**Case studies from peer network of Asian carers in London Borough of Newham**

**These are to be looked at and understood as a family unit as well as individuals, needing support for social care, health and education. As these are families who have been failed by the very system that should be supporting them. Some main areas of concern are disabled mothers of disabled children and the unconventional ways they are being mistreated. In Article III 3 for Families Life and Article 24 for inclusive education being failed and human rights abuse. There are some cases where the ‘right to life’ has been unjustified even before the child comes into the world along with human rights abuse. The breakdown for the very system that’s supposed to be supporting them and these families are now facing these children to be depressed due to the inequalities and direct discrimination. All of this ends up to-be a discerning breakdown for the mother’s health causing various hidden disabilities as mentioned in the Chronically Sick Person Act of 1970.**

**Please take a moment to see all of the cases below of mothers and parents of children who are disabled and the barriers they face on a daily from all institutional sectors.**

***CASE NO. 1 -Anonymous***

I have had hidden conditions from birth and was a young carer. I had a slipped disk at work in 1996. Since then my arthritis got worse and I have suffered continuous pain. During my breast cancer journey, I was not recognised as a carer for my youngest son and my husband and this had a huge impact on my health, well-being and financial circumstances. I had to work part time as a result. I have had my cases go to MARAC 3-4 different times as my family found the Covid lockdown really hard to deal with and it affected their behaviour and also their needs are not being met or seen as a cry for help due to their Autism not being diagnosed.

My husband **X** has anxiety, stress disorder, phobias and depression all his life. He also had heart problems and stroke at a very young age. The stroke was caused by an accident at hospital and we had to put in an official complaint as they left him to die. He has been diagnosed with cognitive impairment which means he can inject himself for his diabetes but he will not be able to remember so therefore I have to supervise and monitor it. He has regular meltdowns due to his Autism which has not been diagnosed which is a lifelong disability. This means he has an sensory impairment and he can’t tolerate sounds and smells. He often chokes due to gagging reflex. His PIP appeal has gone to upper tribunal and we have asked to put it aside as we have not got any representation for him or any specialised social worker for him. No support has been arranged or offered. Also as most of his disabilities are hidden, no adequate support or benefits are put in place and he has to face even more barriers as he finds it difficult and cannot express himself, hence misrepresenting his needs.

I need to inform you that all four of my children have been failed by the education system, health and social care. I would also like to take this opportunity to give you my each of my children’s story which is as follows:

My son youngest, was severely discriminated at school in 1998. However, the discrimination has made my son feel as if he is the problem even when he attended college and later in life did a course, as the support offered but in reality it is never implemented. This has caused my son to have low self-esteem and confidence throughout his life. There have been a number of occasions where there have been huge systematic failures due to this. We were a family in need and the Health Authorities were passing us to the Education Authorities and vice versa. They had a transition meeting where the two main people were excluded. This was against the law. He has had Exceptional Need Funding but the school did not use it to help him. Had it been used to help him get a statement, this would have helped to prevent him later in life when he was unjustly as a vulnerable adult put into prison twice. My son had a life-threatening condition and was therefore received the Record of Achievement Award from a Charity. Unfortunately, unlike other families in our position, who were allowed to plant a rose tree in recognition of this award, we were denied this opportunity, despite asking for this. In addition to this we were excluded from attending the Record of Achievement Award Ceremony that all parents and children were invited to at the end of their time in school. I was a parent-carer for three children as well as for my husband who had a by-pass at the time.

Regarding their personal independent payments, now a young adult and my husband had to request their cases to be heard in the Upper Tribunal Court and still waiting for Enablement to start. Imran has had two mental health crisis, he has had six Acute Asthma attacks. As a family we have not been adequately supported yet. This has meant breaking of relationships again. Imran has had physical injury that is going to be life-long due to no personal centred planning and people not recognising his special needs at work. The negligence and human right abuse that he has had for the past few years has impacted him, his siblings as well as us as his parents with post-traumatic stress. This could have been prevented if adequate support had been implemented.

We are a family in need and we should have all been supported, especially when our young adults (two sons) were children, they should have been statemented. As they were not, this resulted in them going to prison when they were adults as their hidden disabilities were misunderstood.

