and handing out homemade carrot cake.

In April 1997, Caroline teamed up with Kirk Service, a professional R&B and Reggae artist. Together they founded Whippersnappers and worked together to create "Pickny Beat," a fusion of English and Jamaican music using R&B and reggae grooves under traditional rhymes and new children's songs. In January 1999 they started fundraising for the next Pickny Beat Day, used to launch the Whippersnappers Magazine made by and for the Brixton Community.

By 2000 Whippersnappers were running a performing arts playscheme for 30 children aged between 8 and 11 years. A partnership with Abladei UK (a local Ghanaian cultural band) had also been developing and in June 2000, Kirk and Caroline travelled to Ghana with Mr. Joseph Abbey Mensah to build links with Ghanaian artists.

In 2002 Whippersnappers delivered a pioneering SEND music project funded by The National Foundation For Youth Music which was documented with a video entitled "First Steps", working with

5 Lambeth Nurseries to create 5 original songs which were performed at The Queen Elizabeth Hall.

Whippersnappers' under-5 sessions, involving disco lights, African drumming, and puppetry, were accessible to a wide range of children. We started researching musical techniques for children with complex special educational needs and in January 2002 we held a seminar for special needs practitioners and parents with children with complex needs.

Since 2009 Whippersnappers have been commissioned by Lambeth council to deliver specialist holiday playschemes for pupils of the Livity School. In 2010 we were funded by Lambeth and Southwark Aiming High to convert a park keeper's Lodge in Dulwich Park into an Inclusive Community Arts Centre - College Lodge.

We currently offer after school clubs and holiday playschemes to over 70 SEND children aged from 5 - 18 years. They are hosted at three sites: Livity School in Streatham, the Brockwell Park Lido in Herne Hill and the College Lodge.

In Oct 2021 Whippersnappers applied for funding with Lambeth Early Action Partnership (LEAP). In 2022 we were approached by Lambeth ELEVATE neighbourhood fund, a creative arts fund which was set up to re-energise the sector since the COVID-19 pandemic. This project has been funded by combining the funding by ELEVATE neighbourhood fund, and the ELEVATE education programme, with funding from LEAP.

*The acronym "SEND" stands for Special Educational Needs and Disabilities. Children (and adults) who have Special Educational Needs have "a learning difficulty or disability which calls for special education provision to be made for him or her" (according to Section 20 Children and Families Act 2014).





Engaging participants

The initial pot of funding from LEAP was used to run 10 stay and play sessions for pre-school children with SEND and their families

The biggest challenge was finding these families. We started by contacting social workers, and families who's older children we'd previously worked with, and who now had early years children with SEND. We also contacted local community organisations, put up leaflets in target areas and used our social media platforms.

Families filled out membership forms and also had a 45-minute pre-enrolment phone call. We new this would help us understand the family better and their availability and accessibility needs, and made them more likely to attend, and engage once they started.

After 10 successful sessions at Liz Atkinson's children centre, we were approached by ELEVATE to expand our SEND sessions into a 1-year early years project, with a focus on engagement in the arts to enhance wellbeing.

system, which is an "increase of 77,000 in a year"

We ran 30 minute creative sessions for parents which they loved. Many of the children had never been away from their parents and attachment issues meant parent's time was cut short. It was evident that the structure wasn't working. We would have to find a different way to meet parent's demand for time for themselves

What we did

Meeting demand

As a community led voluntary organisation, we have years of experience delivering SEND services and built lasting relationships with families in a different way from statutory services. We wanted to hear the voices of parents with SEND children and help to bring about change.

With inspiration from parent feedback we proposed 6-weeks of Saturday parent-led creative research sessions on our site in Dulwich Park.

Whippersnappers were awarded an additional £10,000 by LEAP to do these sessions. The funding we had from LEAP was invaluable here as it was not earmarked for a particular use, but to spend on what we felt was most necessary as the project developed.

Barriers to the research sessions

Factors such as travel, finances and babysitting were all potential barriers preventing parent's attendance. Most parents reported that they struggled to find babysitters who could work with their early years SEND children.

We were able to solve these barriers practically. We used our minibus and taxis to pick up parents, and we put parents in touch with a team of our one-to-one support staff so they could book them as babysitters.

We provided a baby-sitting budget for each family so that they could attend the workshops, and found that finding SEND babysitters also gave them confidence they'd be able to find appropriate babysitters in the future.





"What was
wonderful about
[the project] was that
it was so organic in it's
process. The parents/carers
were 'listened too' and their
needs put first, maybe for the
first time in a long time. They
were able to relax and
just simply be."

