



Residents United Forum



Residents United Forum Research Report

Working towards improving the lives of
disabled Newham residents

Funded by GLA Roots Incubator Grant

JULY 2022

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1. Statement from Residents United Forum (RUF)

RUF recognise the importance speaking up plays in all social change and how it is essential for true co-production. This is why we were set up in February 2021, made up of representatives of different local groups, all Newham residents with lived experiences as disabled people and carers. Disabled Residents efforts to speak up has been met with resistance from decision makers and have resulted in little change.

"We are met with attitudes that do not seek to understand the personal back stories and ongoing struggles to have our voices heard. Rather than being recognised as allies and 'change makers' we are labelled as 'trouble-makers'. This can leave us feeling unheard, misunderstood and that our lived experiences are dismissed, depersonalised and the issues we face are dehumanized."
Disabled resident.

These attitudes are a direct barrier to the success of co-production in the borough and this needs to change.



2. Introduction to the report

Thanks to the funding from GLA Roots Incubator Grant, RUF have produced this report as a resource for change and 'a call to action'. We understand 'Speaking up' is only part of the process, although this report will outline the problems many face, we also provide recommendations to support change. This report is shaped by the case studies, detailed accounts of lived experiences that show how services have gone down, in some cases not meeting need or demand.

3. Key Findings

In our key findings we will look at the impact on disabled residents, carers and their families. These case studies raise awareness of current issues and where Newham services need to improve. A marker for where we are now and recommendations to support long lasting change. All names have been changed to protect their identities.

3.1 Access and inclusion

There is a need in Newham for disabled residents to be involved in co-production of environmental changes from the design stage.

We spoke to Blind residents who told us of the many barriers they face, some which are easily resolved, such as; training to promote better understanding, so bin men return bins to the drive way the bins belong to or the need for tactile labelling on recycling bins to distinguish the colours.

Our findings from the case study 'dangerous design' shows a more serious side to what happens when disabled people aren't included, it can result in inaccessible community spaces, dangerous pedestrian walkway design, leaving residents isolated and unable to leave their homes.



Case Study dangerous design: Helen Smith is a Blind resident, she told us, "one year ago, Newham council re-designed Station Road toward City of London Cemetery and put in a new highway layout with a dual pedestrian and cycle lane, no thought was given to disabled pedestrian safety. The two main issues are:

- i. The cycle lane on the inside and pedestrian walkway on the outside, placing pedestrians closer to the busy main road, with the busy cycle lane on one side and busy road on the other side.
- ii. No tactile paving or sensory markings dividing the two lanes (cycle lane from the pedestrian walkway), leaving blind people like Helen unsure if she is walking safely in the pedestrian lane, creating an unnecessary risk of being hit by a bicycle.

RUF Findings

Case study Helen Smith - Identifies need for improvements around co-production and partnership working with residents at planning stage to avoid dangerous design that creates unnecessary risk or isolates residents from their community

Statutory Bodies Policy and Strategy

Key Objectives of the Newham Social Integration Strategy

- Demonstrate that Newham Council will 'put people at the heart of everything we do' creating a fair and socially inclusive borough
- Create a robust partnership with the voluntary and community sector in the borough to work together on issues of equality and inclusivity
- Plan resident engagement activities across the council which embed social integration
- Break down barriers and inequalities faced by our residents for a rich and connected community

Newham Well 50 steps to a Healthier Borough, Health and Wellbeing Strategy 2020-2023, page 43. Step 37 of the Strategy is: Promote and increase opportunities for social connectedness to improve residents' health and wellbeing and reduce isolation and loneliness



3.2 Service providers

The right to feel safe in your home

Whether you live in a care setting accommodation or in the community, you have a right to feel safe. Becky's told us of a couple of run-ins with the service provider at her residential care accommodation.

Firstly, Becky's family spoke up about her care package not being met, due to staff shortages. Instead of 1 support worker to 3 disabled residents (1:3), the service was running on 1:6. When this was raised by family members to the service provider they were threatened, told they wouldn't be allowed to visit Becky as they were 'trouble makers'.

This happened prior to the case study 'safeguarding Becky', that we have chosen to focus on. We will look at Becky and her family's experience of reporting a safeguarding concern. What processes and procedures were followed in reference to the **Newham Review of the Multi Agency Adult Safeguarding policy and procedures 2019.**

Case study safeguarding Becky: Becky is a Disabled lady who is afraid to return to her supported living accommodation after being attacked by a member of staff, while she was asleep in her bed. She contacted her family who took her to the local hospital to treat her injuries, she was supported to report this attack as a safeguarding incident to the hospital and local authority. As a temporary measure, her family moved her into their home as a place of safety, until notified it was safe for her to return to the care setting accommodation.

