



Residents United Forum



HIDDEN VOICES PUBLIC ADVOCACY PROJECT REPORT 2024

**MALE CARERS
7 JULY 2023**

**SOCIAL HOUSING
28 NOVEMBER 2023**

**SOCIAL CARE
CHARGING
21 SEPTEMBER 2023**

**SEND EDUCATIONAL
NEEDS
25 JANUARY 2024**

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Hidden Voices

Public Advocacy Project Report

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Executive Summary



In 2023, RUF (Residents United Forum) received funding to commission a consultant who would provide:

- a) training for RUF Trustees and 15 volunteers.
- b) to facilitate engagement at the start of the project through 5 workshop events and other activities,
- c) to facilitate RUF to develop key messages, communications material and a plan for the 3-month public advocacy live project
- d) to provide support and answer questions during the live part of the public advocacy project.
- e) to advise on how to create and maintain a Membership database, in accordance with RUF's Constitution, to provide a formal network of people to collaborate with on future public advocacy projects and to engage in development of RUF and its services.

The commission held meetings with Sandra Amoah the Founder/Chair of RUF, and the rest of the trustees to map out how the project would be implemented.

Through these meetings, the commission, and the trustees of RUF were able to determine the key themes of the public advocacy events that would be facilitated. These were:

- Male Carers
- Social Care Charging
- Housing
- Education

Purpose

This report has three main purposes:

1. To provide an opportunity for the hidden voices of disabled people, their families, and their carers to be heard and for their stories to be told through case studies.
2. To report on Newham London and its plans and pledges to their disabled residents, their families, and carers through Central and Local Government policies and how they have experienced these.
3. To outline recommendations and considerations in respect of the experiences of these people, which in turn may influence the development of any future plans that relate to them.

Male Carers

We are covering these areas to reflect the work being done by Newham council as Male Carers are common, but they are underrepresented. We wanted them to share their experiences so we can incorporate their needs into our recommendations.

Male carers also need information, help and assistance to care for their partners and with cultural differences it can be complex. An attendee to our session mentioned concerns being a male carer looking after young women in the case of allegations which could be made against him.

Social care assessments are often delayed or there can be 'no-shows'. Social workers are needed to follow through Care packages which can at times be 'basic' and therefore not fitting the distinct and individual needs of the people requiring care.

Male carers can be more prone to isolation due to the culture of them not expressing their feelings. The male carers we encountered sometime did not realise they were carers as a result missed out on certain care packages. Male carers are not represented in official statistics, and this is a change that is required.





Adult Social Care Charging

Social Care Charging, we have found that people are being charged for services they cannot afford and that they are also not being assessed correctly.

With ULEZ (Ultra Low Emission Zone) disabled people have to pay to park outside of their homes.

Mental health services have long waiting times and as they are taking too long to be seen people resort to private care if they can afford it or unhealthy self-help.

Housing

There is a lack of adequate housing for disabled people, which needs to be addressed.

Disabled people are less likely to own a home than non-disabled people (39.8% compared to 54.9%), and more likely to be living in social housing (24.1% compared to 7.5%).

It could be said that East Ham has a housing crises, 16.2% of people are homeless according to [Deprivation - UTLA | Newham | Report Builder for ArcGIS](#).

Incomes are substantially lower than the London average and particularly with the cost-of-living crisis due to inflation, households are finding themselves with less disposable cash. 23 of children in the borough are living in poverty.

The above statistics can be found on https://www.newham.info/health-and-social-care/#/view-report/1835e7ef70a748c79aa478f386581700/___iaFirstFeature/G3.



Special Educational Needs and Disabilities (SEND) Life Long Learning



Education, particularly relating to special educational needs and disabilities, (SEND) can affect young people and adult learners' ability to learn.

Special educational needs can result in behavioural issues, their ability to socialise and understand. This can ultimately lead to higher cases of exclusion from school and impact their prospects. Within Newham there is a lack of youth service.

There are no home schooling provisions for children with SEND.

Mental health issues amongst young people have increased. There are fewer safe spaces where they can relax and decompress.

If the young people fall through the cracks they can end up as missing persons, which leads to a concern of human trafficking, as well as murder and killings.

Census information sourced from: [Disability, England and Wales - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk)

The Mayor of Newham Rokhsana Fiaz discusses many of the issues within Newham and has a SEND strategy, which can be downloaded.

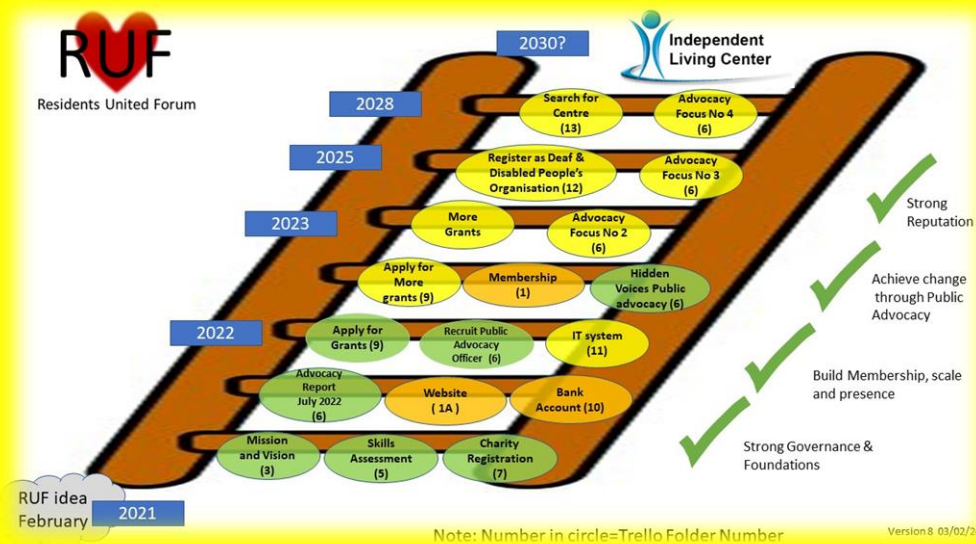
Read the SEND report by Newham London:

<https://www.newham.gov.uk/news/article/1203/newham-s-send-and-inclusion-strategy-improving-outcomes-for-local-children-and-young-people>

Read more about Rokhsana: <https://www.newham.gov.uk/council/mayor-newham-1>

About Residents United Forum - RUF

RUF Ladder



RUF brings together representatives from different local community groups to ensure disabled residents, carers and their families voices are heard, and their views actioned when developing local services.

The group is led by Newham residents with lived experiences as disabled people and carers.

Residents United Forum hope to achieve this change by following a set of principles, which empower, value, respect and support disabled people to make their own decisions.

More information about their principles and work can be found on www.ruf.org.uk or <https://e-voice.org.uk/ruf/>

For this report we will follow the Disability: Equality Act 2010 and the RUF definition of Disabled People.

This includes people with; physical impairments, sensory impairments, mental distress or mental health issues, people with learning difficulties or learning disabilities, people with long term health conditions and hidden impairments, people living with HIV or AIDs and people who use or have used drug or alcohol services.

We also include disabled people of all ages, including disabled children, disabled young people and disabled parents.

Methodology

The London Borough of Newham and the National Picture

- o The National Picture
- o Newham
- o Demographics
- o Disability

Themes explored through Public Advocacy Meetings

- o Male Carers
- o Social Care Charging
- o Housing
- o Education

Mental Health

It is to be noted that the theme of Mental Health was not chosen as a separate Public Advocacy area as it was concluded that Mental Health and the impact of this and wellbeing ran through the four themes selected.

Where possible the training sessions were held on 2 dates to allow in person and virtual attendance completely open to all. We advertised via multiple channels such as WhatsApp, email, X (formally known as Twitter, and word of mouth for attendance.

We recognise that physical health issues are often easier to measure than mental health, and as a result we have decided to look at physical health to begin with and intend to look at mental health in future projects.

Mental health being a 'hidden disability' was much harder to measure and we found that issues regarding physical health can easily create and add to existing mental health issues and are connected.

Volunteers

RUF Board of Trustees

The Trustees met as a group with the commission and had one to ones to draw on their knowledge and expertise in the area of disability, discuss their role at RUF and to share their thoughts on how the project would progress.

All board members are experts by experience and have a deep understanding of the current landscape in Newham.

Volunteers and volunteering

The aim was to attract volunteers who could not only assist with the Public Advocacy events but to add continuity to having more Public Advocacy events post this funded piece.

The volunteer pool was achieved by:

- Raising interest within those who accessed the voluntary sector groups either as volunteers or utilising the service for themselves or their loved ones.
- Social Media Platforms using posters that were designed and created through collaborations between RUF Trustees and the commission.
- Word of mouth
- To make the opportunity accessible, we provided all meetings and training sessions both face to face and online. We had very good participation with the larger attendance via the online option. The online sessions did not work as well as the in person.

Volunteers were offered the training in two parts so that they could absorb each aspect prior to moving on to the second part. The training centred around Public Advocacy and how to utilise the techniques going forwards.

Participants were given support to engage and access guidance from the trainer. The volunteers were reflected of the demographic with most either having disabilities, carers for those with disabilities or both.

Public Advocacy Training

Public Advocacy can be easily described as “speaking up”. Advocacy can involve activities such as:

- o Educating the public around their rights and other areas of interest.
- o Providing information and a range of resources to individuals and groups that need assistance.
- o Commenting on regulations, i.e. legislation, plans, processes, and policies that affect the lives of a community or individuals.
- o Helping groups or individuals access benefits, services, or resources that they are entitled to.
- o Promoting and protecting the rights of those under protected characteristics from neglect, exploitation, and abuse
- o Encourage the development of service provision that assist those in need of additional support to reach their greatest degree of autonomy in their lives.

As participants, those attending the training would be able to develop a greater understanding of the role and increase their confidence in advocating effectively.

Introduction To Public Advocacy

Part One If you would like a copy of the slides, in a more accessible format; please contact us)

We began the workshop by talking about the aims, which was to develop and enhance their understanding of advocacy, develop awareness of skills and attributes required, and develop awareness of the difference between advocacy and other methods of being heard and helping professions.

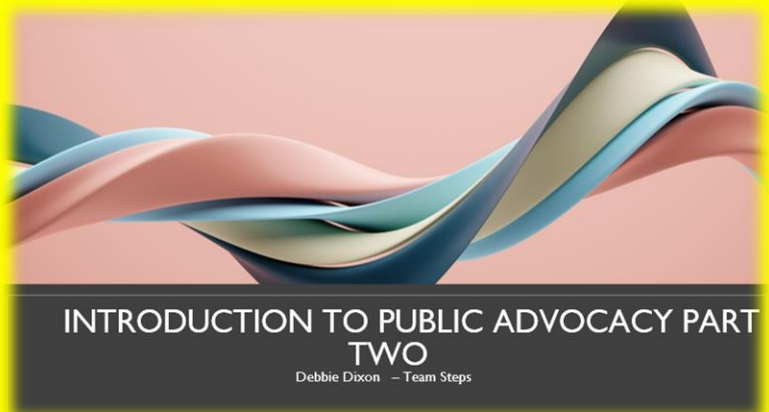


We aimed to allow them to identify common principles and use advocacy with clarity and confidence.