The structure of the research sessions

Our aim was to do qualitative research. This type of research focuses on finding themes, narratives, and ways of describing and expressing people's experiences. We wanted to understand more about the predicaments of families that we worked with and to understand how to further improve their lives.

We wanted to make our sessions a friendly, accessible, and welcoming safe space where parents could meet and share experiences, express emotions, and feel supported.

We provided a wholesome lunch and beverages (supplimented parent's home cooked goodies) which contributed to the feeling of togetherness. We wanted to make sure that we were offering a day of respite they would look forward to, as well as an opportunity for them to tell us their stories and share their ideas.

Parent's bonded over similar experiences. For some this was the first time meeting other parents of a child with SEND. Being around those who understood their lived experiences, parents felt they could speak without judgement or interruption. We encouraged time to chat and relax.



How we did it

Co-production and being parent-focused

Co-production is at the heart of Whippersnappers' ethos, and we wanted this to be embedded in the project. Coproduction is:

'...a relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities.'

We shared 'power to plan' by planning sessions with parents, keeping sessions unstructured and open to being moulded by the parents' discussions. We wanted sessions to be parent-led, engaging and

Both Whippersnappers staff and the parents were able to share their lived experiences of caring for children with SEND. Through recognising both our 'vital contributions', we were able to build a trusting and mutually beneficial relationship.

The key to success was trust. As research facilitators, we had to accept that things may not always go in the intended direction. It was interesting to let go of our preconceived ideas of the project, and not only did parents have to trust us, but we also had to trust them to create a successful research project.



Accessibility in our parent research sessions

We had a neurodiverse research ground and found some individuals needed to be in a quieter area of the room, allowing them to be at a distance from the activity. This did not mean they wanted to exclude themselves from the activity, it was in fact a coping mechanism to prevent feeling overwhelmed within the group environment.

Having several parents with autism and a range of other additional needs meant we were able to explore how the sensory environment could affect individuals differently.

We were also made aware of background sounds such as a speaker letting out static or quiet buzzing sounds, and how profoundly this might affect some adults in the room. Flashing lights would also cause disturbance and should be avoided when necessary.





Meeting people 'where they are'

Families that are considered 'hard to reach' "are only hard to reach if you have not been looking to meet them where they are, literally and figuratively." Our decades-long experience in community arts meant we found far less of barriers:

"The funday made me feel really comfortable... I'm usually quite nervous about being around other children & parents because I feel judged or they make me feel uncomfortable."

For services and organisations looking to engage families and individuals deemed 'hard to reach', inclusive community organisations could be one way to find both a different demographic and a perspective which encourages participation. For example;

"Ethnic communities are often referred to as "hard to reach" but are only hard to reach if you have not been looking to meet them where they are, literally and figuratively."



Greativity and wellbeing

Whippersnappers believe that providing children and adults with opportunities to explore their creativity can immensely improve their wellbeing.

In the research sessions many parents expressed that they love being creative but said that they don't always have the time, energy, or resources to do this at home.

We decided merge our research activities into a range of creative sessions. Giving parents a range of ways to express their creativity and by discussing as we worked, helped us to find out about each other and our ideas. We found that parents

were more relaxed and open during our discussion groups when they were being creative and busy with their hands.

Through collaboration with artists and workshop facilitators the parents were able to be involved in a range of creative activities including slow stitching, pinch pots, knitting, collaging, designing T-shirt and mugs and creating a group patch work piece.

Parents used these activities to express themselves, such as T-shirts that advocate for neurodiversity and disability awareness.



We understood from the start that our intention for the project and research was action-based outcomes, not just identifying problems we had no power to tackle. We wanted to come up with practical solutions together and find ways we could go from sharing ideas to action, both in the short and long term.

We challenge you to consider how we could all work together to make these changes happen.

At the end of the project in March 2023, Whippersnappers hosted an event at Lambeth Town Hall where we showcased the work we had accomplished. We want to reach those with power to change the system.

Parents had many 'why not?' questions about services and how they could change, we want to help take these to decision makers, in order to inspire them to change the SEND system for the better.

"Nothing is changing, things aren't being implemented and what we need is for people to listen to what they are asking us... and really implement the change we need!"



Parent's wellbeing

Work and Finance

Nearly all of the parents we worked with were unable to work or had reduced the hours they worked significantly to care for their children:

According to an analysis of national data carried out by Contact and the University of Leeds "24% of parent carers provide 100 plus hours of care every week - the equivalent of working three full time jobs." In 2021, of 3,000 families surveyed by Contact "(61%) say that caring responsibilities meant an average loss of £21,270 from their family income."