 My eldest son, he was a looked after as a child and he should have been diagnosed at school and was vulnerable. Unfortunately, because of his vulnerability, he was picked up by a gang. In 2015, he got kidnapped and battered by this same gang, who wanted him to stay with them and do as they said, but because he did not, he was battered and left to die.

My daughter, she has SUDEP – Sudden Death in Epilepsy – therefore, it is dangerous to leave her on her own. Despite the fact that she is vulnerable and her ex-husband would play on her vulnerabilities, for example he stole her passport.

My daughter has phobias and anxiety and phobias of hospital. She is also vulnerable and had her passport stolen by husband.

***CASE NO 2***

I Anonymous, have been asked by my advocate to send you Private and Confidential details regarding my sons X and Y and myself.

I had cancer as a child when I was six years old and was treated with radiotherapy. When I had my first child I was given a blood transfusion in 1990 . However they have lost my records of this blood transfusion as well as the births of my two sons. I do not drink or smoke, however in 2011 I was diagnosed with Liver condition Hep C and I was not informed of this until 2016 when I requested a full blood test. By this time my liver condition had got much worse (and although they were able to get rid of the Hep C part, I still have to deal day to day with the symptoms of Advanced Liver Fibrosis/Cirrhosis and was given a fibro scan reading of 15.2. The symptoms cause me to have fatigue, tiredness, low energy, falling asleep inappropriate times, issues with my eyes, back and memory. Hence I am working part time and have had to cut my hours at work. I have applied for PIP but have been refused and am overwhelmed with my symptoms, caring roles for my sons and the mountain of paper work that is involved. To the extent that despite asking Catch 22 agency and social services to help me with paper work to help my youngest son, who was unjustly penalised at university due to his needs assessment not being fully adhered to, no one helped. This had a huge impact on my youngest son’s health, well-being and education. Trying to break barriers and get adequate help for both my sons is exhausting and delays in services is causing serious issues and causing my young people to suffer in silence. When they could be out in the community helping others as well as living a well-balanced life themselves.

My youngest son X lives with me his progress has constantly been hindered as he has hit barriers, which have not only impacted on his whole health, well-being and education but also has had an impact on our whole family. I have two sons who should be entitled to live a good quality of life but have constantly hit barriers due to their hidden conditions. X was a happy child who enjoyed going to nursery and playing with his friends and family. Due to him being summer born he had to start school early at age four, and his best friend two weeks younger than him remained in nursery for another year. He has always been a very smart and intelligent individual. However he did not fit in the box when it came to reading and writing and found this very stressful. He did not have adequate support at secondary school and at one point had to revise from his older brothers books for his exams as the school had not provided him with sufficient information. Often I would reschedule or cancel my work to try and help him and to help build back his confidence and self- esteem. It was not until he went to college that it he was FINALLY DIAGNOSED with Dyslexia which was the underlying cause of the build-up of his stress, anxiety and impacted on his health and wellbeing. Lack of sufficient support added to this. Despite hitting barriers due to his complex health conditions including dyslexia and anxiety, had some support during school, college, apprenticeship. Although he hit many unjust barriers, he kept trying and worked hard. Hence he did well, passed his exams and after his Clinical Health Care - Nursing Assistant Apprenticeship at University College London Hospital, he was offered a job as a Nursing Assistant. He worked hard and was valued and appreciated by staff and patients. Here he was encouraged to further himself and go to University and gain a Degree in Adult Nursing.

In September 2014 he started off well at University of Hertfordshire and passed his exam, he did well and worked hard in his 20-40 hour placements. As time progressed, the pressure of the academic work load increased and the University had failed to put into place the adequate support required. This made matters worse and increased his anxiety level.   In addition to this it was very Unfortunate that the Needs Assessment was done Late in January 2015 and the 1:1 support was not given until June 2015 towards the end of the year and only for 1 hour and 30 minutes for the whole year. When Jordon tried to get help from a tutor who knew he had dyslexia, she was very unprofessional, extremely rude and unhelpful in her response by saying 'just READ the question' Then she asked him if he was feeling alright and he had a lot of work to do.  The disturbing part was that she was also a counsellor!  The University support centre was open once a week for 2 hours once a week and clashed with his lectures and placements.