We took the participants through several exercises such as defining advocacy and thinking about what makes a good advocate. We looked at the skills and qualities and what independent advocates do, as well as talked about the impact of advocacy and what makes it successful.

Introduction To Public Advocacy Part Two

We began the workshop by talking about the aims, which was to enhance their understanding of public advocacy, develop awareness of how to develop an action plan and a call to action. The outcomes would be to define and identify key themes for public advocacy identify areas for action planning and use public advocacy with more clarity and confidence.



We defined, talked about, and gave examples of various advocacy methods, such as grassroots advocacy, lobbying and media advocacy.

The group participated in an activity around the various types of media people can use to ensure many people hear their message. A discussion was had around activism and some of the outcomes which can make public advocacy successful.

We touched on consultation, volunteers and roles within the group, themes and deciding what is the call to action. The session ended with discussing selecting the right venue, time of day and best practice in order for it to be a success.

Equality Diversity & Inclusion

The case for change



According to the Office for National Statistics (ONS) Census in 2021 Newham had 9.1% disabled people Disabled and limited a lot and 8.4% Disabled and limited a little (totalling to 17.5%).

The Equality Act 2010 makes it unlawful to discriminate against someone, who is considered to have a disability. People with these conditions and impairments are automatically protected under disability discrimination law.

Newham is a very diverse borough with 72% Black, Asian ethnic minority communities.

According to the Newham Recorder, [Over 100 languages spoken in Newham schools | Newham Recorder](#).

RUF covered many of the issues faced by disabled Newham residents in detail, in our Residents United Forum Research Report – July 2022 (If you would like a copy, please contact us using the QR code on the final page. Alternatively this can be downloaded from: <https://www.onenewham.org.uk/networks/special-interest-theme-groups/residents-united-forum-for-disabled-people>).

This report was created as a resource for change and a call to action. It was shaped by current long standing case studies and detailed account of people's lived experiences.

In this report RUF found many individual cases where disabled people were ignored and left unsupported. Newham disabled residents weren't always consulted leading to issues such as inaccessible community spaces, dangerous walkways leaving residents isolated and unable to leave their homes. RUF made a series of recommendations in this report to empower, value and include disabled people in every step of the process.

Support for people with disabilities is reducing due to government cuts, so the people impacted by these issues are unaware of the discrimination they face or unaware of their rights and the legislation created to protect them.

The government's ongoing commitment to reduce the gap between the employment rates of disabled and non-disabled people (known as the disability employment gap). The government reaffirmed this commitment in the Health and Disability White Paper published alongside the Spring Budget 2023.

More information about the Equality Act 2010 can be found at: <https://www.gov.uk/government/publications/equality-act-guidance/disability-equality-act-2010-guidance-on-matters-to-be-taken-into-account-in-determining-questions-relating-to-the-definition-of-disability-html>

A full copy of the Act can be found at: <https://www.legislation.gov.uk/ukpga/2010/15/contents>

Male Carers

Case Studies

Nevilles' Story

Neville* is 73 years old. He was born in the Caribbean but made his home in the UK over 50 years ago. He is married to Janet* “the love of his life” and has been for many years.

Janet is 71 years old and has Dementia. Neville describes her as having been a very active woman prior to her diagnosis.



Neville struggles daily with caring for Janet. He is scared to seek support from the Newham Council because he is worried that they will put his beloved wife in a care home. He worries constantly that she will fall and that he will not be able to help her as he himself uses a walking stick.

Recently, Janet needed some new bras. Neville, having never been involved in the purchasing of female underwear, did not know how to measure her size, style, cost, or even where to buy them.

Neville felt embarrassed that he could not do this for Janet and felt quite upset. Whilst thinking and worrying about how he would manage this task, he remembered “a lovely woman” who runs a support group for carers. He decided to push beyond his embarrassment and reached out to her. She was delighted to be of assistance to him and Janet and supported Neville to get the right underwear for his wife.

Neville expressed that he worries constantly about what will happen to Janet if anything should happen to him. He explained that in his culture, a husband takes their vows seriously and looks after their wife until the end of their lives. He added that putting his wife in a care home would not be culturally acceptable and that there is an expectation that he will continue to look after her himself.

Neville said that he would benefit from some help but his fear of having his wife removed from care has stopped him from accessing this from the Newham London.

Hanif's Story

Hanif*, is in his late forties, is the father of two daughters. His wife Kadijah* died after a long illness, leaving Hanif to look after their children. Hanif had nursed his wife and

cared for their youngest daughter Aisha aged 17, who has complex needs and requires high levels of care. Hanifs' elder daughter Saleema also helped and had, despite these factors, qualified as a teacher.

Hanif described how hard it had been for him and as a male carer, he felt that he needed to be particularly vigilant in case any allegations were made about his being a man and caring for his daughter.

Aisha has a care plan and until recently the plan had not been updated since 2018. Hanif said that there had been numerous delays in getting a social worker to carry out the reassessment as social workers would contact to arrange a visit and then not turn up. Sometimes, a social worker would attend unannounced, carry out an assessment and then not send the associated documentation to him. This would result in the 2018 care plan remaining in place even though Aisha's needs had increased considerably over the five years since the last plan was created.

Aisha struggles with meeting new people and having several social workers coming as strangers to assess her unsettled her greatly; leaving Hanif and Saleema to cope with the resulting fallout. Hanif has tried on numerous occasions to contact the social work team to get updates and to ask that they give him notice of their intended visits so that he can prepare his daughter. He is either told that someone will return his call and no one does or he is assured that they will notify him in advance of their intended visits, and this does not happen.