"I made the difficult decision to have a career break to care for my son. His nursery refused to have him for more than 2 days and I found it impossible to keep up with my workload."

"Parent carers
are more likely than other carers
to say the care they provide has
affected their health, with nearly a
third (31%) saying that it had made
them depressed." From a study
done by Contact and the University
of Leeds.

Admowledging feelings

In our research sessions we asked parents to write about how they felt being parents of children with SEND. The comments documented a conflict of feelings and often these were simultaneous.

"I feel proud - every small thing he acheives makes me happy."

"Sad... I can't do certain activities with my child."

"Exhausted, haven't slept for 5 weeks."

"My son has to have constant attention or he may harm himself and I have ADHD."



"Making things, having a massage and being together with other people who understand what I am going through... It's been like a holiday."

"I feel relieved any time I am here."

"Stress washed away...
beautiful moments,
no stress, no pain."

We found parents had little opportunity to relax and unwind. Others simply said, "I don't relax." Parents identified lack of support, time and tiredness as barriers.

Wellbeing sessions for parents

As part of our research project parents requested a wellbeing day. We brought in independent therapists and held a session which involved one-to-one massage and group sound therapy.

Some of the parent's experiences were profound. One father had been diagnosed with autism at 11 and had believed oversimplified views of others who had assumed he did not like touch. This meant years of what he described as "touch starvation." He described what happened after the massage;

"I thought 'Oh god!.. this is what I had been missing'. I cried afterward."

Increased focus on the mental health and wellbeing of parents could result in less children with SEND going into residential care and foster homes. As Dame Christine Lenehan, director of the Council for Disabled Children, discussed in her recent article:

"Autistic children and those with learning disabilities and complex health needs are moved hundreds of miles from their "desperate" families purely because there isn't sufficient local community help for them in England."

Discrimination and Stigmatisation

Stigme from the very



One parent described feeling pressurised to terminate her pregnancy on the condition of the baby's disability and not the baby's health. Another described how stigmatising it felt to be asked "so you decided to continue the pregnancy?". We also found many parents had experienced doctors referring to their baby's disability adversely.

With SEND specialist nurseries limited (and often not non-existent), parents reported that SEND children were discriminated against in mainstream nurseries. Parents discussed only being offered the occasional half day because nurseries don't have the staff or resources to manage children with SEND.

Many parents have even reported that their child is only able to attend nursery for one hour each day and they have to wait outside the nursery, meaning no respite is offered.

"We don't get nursery places because of special needs."

Public and private

We discussed cases of open stigma and discrimination happening in public spaces. A parent described "receiving filthy looks, being called mental on a bus, and sworn at."

Discrimination was also reported amongst family members:

"I do not go to a lot of family events because they have made comments to both my boys... "You're too big to not be talking?" "Why are you always running?" "Stop making that noise and talk?".

In our questionnaire, one parent described many subtle ways in which she is made to feel her child is a problem:

"A lot of adults I interact with assume my child is making my life hard, "you're causing so much trouble for your mummy" was one particular comment. I tell them that the child is not the problem, she's fine being herself. It's the society she lives in that is the problem."

Discrimination and stigma leading to seeking asylum in the UK

A Nigerian mother seeking asylum in the UK regularly attended our stay and play. After engaging fullheartedly in the sessions with her two boys, dressing up and dancing we asked her if she could sing us a traditional Nigerian song. She told us she is no longer able to sing due to the deep sadness in her heart from losing her husband, and the pain and struggle her in-laws have inflicted upon her and her two sons before she came the the UK.

Another Mum from Kenya joined our stay and play sessions and then went on to join the Saturday research sessions. She also shared her story with us:

"In Kenya, there were very few services for my child. When my son was born I had to pay a large sum of money to keep him alive in an incubator. My husband and his family refused to support my youngest child and did not want him to go outside of the home. The situation worsened and after experiencing domestic violence I decided to flee Kenya leaving my eldest son with my in-laws so I could try and help my disabled child. I am now trying to get a visa for my eldest son to join us in the UK.

When I arrived in the UK I was not given a buggy/ wheelchair for my son who was 4 years old. He has cerebral palsy, low muscle tone and is very heavy. I also had no free bus pass, so I had to carry my son everywhere. There were no family members to look after him in the home.