Although we went through the traumatic experience of the appeals which went on until two weeks into the new academic year, we were shocked that despite the evidence the University of Hertfordshire did not uphold the appeal.

Considering the impact of this experience was so negative on his health, well-being and education, Jordon was determined to try again. However to repeat the first year, he ended up having to pay the fees from money he had saved from his apprenticeship. We thought it was too late to get help from Student Finance and did not know how to manoeuvre through the system.

Sadly yet again the University failed to provide him with adequate support, kept unjustly penalising him for things that were out of his control e.g. his work was ready to submit but the University's portal was not open so he had to wait anxiously all day before he could submit his work, the tutors said he would not be penalised, nevertheless the examiner was not informed, extremely harsh and marked him down.

It was soul destroying as despite after all his hard work and the tutors saying his work was good enough to hand in, he obtained an extension to improve it further. However the examiner was again ill informed and unjustly accused him of not obtaining an extension, unfairly marked him down yet again and marginally failed him. The tutors were just as shocked as he was. As a result he was given no option but to waste valuable time to try and improve this work, (when he could have focused on other assignments), only to find that after our appeal they passed him.

He was also traumatised as he was unjustly accused of plagiarism, we appealed and explained that the University failed to put adequate support in place, fortunately this appeal was finally upheld and he was no longer accused of plagiarism. Nevertheless, he had to endure unnecessary pressure during appeal process and added pressure as it took up precious time which disrupted his studies.

The Needs Assessment Report Assessors said, had the University sign posted Jordon back to them, they would have provided a mentor for him in the first year. But even when assessors tried to get a mentor, when he was repeating the first year, they said the University had not even told the necessary body that Jordon was repeating his first year, hence created another barrier for him to have access to a mentor which would have greatly helped him.

Yet again we went through another traumatic and draining appeal process, only to be told it was not upheld. We wanted to take it further to the Independent Adjudicators Office, but did not receive the letter from the University for this until January of this, year 2017. Unfortunately, I was told too late that I developed a serious health condition which got to this stage as result of NHS not informing me of my diagnosis made in 2011 until 2016. Therefore, I have not been able to give this the time and energy it requires. Although I desperately wish to try my best to help my son, juggling my health condition, caring roles and lack of services which are promised but never delivered left me overwhelmed and not able to deal with the huge amount of paper work. Hence the University has got away with discrimination, inequality and abusing my son’s human rights.

X was devastated as not only was he prevented from continuing with his Adult Nursing Degree, but he used all his savings earned from his apprenticeship, to pay the fees for a service from the University which was not adequately delivered and there was a breach of contract as his Needs Assessment was not adequately adhered to. X is a young man who was working hard in hospitals, helping and supporting people in the community on the road to recovery, doing a number of jobs including helping people with dementia and preparing patients for surgery in theatre. Patients responded well to his care, compassion and professionalism, but after this unjust negative experience at University he is questioning if he can even do the smallest task properly. To be told by many tutors and people saying he was doing so well then constantly to be Unjustly penalised and put down by other tutors/examiners and the system, has crushed his confidence and self-esteem questioning his ability to function. Although he has had sick notes from the GP, it is questionable why his ESA has been stopped since February 2017. It has been exhausting, no support and constantly appealing for justice! Only after a supporting letter from our MP, X finally after seven months received backdated ESA.

As advised and  informed by XXXX - Disability Advisor at XXXX Job Centre, since June 2017, I  have many times been contacting XXX who is an Employment Specialist, to help XXX my son to recover from his traumatic experience at University of Hertfordshire, but she said because he was not on her data base as being in touch with mental health services, she could not help, but he could seek help from IAPT.  At beginning of August 2017, I contacted XXXX again and explained after July 2016, he had to, through no fault of his own, step off the course at University and how unfairly he had been treated. He has been having IAPT increased access to psychological services - talking therapies due to severe increased stress and anxiety.