Hanif shared that he has installed CCTV cameras around the house so that he can have "evidence" around any incident or allegations related to Aisha's care either by him or by the carers who come to the home to look after her needs.

As a result of Hanif's worries, he has been diagnosed with several health-related issues. Due to the impact on his own wellbeing, Saleema has given up work and is supporting her father and Aisha.

Hanif is saddened that his daughter has given up her dream job to support him. Saleema does not have a social life and he wants her to be able to enjoy her life, get married, and be happy.

He is hopeful that the latest assessment will yield results, that they as a family can have more support and in turn, have a more fruitful life.

Piotr's Story

Piotr* has three daughters and one son. His middle daughter Leyla aged 13 has a diagnosis of Autism, ADHD and OCD. Piotr had a job working as a forklift driver; however, due to developing back problems after repeatedly manually lifting Leyla; he had to give up work.

Leyla and Piotr have a very close bond, and this is in part because they spend a great deal of the day together. Piotr's wife Lexi suffers from depression and anxiety and struggles most days to get out of bed.

Their son and other two daughters go to mainstream schools and college and are doing well. Despite Piotr's back problems and his wife's mental health issues, Leyla's care package does not include transportation to and from her school. Some days, Piotr can barely move as he is in constant pain, but he is still expected to take Layla to school. Piotr does this because he says that school is the place where she gets to socialise, and he refuses to stop this happening no matter how frail or ill he feels.

Piotr feels that the care package is very basic and that it does not make much difference to their lives. Leyla would very much like to socialise more, but her sisters tend to exclude her and do not invite her out with them. Piotr asked them why they exclude Leyla, and they told him that they love her but are "embarrassed" by her behaviour around their friends. This upset him and whilst he understood this, he felt bad.

The family do not get invited to family events and the friends that he and his wife have are dwindling as they struggle to go out as there is no one to care for Leyla if they want to go out as a couple.

Piotr tries hard to keep his daughter happy but knows that this is limited due to him being male and her wanting to relate to her peers.

Summary

Male carers

What was common in all the attendees' stories and responses were that they all shared a sense of bereavement. The loss of what could have been in terms of a life where care was not in the centre, and where the male carers could be fathers or husbands to their respective cared for was tangible.

The culture of men not expressing their feelings around this aspect of their lives was clearly impacting on their wellbeing with all attendees sharing feelings of being overwhelmed, isolated, experiencing low moods, and being constantly fatigued.

What is obvious was that the ratio of male carers to female carers is likely to be incorrect as not only did those attending the event not recognise themselves as male carers, but many were not in receipt, as in the case of Neville, of care packages for their loved ones and therefore would not be included in the official statistical count.

Social Care Charging

This event centred around the situation in Newham and the charges that disabled residents and their carers faced.

Attendees expressed complete confusion around Social Care charging. This was amplified by the fact that not all boroughs charge for social care including Hammersmith & Fulham. There was not a clear understanding as to why one of the most impoverished boroughs were being charged.

There was also no clear policy around charging and those who attended the event could not understand why there appeared to be no real understanding as to how charges are assessed.

Transportation

Newham does not have a good transport system for disabled people. There is a border policy implemented by Dial a Ride who will not go over into other boroughs. Therefore, if you live on the edge of Newham, Dial a Ride will not take you to the neighbouring borough e.g. Redbridge as their remit is for Newham only. At the time of the event, there were 89 Dial a Ride buses but only 36 drivers.

There is a taxi card in place, but this is also problematic as the current allowance was £104 per year. This amount is quickly exhausted as a cardholder can only swipe once which is £7.50 per swipe with the top up reliant on the user.

For those who can access a taxicab, they are hard to get, even when they have been prebooked, with many cab companies cancelling the trip. This impacts appointments at hospital and other vital services being missed through lack of or cancelled taxis.

As Newham has a large Asian population, many said that during religious periods such as Ramadan and Eid, the already small number of taxis available became significantly less at these times, making travel even more difficult.

As a result of the dire lack of access to transport for disabled people, the numbers of people reporting that those with disability were becoming increasingly isolated, leading to an increase in their mental health challenges. One person described their circumstances as being “a prisoner in their own home”.

The mayor has segregated the Borough, shops should be more inclusive for other faiths. Jane* struggles with her necessity shopping in Green Street. She must travel all the way to Stratford because Green Street shops are mainly Asian Accessories.

Assessments

Those in attendance were unanimous in their view that the current Social Care Charging system is broken and unusable.

As of October 2023, Newham's Day Centres were beginning to implement a charging system which would essentially result in some current users of the service being unable to afford their days at the centre. It is to be noted that there are very few provisions of this kind in the borough, and all are oversubscribed.

When making an application, there is a form that needs to be completed. Those who had already completed the expenditure part of the form said that they had not fully understood what was required and had inadvertently missed several costs associated with this.

One attendee said that in the case of his daughter who is Autistic, finds running water soothing. She can run the water for a significant period in order to counter her dysregulation. This results in a large water bill which is not considered in the expenditure form.

The attendees said that the form is not easily understood by those who either had a poor experience of education or those for whom English was not their first language and felt that they would not be able to give a true picture of their situation. This coupled with a fear that if they did share the true extent of the challenges faced by both the disabled person themselves and or their carers, that the Newham Council's assessors may deem that they could not cope at home and place them into care. Something which filled all with dread.

The participants said that they had no guidance on completing the form or the process for assessment and so had no real understanding of how an outcome was reached.