My son now has a wheelchair, an official diagnosis of cerebral palsy an EHCP plan and is attending a local SEND school. I am grateful for all the help I have been given. I would however recommend that the Home Office offers more support for parents of disabled children when they first arrive in the UK."



Accessibility for all

"Make everything accessible for all! ...Everywhere accessible to everyone, all the time."

One of the biggest challenges for parents and carers taking their children out into the community is avoiding "meltdowns triggered by things that could be prevented".

One parent shared that his child is terrified of dogs. The possibility of meeting dogs off-lead on any street and the lack of spaces that are dog-free means that places they can access are very limited.

Parents felt that within SEND services as well as society as a whole, the needs of SEND children were overlooked, misunderstood or badly categorized. For example, 'autism friendly' sessions only catered to a specific perception of autistic children, rather than trying to accommodate the full range of needs that children with ASD may have. An autistic Mum said "Autistic adults used to be autistic kidel Se talk to use bout what any kide read!"

A parent wrote about how she tries to prepare for a good day out:

"My theory is you can never over plan a holiday or day out - pre-check the cafes and restaurants nearby to make sure they cater to your child's needs or bring a packed lunch. Check the route there and make sure it's pram/wheelchair accessible. And make sure there's something for everyone."

One parent stated "there are two journeys, the child's journey, and adult's journey. Let's talk about us."

In one case, an audiologist failed to ask about or account for a parent's hearing disability. The audiologist talked from behind a screen, so the parent was unable to lipread.

Asking about the disabilities and requirements of parents/carers on registration forms, as a statutory procedure, could be one way to combat these issues.





Parents described how much of their time is consumed advocating for their child's needs as well as their own. Advocacy work is one of the many things parents with SEND children do that goes unrecognised and unpaid.

"The hoop-jumping and time this takes for already stretched parents of disabled children is mind blowing. I now go into most applications with the mindset that it will be a battle and we will have to appeal/ re-apply."

Reforming Education, Health and Care Plans (EHCPs)

Lack of professional help means parents must help each other. One parent, who filled out an EHCP within 6 months of arriving in the UK, is now helping other asylum seekers to fill out forms and complete their EHCPs. One parent suggested a possible solution; "independent advocates available to aid parents through the EHCP process".

Having a professional advocate would help parents feel supported by someone that is on their side and ensure that they can be involved and understand the future plan for their child.

Another option would be to employ parents to be paid advocates for other families of children with SEND. Parents who have already been through the system have valuable lived experience of not just the logistics, but the emotional journey.

Maximising use of

resources

Lambeth currently has six SEND specialist schools in the borough, but these are not being used to their full potential.

The spaces are often empty out of hours and during the holidays, and yet there is a huge demand for accessible spaces and activities for SEND children. These schools often have large secure playgrounds and hydrotherapy pools.

Parents fed back the improved access they'd like in the following phsycial resources:

- Public Swimming pools with SEND specific swimming lessons taught by highly qualified SEND swimming teachers.
- More SEND stay and play sessions and creative messy play.
- Restaurants that accommodate families and their SEND children.
- Safe spaces for SEND children to run and be active.
- Inflatables that allow adult supervision and participation.
- More relaxed sessions in theatres and museums.
- More SEND sessions for trampolining/ climbing/soft play etc.
- SEND transport as traveling on London Transport with SEND children is challenging if not impossible.
- More dog free public spaces and safe areas within parks.



Adventure playgrounds, which are ideal for active children and young people with SEND are also frequently vacant during the weekdays. These are resources that are not being used to their full potential.



SEND centres

A parent suggested that there should be "one person/ centralised support for SEND child." From here, we developed the idea of a SEND centre which would pool services together.

A centre where all this information is available would reduce the amount of time services spend signposting. It could also solve other issues, them



Conclusion

Valuing Carers

Overall our work found that carers (which includes parents, family members, one-to-one support workers, babysitters, nannies, child minders, teachers, teacher assistant and, nurses) are not valued or recognised enough, and their salaries do not reflect the highly skilled work they do.

Society forgets that parents of SEND children are full time carers, often 'on shift' 24/7, especially during their child's early years. Many families experience a high turnover of paid carers or are simply unable to find them.

Many parents report that they feel overwhelmed and exhausted, and this is affecting their mental health and wellbeing. Research shows that this can directly affect their child's opportunities to thrive.



More co-production with families

We have been able to work alongside families with a wide range of needs, including households with 4 disabled people, newly arrived migrants with SEND children and families where mental health has severely impacted lives.