At end of August 2017, she sign-posted XXXX to Serco. However, I replied to her and explained he is now attending secondary service talking therapies with XXXXX. She replied and said he is not on her list so she cannot see him.

In November 2017, He was offered and informed by agencies e.g. Serco, Catch 22, Five E that he could do a Level 3 IT Apprenticeship and get work, but he had to do level 2 first, which my son completed in April 2018. He has been asking for help and support constantly and it is now September 2018 and they have still not delivered their promise. This is the same with enablement team who saw him in May 2018 and we are still waiting to hear from them regarding help getting my son back on track.

He needs a genuinely decent trained professional who understands his needs and someone he can trust to help Guide him to Heal and Recover from this appalling unjust experience so that he can get the Appropriate Support he needs and get Back into Work or a Paid Apprenticeship and continue to help and function in the community.

My eldest son did well academically at school, college and university academically however struggled with social areas and this impacted certain areas of studies as well as with non-verbal communication. He attended University of Surrey where he studied Aerospace Engineering and it was not until this point that he was diagnosed with high functioning Asperger’s.

He also hit many barriers as he was not receiving adequate support, especially at University. At the end of all his hard work, he received a very unpleasant letter informing him he was not allowed to graduate with his peers but had to wait the following year, as student finance had not put the money through (£1,000). This hindered him when looking for work as they would not release his grade until the money was received which was after original graduation date. Finally, his hard work paid off and he graduated – (grade impacted by insufficient support).

However, a year later although his money from student finance had already been paid, a lady from the University kept harassing him to pay up £1,000. He was trying to find a way to pay her and did not want to worry me. Just by co-incidence and by accident I found out. I spent the best part of a day trying to find all the paperwork and then had words with this lady. Prior to the job he is doing at present as senior computer analyst, he had £1000 in pension owing to him from his internship. When he started to work in his present job, they said he would train for three months then may be offer a job. They kept him working for them as a trainee and did not start his employment permanently until October. This delay caused him to lose £1000 pension. He was told not to worry they would sort this out for him. But to date this has not been resolved. He has issues talking and has told me to just leave it. Personal Independent payment does not cover funding for essential help e.g. Integrated sensory O.T., help with Stammer, and help from Speech Pathologist re pragmatic language therapy, help to improve relationships and social skills to avoid suffering in silence, isolation, living restricted life. The local authorities do not fund these extremely necessary services. This is just the tip of the ice berg we have been through so much more than this. I hope this information can help prevent other young people/families from going through this trauma and that sufficient training is provided for professionals so that barriers can be broken, adequate support can be put in place and we can feel safe to contribute and live in an inclusive society.

**CASE NO. 3**

Anonymous’s son was a child who was in care because she was a parent with hidden disabilities and due to lack of support she could not cope with the impact of the stress which led to the breaking of relationships with her son. She was physically and mentally burnt out as a mother and she had no choice but to put her son in care. He had hidden disabilities and was told only verbally and not in writing that her son had Asperger’s, as a result of this he was not given the support he desperately needed and was misunderstood and excluded in school. He was not statemented or diagnosed as a child. As a result of his vulnerabilities and his hidden disability not recognised, he was unjustly put into prison twice. This young man deserves Restorative Justice.