There were concerns raised in how the number of care hours were calculated as there was a consensus that physical disability was somewhat more quantifiable whereas mental health being a 'hidden disability' was much harder to measure in terms of support; particularly as for many there was fluctuation in needs. The result of this was that the assessment would be skewed as there was a low degree of accuracy and needs not being adequately met.

Once the assessment is completed, there is a lapse in response with, in some cases, a considerable amount of time lapsing before an outcome is shared.

There was no consultation on this process and attendees felt that decisions were being made for the disabled community.



Personal Budgets/ Direct Payments

There was a lack of knowledge around personal budgets and direct payments with the majority of those in attendance not being aware that they can be in receipt of Direct Payments whereby they can, by using the budget given by Newham London, they can manage that fund directly.

Once this was explained, there was a mixed reception to this concept. Some felt that they would struggle to manage a budget as there would be a need to keep receipts and evidence all spending, have a separate bank account and potentially become an employer should they choose to employ their own carers. Others welcomed the freedom of choice and said that they would access more information on this.

The budgets allocated were not considered sufficient for those in receipt of them to live a good quality of life. In addition to this, there were 'hidden costs' for disabled people that fell outside of the budget. An example of this is that those adults with a learning disability were not eligible for pull up pads or incontinence pads. This meant that these needed to be purchased independently which incurred significant cost.

When there was an element in the budget for domiciliary care, there were numerous concerns raised. These included:

- There is an issue with getting appropriate staff with the correct training and when these can be located, they are not always available.
- Domiciliary care workers are often registered with several agencies making continuity of care problematic or impossible. This was particularly important for those who struggle with change because of their disability.
- Those who chose Newham London's in house carers had poor experiences as the council would often send 'anyone' many of whom were not able to meet the needs of the client e.g. sending male carers to a Muslim woman.

Service Provision

The stories shared by the attendees indicated strongly that there was a distinct lack of services available for disabled people in Newham. An example of this was that for those who have Dementia, there are no places for them to go to socialise and to enjoy their lives.

The day centres for those with Dementia are only able to access these one day per week, leaving six days with no meaningful activities. It is to be noted that this service has a cost impact and is therefore limited to those who can afford to pay.

Emergency/ Continuity Planning

As a significant percentage of attendees were carers of their children or spouses, there were concerns around what would happen in the event of them not being able to continue to fulfil their caring role.

There is no provision in place for emergencies or when a carer dies or needs care themselves within the councils' policies.

Concerns were raised about what would happen to their loved ones as if there was no provision for them. There was a call for conversation to be had by RUF (Residents United Forum) with Newham Councillors around this matter.

Fred's* Story

Fred has three children. His forty – two-year-old daughter Betty* has a learning disability and is reliant on him and his wife but more so Fred as his wife has become frail.

Fred tries to keep active and supports other carers when he can as it helps him to enable others in the way that he was not.

Fred is now seventy – nine years old and is constantly worried about his daughter. His other children have married and moved away from Newham with one living in the United States of America.

He has fought for the last forty years to ensure that the needs of his daughter are met. He is a quiet man but when he is advocating for his daughters' rights and that of other disabled people in Newham, he is unapologetically vocal.

He is keenly aware of how much support Betty needs and will continue to need for the rest of her life but worries as he is also aware that resources are stretched and often difficult to access.

There are currently very few social activities available for Betty and he sees her sadness, frustration, and growing isolation daily and feels powerless to change this for her.

Fred knows that he is becoming frail too and worries about who will care for Betty when he and his wife are no longer able to. He does not want to rely on his other children as they have, as he sees it, enough responsibilities of their own.

Sadness is never far from Fred, and he carries this around in silence as he waits for Newham London to give him a solution that will allow him to find solace. He knows that this is not the case yet, but he continues to wait.

Summary

There is an urgent need for a more 'joined up thinking' approach to be applied to Social Care and an urgent Cabinet meeting regarding the impact of charging for social care, the ramifications for this and how it may potentially breach the Human Rights Act (1998).

All care assessments should be closely scrutinised by independent bodies such as Care Quality Commission (CQC) to ensure that the process, determinations, and budgets are appropriate and unbiased.

Social Housing



For the purposes of this public advocacy meeting we used a Letter by Newham London's Mayor and their State of the Borough documents as discussion points. The following case studies reflect the ensuing discussions.

Randeep's* Story

Randeep is 36 years old and has numerous health and disability challenges which include sight loss, cerebral palsy, and a heart condition.

Randeep longs to have a place to call his own; he lives at home with his aging parents and his siblings.

Randeep once occupied a big bedroom but as his brothers married and brought their wives to live in the house as it is in keeping with their cultural norms, Randeep now finds himself in the box bedroom which means that he has no space to move around and is constantly banging himself against the furniture.

Randeep loves to socialise and goes to a local support group that helps him speak to other people and to assist him to get help with things like claiming benefits and making application to be housed by Newham Council.

With the help of the leaders at the support group, Randeep submitted his application and was accepted onto the housing register. However, he has been informed that there is no suitable housing for him in Newham. Randeep is very depressed and whilst he loves his family, he wants the chance to live independently, to have the opportunity to have a social life, and make trips to the Essex coast which he really enjoys.

Linda's story

Linda* is in her late fifties, she has a serious heart condition. She nursed her husband until he passed away from cancer and was left alone and afraid. One the death of her husband, she moved in with her son who also has cancer and his wife and their daughter. The flat is very small and is situated up numerous flights of stairs with no lift. This means that Linda struggles to go out as the walk makes her feel breathless and ill.

Linda is in her granddaughters' bedroom, and this has meant that her granddaughter sleeps in a room that has no proper window. Both Linda and her son have applied for either housing for Linda as a single tenant or as a family. Neither application has been successful as there is no housing available to meet their needs.