Many grassroots community organisations have creative ways of working that mean that they have a greater level of real participation from people whose voices are often marginalised in many institutional settings such as schools and hospitals.

This community-based approach and knowledge can be utilised better. On top of delivering services experienced organisations can, with the right support, advocate alongside families for their rights and for their voices to be heard.

Recommendations

Supporting families properly includes increasing financial support, increasing holiday and out-of-school provision and accessible/inclusive activities, providing better help navigating the SEND system, as well as recognising the prejudice and stigma they face.

While recognising the range of work that needs to be done, we have two practical recommendations which we feel the council could explore immediately and be implemented at the first possible opportunity.

Empower carers to move away from agency work

By moving away from working for agencies, carers can have a higher salary with more control and investment in their careers. Self-employed carers could pay to join an accredited carers association and build small caring teams and local hubs.

As members of an association, carers would be required to be DBS checked, complete safeguarding and paediatric first aid training. They could then complete additional training, such as manual handling, to suit the needs of children they wish to support.

Carers would no longer work for agencies and would receive a higher salary. They would have the opportunity to build long-term trusting relationships with children and family members, and really feel that they are making a difference.

The cost of residential care homes for children is extortionately high. Providing a local care system which would allow many children to stay at home would save money, improve the lives of children, and enable families to have their children as day-to-day members of the family.

Centralise and better use the resources we have in Lambeth

In discussions, we all recognised resources are not being used to their full potential, and better inter-organizational working can ensure resources are used more effectively.

The result of under-used resources and lack of partnership working means that information and services are spread out and difficult for families to access.

We propose a SEND hub in every borough, and believe that our local council can be the ones to instigate this initiative. Potentially a children's centre or closed school site could be converted into a SEND specialist centre.

The centre will be a 'one-stop-shop' where parents could find out about local activities, attend stay and play sessions, special interest clubs, speech and language therapy, music, art, drama therapy, counselling, parent wellbeing sessions, support with EHCP plans, information about SEND schools and much more.

For council staff and professions in social care, health and education, the benefit would be a site for closer working relationships across all those working within SEND provision.



Changing the system

Positive experiences of care and support transform lives. One family described how they "finally have a teacher who understands my son's needs and has helped facilitate a sensory circuit for him. It's made ALL the difference, and he enjoys nursery now."

Changing the SEND system will require many hands. For example, a SEND centre can be run in partnership with the local council and voluntary organisations such as ours. Our project was a collaborative effort and highlighted the benefits of collaborative working and sharing of resources.

In the care sector, community organisations and businesses, need to recruit and retain loyal, enthusiastic, energetic, and caring one-to-one support workers and carers, and have an understanding of how to do this.

For example, Whippersnappers has found young people who attend our setting as children go on to volunteer within the organisation, joining the payroll aged 17. Many have gone on to work privately as carers with families who they have met through Whippersnappers.





Legacy

Parents felt they had spent so much time and hard work researching and understanding the SEND system that they wanted to see this information passed onto new families, and to see real changes made to improve lives.

In March 2023, Whippersnappers hosted an event at Lambeth Town Hall where we showcased the work we had accomplished during the project, including the film, the patchwork and parent testimonials.

We invited MPs Lambeth Deputy Mayor, Councillors, Social workers, Commissioners, and funders. Parents volunteered to be involved in planning and delivering the event. It demonstrated that their voices matter, that their actions can bring about change, and that they belong to a wider community that cares about their lives.

After the event MP Helen Hayes was kindly able to send a letter to The Home Office requesting further information into a parent's asylum case.

Why we all need to act now

There is a need for more specialist services to meet the rising demand of families with children with SEND. According to the 2021 census, there are nearly 1.5 million pupils who have SEND in England's school system, which is an "increase of 77,000 in a year".

Lambeth has a higher child poverty rate than the national average (39% compared to the national 23%) and 1.4% of people aged over 18 years registered with GPs having a severe mental illness.

All of this points to why a focus on SEND provision, which must include a focus on the wellbeing of parents and the whole family, is even more important in areas like Lambeth.

Parents with SEND children are most qualified to speak about the hardships and joys of parenthood in all its extremes, and to feel the effects of poor support services and discrimination. They can candidly tell the story of how good care, medical support and education can improve their child's future and family life.

This project has started the ball rolling for our parents and for all of us who care about and understand the struggles of children, parents, and those who try to support them through the SEND system.

We need to come together to find the best ways to continue this path.

A huge thanks to our research team;

- 10 parent researchers, including:
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