**CASE NO. 4**

 The following is the history of my daughter who was only diagnosed with autism last year aged 17 years old!. My daughter, is now 18 years old was born prematurely at 32 weeks. At her 6 week examination her visual behaviour, hearing and speech and language were assessed as being a possible problem. During her 18 months health check-up, her fine motor skills and physical health was highlighted as a possible problem.
Then at her 3 year examination her speech and language assessment was unsatisfactory and she clearly needed help in this area. During her primary years she was referred for speech and language therapy. We were seen for a few appointments at Westham lane clinic.
At school she was put on school action plus. However, I was concerned she wasn't making much progress as all her yearly reports used to say "below expectations". I was told she was making progress but the reports indicated otherwise.  After raising a few concerns with the school, they decided to carry out an intervention called toe by toe with her. Also I requested that she should be seen by an educational psychologist. She was put on the waiting list but unfortunately was never seen as apparently the waiting list was too long. She was due to start secondary school and I was advised to pursue the educational psychologist route from there. At this point I was unaware of EHCP's or statements as they were known back then. I feel the school should have picked up her difficulties and started the statement process there and then. It would have provided her with the necessary support and intervention to aid with her learning and social development. It would have also helped to prevent the psychological damage she went to endure later on in her life.
She had difficulties with social interaction and struggled to make friends she suffered bullying in year 8 and had girls from year 11 pick on her and accused her of bullying another girl who had autism
My daughter has higher functioning autism (Aspergers). She appears and looks normal but her level of understanding and mindset is way below her age. As she was getting older she became more aware of her difficulties and felt left out in pretty much everything from the classroom to the playground. As the years progressed students were placed in different sets according to their ability. She was placed in the lower ability class, unfortunately this meant she was also placed with students that were quite disruptive and didn't really want to achieve anything in relation to their education. This further affected her self confidence and self esteem.
As I wasn't getting much help from school I started researching myself online and came across various bits of information. I came to know I could pay for an independent Educational psychologist to have her assessed and that I could request for a statement myself. At first I was refused a statement. I wasn't happy and appealed to go the tribunal. I went ahead and paid around £500 to get her assessed by an independent Educational Psychologist. They also supported me in recommending she have an EHCP. The LA later revoked their decision and agreed to the EHCP. Currently we are still trying to get an EHCP. I also paid for her to have private tuitions to support her with her GCSE's as she was struggling and really stressing about this. I am so proud of my daughter. Despite all her difficulties and hurdles she managed to complete her GCSE's, managing to secure two C grades as well as D-G's. She worked so hard and tried so hard to fit in with everyone that eventually it took a toll on her health.
After she completed her GCSE's, she became unwell and very depressed. She wasn't able to carry on anymore and became isolated, preferring to stay in bed all day. We had enrolled for college but she wasn't able to attend. Her mental health suffered a great deal and she was referred to CAMHS by the GP. She was put on medication and was seen regularly by a psychotherapist and psychologist. She had further assessments and was diagnosed with Autism. I felt anger, betrayal and relief all at the same time. I felt angry and betrayed that I kept telling the school something was wrong yet they convinced me otherwise. At present she is recovering well and has just started a supported internship. However, her trauma and experience has left deep filled scars. My daughter missed out on 2 years of her college life and the whole experience has broken her and led her to have a mental breakdown. We are left to pick up the pieces. No one should have to go through or suffer the way she has. Thanks

**CASE NO. 5**

She is a carer for her husband who has severe physical disabilities and her daughter with down syndrome and learning disabilities. She was not getting the right community care support for her daughter until we went and helped her. She was on DLA for life with high rate mobility and care and when it switched to PIP it got stopped completely but now we have managed to get her the standard rate. Last year before Covid they travelled to Pakistan and they got left stranded without support there as a family due to Covid and nobody was checking to see if they were alright and she contacted me for help and I then got in touch with the local MP who helped get them back safely. She was not getting the care and support that she needed as a disabled woman herself struggling with her own personal care. Five years ago we tried to make this happen for her but they did not make any reasonable adjustments and because of that she stopped asking for the support that she desperately needed due to her language barriers and the lack of cultural appropriateness even though we requested that someone from her culture and beliefs would support her. This has lead in health equality and social care equality and she will now have early mortality due to this neglect. Even this year we applied for that service again for her and it wasn’t until I challenged the local authority to put her onto direct payment where she could have cultural and appropriate support that she needs and for her to feel safe in the support that she needed.

**CASE NO. 6**

Her son has been failed by the education system. Hence, he kept running away from school, but no one followed this through. He was extremely bright, but due to no support given this impacted on his mental health most of his life. Her daughter has also been let down by the education system and did not get the schooling she needed.

**CASE NO. 7**

Her daughter has been badly failed by the Education system, and made the mother feel that she was the problem and this damage has left her damaged with low self-esteem and impacted her mental health and wellbeing. Her daughter still does not have the right diagnosis even though she has a EHCP.