Linda cries herself to sleep at night as she feels guilty that her granddaughter has sacrificed her room so that Linda can have somewhere to sleep. Linda worries about the effect that her presence is having on her daughter in law who is caring for the whole family, her granddaughter and her son who is also having treatment. Linda prays that she will go to sleep and not wake up.

The Khan Family Story

The Khan family* lived in a private rental for a number of years. The Landlord wanted the property back as he planned to sell it. The family had not had enough time to find alternative accommodation when they received a call from the landlord's office to say that the family needed to come to the office as they had another property for them.

The family went to the office and when they returned home after visiting the office, they discovered that the locks on their current home had been changed. Mrs Khan is the mother of five children with her husband Mr Khan. Both Mr and Mrs Khan are disabled as are two of their children.

On discovering that the locks had been changed the family were distraught. Having never been in this position before, they were unsure of what to do as all their possessions were in the house that they called home.

A friend told them* to go to Newham's homeless unit where they were given temporary accommodation. This accommodation was not in the borough and was in Kent. Mrs Khan told the council worker that they did not want to leave Newham as that is where their support network was. The council worker told her that she had to accept the offer as they did not have an alternative. Reluctantly, they went to the property that was offered.

Mrs Khan reported that when she and her family arrived at the property, they thought it was the wrong place. The house looked derelict and was filthy dirty. There were broken work surfaces, urine-stained beds, and mouse droppings among other unsanitary items. The property was also in a high crime rate area with anti-social behaviour happening all around them. This was in total contrast to the area that they

had lived in and one that her disabled children, both of whom have Autism were dysregulated by.

Mrs Khan telephoned the council worker who did not apologise and reiterated that this was all that was available and that this was the only option. Deflated, Mrs Khan did her best to make the house habitable. Mr and Mrs Khan believing that they were likely to be in this accommodation for a few days at worst, decided to try and make the best of a bad situation.

The following morning Mrs Khan called the council worker again to discuss how they would get their possessions and to enquire where and when they would be moving back to Newham. The council worker said that she could not give them a date as they would need to wait until there was a vacant property in Newham that would house them.

Weeks passed and the Khan children hadn't been to school. Once again Mrs Khan called the council worker who advised Mrs Khan to register her children at the local schools. Mrs Khan told the council worker that this would not be a good idea as her family would soon be returning to Newham. The council worker reminded her that there were no guarantees around whether they would return to Newham and advised Mrs Khan to contact the education department for assistance.

Mrs Khan was devastated. She has numerous health issues and was struggling to keep optimistic about the future. She tried to shield her husband who had recently had a triple bypass and had mental health issues from the stress but had no choice but to tell him what she had been told.

As a result of the family and their numerous health issues which required them to see several different specialists based in Newham, combined with the fact that their children could not access their schools, they took the decision to find a private rental in Newham.

With the help of a family relative, they found a private rental back in Newham. The cost of this house exceeds their income and so a family friend has been subsidising this. Mrs Khan recognises that the family friend cannot sustain this but cannot find a solution.

Newham council informed Mr and Mrs Khan that as they left the property in Kent, they have made themselves intentionally homeless and as such, the local authority has no responsibility for them. Mr Khan has had his mental health medication dosages increased and Mrs Khan has been recently diagnosed with Anxiety and Depression.

Summary



Many of the attendees had no meaningful awareness around the intention of Newham Council as detailed in their State of the Borough document.

The document itself was not accessible as whilst there were visuals, there was also a great deal of text that was not in plain English, which was counterproductive.

The majority of the attendees spoke of a 'disconnect' between Newham Council and the residents. The respondents said that they did not trust Newham Council to deliver anything that they

said that they would as they had not been the beneficiaries of any of these things such as suitable housing.

What is clear from the findings from this event was that Newham's housing crisis is particularly impacting on those who have one or more disabilities within the family. This is also compounded by a lack of knowledge of the housing rights of disabled people who are from minority communities especially when they have limited understanding of complex written and verbal English as used in legal references, statute and issue related legal environments.

Recommendations: The London Borough of Newham should do more to provide accessible training, information sharing events and consistent support for this community of people.

Education

Special Educational Needs & Disability (SEND)

Newham Council Commissioned the University of Warwick to report on SEND. This commission started in 2021 and completed in July 2022. This was used as the backdrop for discussion at the Education Public Advocacy Meeting

The attendees shared their experiences.

Simeon's Story*

Simeon has had numerous struggles when he attended a local Primary School. His mother has several health issues of her own which cause her to experience chronic pain. Despite her challenges, she had supported her son Simeon to attend school. He is diagnosed with special needs and whilst needing additional support and despite of being bullied by his peers for being 'different', Simeon was able to achieve 100% attendance at Primary school.

Simeon's mother was very concerned about his transition to Secondary school as she was aware that there were likely to be higher expectations there. Simeon's mother highlighted the need for him to have a good transition from his primary school into secondary school; particularly as he was going to a mainstream provision.

Even though both his Primary and Secondary schools were aware of his additional needs, neither made adequate preparation for this. The bullying that Simeon experienced in primary education exacerbated; leaving Simeon trying to manage this plus numerous challenges in doing his best to adjust to the new environment.

This resulted in Simeon displaying behaviours and attitudes that the secondary school were ill-prepared to manage. As a result, in 2021, Simeon was excluded from the school.

Simeon's mother has been battling to get Simeon back into education. All attempts in the last 4 years have been futile. His mother does all that she can to keep Simeon occupied during the day but of late, he goes out of the home and has been seeking companionship.