**CASE NO. 8**

She was diagnosed with cancer lives with her son and he is on the autistic spectrum and has an EHCP for him but is not getting adequate support for him and being let down by the education system. He did not have a proper transition from primary school to secondary due to lockdown and his mental health deteriorated since being in the second lockdown. He was bullied in his primary school for a very long time and is has impacted him since he left primary school and has been playing on his mind to a point where he is suffering from PTSD. Mum flagged this concern around the impact of bullying from primary school and requested for more support like counselling but the school never offered it. Mum also made many other suggestions for training courses to support her son but again school never put in the support the mum asked for. Not having the right support has resulted his behaviours to worsen to the point he got excluded from school. He was attending mainstream specialist sikh school. Mum is made to feel she is the problem and he has been attending a smaller provision but he only attends 1 hour a day and his education is suffering. He has a care package. The family feel the system have failed their son by not putting the right support in place for him and instead excluded him.

**CASE NO. 9**

Anonymous, is a young man who is a vulnerable adult and his mother had an early death. He went to special school, he is getting some support but even when his mother was alive they did not get support until quite late, when we the Disability Rep stepped in. But due to the long term negligence Anonymous mother died prematurely and sadly he is left and desperately needs life long support to meet his individual needs.

**CASE NO. 10**

Anonymous is a disabled deaf parent who is carer for her son and husband who have physical disabilities and she has not had carers assessment. Her son not diagnosed until he left school. He had late diagnosis.

**CASE NO. 11**

Anonymous has two adult children with LD that went to an inclusive school, one with ASD both statemented at school. Annul reviews for her daughter never happened leaving her very vulnerable and struggling and not accessing the social care and health care that she needs. This has had a massive impact on her and her mother’s health and wellbeing the equality they faced in both health and social care means that their life expectancy and indentured and lowered by 20 years.

**CASE NO. 12**

She had enablement for six months, no direct payment package given, he needs continuous care all her life, as well as her son as they both have autism.

**CASE NO. 13**

I have three children. My son has Autism, global delay, eating disorder, speech and language issues and learning difficulties.

My eldest daughter is age seventeen years and six months. If she was diagnosed at her eighteen month check up she would have had appropriate support and a better quality of life, but unfortunately she was not. She was diagnosed late with autism when she was twelve years old. Her conditions is life long but she was only give six times 1 hour sessions with the OT for the whole year and this was the same with the speech and language therapy sessions. If all professionals diagnosed children with autism early, it would have improved help. She missed out on essential Play Therapy, equipment, Integrated Sensory OT. We need funding for this for all our autistic children. When they are 16-18 years old, there is no where for SEN children to go for full time education. They only have EHC Plan which has limited resources e.g. Newham College of JFK and this is only until eighteen years old and not up to twenty-five years old as set out in EHC Plan. For the Child/Children/Parent and whole family – this is extremely unjust!

My youngest daughter finds it difficult as she doesn’t understand her older sister as she sometimes acts younger than her. Like a number of other parents of autistic children I do not know my rights and our human rights are not met by Social Care. GP’s never mention social care unless a child has a bruise or bump. Thanks to being helped and informed by the Disability Rep Group Charity, otherwise I would not have known that care could be accessed. Parents have negative feed back about social services, that they only take children away and split families up. When the social workers do come, they make you feel intimidated when they should make you feel confident and able to trust them.

When social care do come and do assessment, we do not get a copy of written report. So as our children constantly grow and change, it is traumatic to have to keep repeating upsetting and distressing issues again and again. This could be avoided if we are given a copy of the report.

Also the school SENCO does not give me a report or sign post me and other parents in my position to the right services. Parents only get sign posted for the wrong reasons, such as when parents are struggling and desperate to help their child and are wrongly suspected as the cause of the child’s distress instead of getting the support to meet their child’s needs.

**Why is there so much late diagnosis for our children? This needs to stop. Why is primary care, GPs and schools not picking it up – it is their Duty of Care. Most of these cases have autism/Asperger’s, which is life long hidden disability requiring continuous care. Some of these cases have not been diagnosed and many have been diagnosed very late which has had a huge and detrimental effect on their lives. Since the Autism Act of 2010, no changes have been made for these families. We would like to see the Autism Act implemented.**