He is very vulnerable and there are serious concerns around his safety and the possibility of him being groomed and or exploited.

The long period of time that has elapsed since he was last in education has made Simeon very anxious about a possible return to education. His mother says he appears to have given up hope.

The provisions that he has been offered are not suitable for his specific needs and do not offer anything that is meaningful for his future development in terms of employment or further education. His mother is clear that had Simeon had the right support at the crucial point of transition, that he would have flourished. She is now concerned that he will become entangled in the world of criminality and that he will find himself in the criminal justice system where no mother wants their son to be.

Rosie's Story*

Rosie is 25 years old and has Learning Disability. Rosie spends much of her time with her ailing, elderly, mother who is eager for Rosie to have a well-rounded lifestyle.

Rosie is a very sociable young woman who loves to go out and socialise. She continuously asks her mother to help her to find activities where she can lessen the isolation that she experiences on a daily basis. Rosie also wants to go back to education, which is also an area where she can learn new skills and make friends.

Due to the lack of provision in the borough of Newham, Rosie has nowhere to go to broaden her learning and has been on waiting lists for courses and activities such as Zumba and support groups targeted for her age group.

Rosie was placed in a day centre which is designed to cater for residents aged 60 plus. This is not a suitable environment for a vibrant young woman and so could not continue to attend.

The provision in the borough does not have sufficient resources to meet the needs of its disabled residents and therefore any groups that are offered, generally have a short lifespan for those attending them i.e. 6 to 12 weeks. This means that the attendees become settled and then the service is removed, leaving young women like Rosie very de-motivated.

Rosie has carers who her mother states do not meet her needs. Rosie likes to go for walks and asks her carers to take her out so that she can walk. They in turn take her on the bus which defeats the object.

Rosie has not had a review of her educational needs and her mother says that this should be carried out regularly to ensure that her needs are being met with appropriate steps taken to address any unmet needs in a timely manner.

Neha's story*

Neha is 17 years old. She has Learning Disability and Anxiety. Neha's anxiety can create an added layer of challenges for her and her mother who supports her. Despite having experienced the very unpleasant symptoms of Anxiety, Neha was able to complete her primary and secondary education. With her mother as her advocate, Neha has been able to secure a college place and enjoys all that being in the college environment brings. In order to attend college and get the greatest benefits from being there, Neha has one- to one learning support staff. These staff help her when she may be struggling with understanding or when she is feeling particularly anxious.

Neha's one- to- one staff are crucial to her in the college setting and she relies on their support to empower and enable her.

Neha and her mother reported that on numerous occasions the staff do not arrive to support, and Neha is unaware that they will not be attending in advance, which would give her and her mother the opportunity to plan how Neha will manage her day.

Neha's mother says that when the support staff do not attend, the teachers expect Neha to deal with this on her own, without understanding the impact on her and without explanation.

Neha often becomes anxious as a direct result of her concerns around whether her support staff will be there to support her. This situation hinders Neha's ability to concentrate as she worries that she will have to manage on her own.

Gurdev's story*

Gurdev is 7 years old and has a diagnosis of Autism. His mother has also received a diagnosis of having Autism. English is not her first language, and she says struggles to express herself as she would like as a result. She says that she thinks that her language difficulties add to the inability to get support for her and her son.

Gurdev is in a mainstream primary school and despite having a formal diagnosis, has very limited support. Gurdev is constantly distressed at school and requires a significant level of support to engage with his education.

His mother has tried to contact the school and the SEND team to seek support. However, even though she has made numerous phone calls to both the school and the local authority, she says that they either say that the person she needs to speak

with is unavailable and will call back or tell her that they will investigate and phone her later, but do not do so.

Gurdev's mother stated that she is becoming increasingly concerned about how her child will continue to cope at school in light of the lack of support they are receiving. He is becoming less keen to go to school and his mother is worried about the outcome.

Gurdev's mother is unable to find methods of ensuring that those responsible for Gurdev's care in respect of his education are responsive and act before matters escalate to unmanageable levels.

Jermaine's story*

Jermaine is 17 years old and has Learning Disability. His mother says that those who should have been invested in improving his chances of receiving a meaningful education, decided that he would not achieve much and should be given minimal support.

Despite Jermaine's challenges, he embraces the school environment with not just a willingness to receive education but with a real desire to learn.

Jermaine's mother said that she had no choice but to continuously challenge the local authority and their decision-making processes for her son. She stated that this, as a lone parent who has a full time job as a civil servant and carer for her son, took incredible levels of resilience to get results.

Jermaine's mother cited the fact that she understands the British systems as the reason why she was able to take the steps that she must to get her son the appropriate education that he deserves.

She stated that if she were like many other parents and carers who do not have a working knowledge of these systems, that she would not have been able to make progress.

Jermaine's mother stated that as a direct result of Newham's attitude towards Jermaine's education, they have failed her son and left her no alternative but to navigate her way to provision outside of the borough.

Jermaine's mother said that he is flourishing at a college in one of the counties outside of London and has plans to go to university in the future.

Summary



The borough was supposed to meet parent needs, SEND guidelines & recommendations should have been followed and implemented but they have not.

Newham is a diverse community with over 240 languages spoken. We have found that, reports are not available in different languages and there should be both online and hard copies.

There are insufficient resources in the local area and Newham funding cuts have caused an impact.

From our meetings with the residents, we have found that parents with SEND children do not have guidelines for where to ask for support. They have voiced that they require coaching, they are not equipped to ask for help, as they are overwhelmed with their disabled children. They need an induction step by step e.g. what forms are being signed.

After a child is diagnosed and given an EHC plan, the parents are unaware of what the money is being used for. Within the system, officer transition is not being done properly, Statement of Action Inspectors speak to parent and carers.

There is a lack of therapies available e.g. physiotherapy, occupational therapy.

Diverse Community Borough - split communities, Newham is the only Borough who does not have a voluntary organisation.

The Mental Health Service of too many children is not being met. Young adults are being missed, they are excluded and getting bored. They get sectioned from crisis line, sectioned meaning – children retained as dangerous for the community due to learning disabilities.

The vulnerable children are not allowed to be taken to police stations and be locked up in cells – but they still are.

Special needs students are told 'they cannot progress'. Young adults have no college after the age of post 18 yrs. East ham college does not take students post 18 years with special needs.

Students with special needs should be allowed to use their mobile phones as coping strategies in college if they need to. Colleges need mentors to support individuals with disabilities. These points should be written in the EHC plan.

Children excluded from school are at high risks to be with gangs and the Local Authority should provide external provision for children in schools that need the required support.

Nobody responds to parents concerns at school claiming child is 'fine', when they are not even progressing. Or alternatively when parents raise their concerns with teachers about their children they are told: 'There are worser kids than your child in the school'. This should not happen.

There are also issues for those who are adults who wish to attend educational facilities. There are few available and most will only allow, due to apparent lack of resources, adults to attend one day per week. There are also many who cannot access these provisions due to waiting lists and not meeting the criteria for a variety of tenuous reasons.

Recommendations

Following this report, we would like to equip the residents with the tools and knowledge needed to advocate for their rights. From the sessions we learnt that many were unaware that they had been discriminated against but were feeling the aftereffects from the trauma of the refusal of treatment/opportunity.

Recommendations

- Funding should be accurately apportioned/ awarded and the local authority made accountable for ensuring that the funding is in line with the need and assessed in line with the policy.
- Mapping Diverse Community groups and to halt describing these communities as 'Hard to Reach'.
- There should be an accessible booklet in place for child-parent rights given to every parent in the borough.

- There is a lack of social workers for parents of children with special needs this needs addressing with extra funding allocated for the recruitment and retention of staff to avoid the current lack of continuity.
 - Good Thinking App to help with stress, anxiety and low mood made available to all residents with disability with no cost impact to them.
 - Hate Crime and Racism should be stopped in the Borough. Women 'spat on face' case has been ignored. Greater access to legal support to challenge these types of criminal activities.
 - Pastoral Care needs more funding in schools so that children can get intensive support urgently when required.
 - RUF should be funded to have an independent centre to help disabled people
 - The free local events which used to take place in the summer of Newham have been stopped. For e.g. 'Under the Stars' free public event at Central Park. Residents suffering with Mental Health problems used to benefit from those social events. Our recommendation is for this to return and for the borough to invest in more into the community.
 - Disabled children have been experiencing discrimination with stop and search by the police. They should not be criminalised; they should be supported.
-
- Parents need to be educated on topics such as Online grooming and how to guard against this, and how to report this.
 - SEND families need support to know their rights.
 - The parents of disabled children should not have to worry about their children's safety, when sent to faith places. Higher levels of policing needed to combat this with report and support systems in place that enable victims to report without the fear of reprisals.
 - Children with special needs require sexual health training in an accessible way. This is causing teenage pregnancy rates to increase and needs addressing through schools, social care and voluntary sector services.
 - Care Co-ordinators should be allocated at point of referral to social care and within 48 hours of that referral being made.

Mental Health

Mental Health services, particularly since the Pandemic have been overwhelmed with people wanting to access these services. Throughout this commission, the mental health and wellbeing of those who participated and those for whom they cared for has been unequivocally impacted by their experiences and as a direct result of the lack or poor care given to them as residents in the borough on Newham. The following statistics demonstrate the following:

Newham (1.12%) have a higher prevalence of severe mental illness than England (0.95%).

Newham (401), have a rate of inpatient stays higher than the England (243 per 100k population) average.

Newham (140) have a rate of under 75 mortality for adults with severe mental illness higher than the England (103.6 per 100k) average

Newham (24%), have an estimated prevalence of common mental disorders higher than the England (17%) average – (Source North East London Population Health Profile Key Findings May 2022

With the additional barriers of an array of disabilities, health inequalities, caring responsibilities, living in substandard housing, language barriers, challenges in navigating often complex and heavily bureaucratic systems e.g. Health, Housing, Education, it is little wonder that the mental health of Newham's residents is impacted.

It is to be noted that the figures for mental health statistics may not be truly representative as there are likely to be residents who do not come forward or who are unknown to services. These reasons may be as a result of mental health being a cultural taboo, being undocumented in the UK with no recourse to public funds, transience, and a host of other factors relating to accessibility in relation to cultural appropriateness and or not reaching the criteria to access particular services. Lack of funding cannot be accepted as a reason for poor care and provision by Newham Council as they have a statutory obligation to ensure that the welfare of each and every resident is paramount irrespective of any characteristic including those protected under the Equalities Act 2010.

More on mental health required – this is not enough. More stats from Newham London.

Next Steps

There needs to be a continuation of Public Advocacy events in Newham to ensure that the residents who have disability or care for those who do have a safe space to share their issues and find ways of approaching or lobbying Newham Council to ensure that legislation and policy reflect the needs outlined and that these are acted upon under Newham's Duty of Care.

A copy of this report should be handed to the leaders of the council, councillors, MP, and all statutory bodies within the London Borough of Newham, demanding a coherent response and resolution to the issues raised in this report.

RESIDENTS UNITED FORUM



Residents United Forum

HIDDEN VOICES PUBLIC ADVOCACY PROJECT REPORT 2024

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