It has been 3 months and with no communication since the initial reporting of the safeguarding incident. Becky remains too scared to return to the care setting. They also worry about the safety of the other Disabled residents who may not be able to speak up for themselves, who live in the supported living where this safeguarding report took place.

RUF Findings

Case study 'Safeguarding Becky' Identifies the following issues:

The need for service user voices to be heard and acted on, when concerns are being raised

Safeguarding policy doesn't translate into practice

Becky's experience was not person centred, they have been left with no follow up communication or discussions on whether any action has been taken, she has not got a plan in place to return to her home at the care setting or given any emotional support for the trauma she experienced.

Commission services not meeting their contractual agreement

Support being given 1:6, was not what had been commissioned 1:3 and therefore not fit for purpose

It was unclear if the Local Authority continue to pay for the accommodation and support service Becky was unable to use for her own safety, since she left almost 3 months ago.

The commissioned service had clearly broken its contractual agreement to keep Becky safe whilst under their care.

Lack of communication between social worker and disabled resident and her family Becky remains too scared to return to the care setting as they have had no communication to reassure them the risks have been removed

Statutory Bodies Policy and Strategy

Care Act – Promoting Individual well-being

1) The general duty of a local authority... is to promote that individual's well-being.

2) "Well-being", in relation to an individual.....a) personal dignity (including treatment of the individual with respect);

b) physical and mental health and emotional well-being;

c) protection from abuse and neglect;

d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided); ...

h) suitability of living accommodation;

3) In exercising a function... a local authority must have regard to the following matters in particular—

g) the need to protect people from abuse and neglect;

Newham Safeguarding policy, in practice following policy this is the expected experience. Contacted from an Enquiry Lead or Enquiry Office to informed on whether any action was being taken under Section 42 (Care Act 2014) regarding the safeguarding incident reported in January 2022.

The need for 'making safeguarding personal and person centred with outcome focused practice, positive approaches to managing risks to their safety. Involving and assuring them that professionals have made a difference by acting on what matters to them and is personal and meaningful.

Recognising that the adult at risk is best placed to identify risks, provide details of its impact and whether or not they find the mitigation acceptable.

Working with them to lead and manage the level of risk that they identify as acceptable creates a culture where: Adults feel more in control, empowered and have ownership of the risk; There is improved effectiveness and resilience in dealing with a situation; There are better relationships with professionals; Good information sharing to manage risk, involving all the key stakeholders



3.3 Service delivery and service user wellbeing

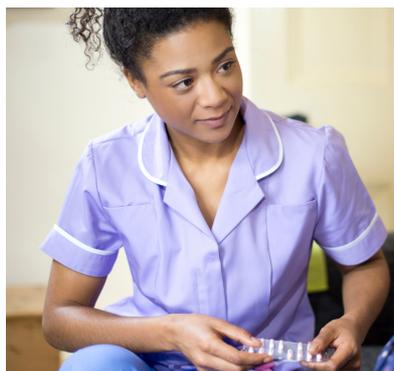
RUF believes in a holistic approach to service provision, as MIND findings confirm Mental health issues are increased by circumstances around us such as issues with health, poverty, housing, economic, social isolation, exclusion, discrimination, attitudes and stigma.

Case study Fiona Davis: Fiona has a diagnoses of Emotionally unstable personality disorder (EUPD) and complex mental health issues. Living in Newham she has experienced stigma and discrimination from the very services that are meant to support her. She faced a 15 year battle to get service providers to put services in place that meet her needs.

The lack of understanding of Mental Health issues, discrimination in the way she was treated by staff; not recognised as a carer, as staff believed she couldn't be a carer because she had mental health issues and wrongfully blamed for circumstances that resulted in her being made homeless.

This coupled with inadequate services have had a negative effect on her mental health with multiple attempts to take her own life, she has also self-harmed and relied on substance misuse to cope.

Commissioned services: Fiona's support is specialist in that it helps if the support workers understand her condition. With services being so inconsistent, left without support for months at a time (service provider claims it's due to shortage of staff, training or sickness) and when she does have support it is an inadequate service (staff don't speak English, cultural barriers which prevent them from being able to do the work, staff that are late, rude, bullying behaviour - making her feel guilty for reporting them and calling her ungrateful).



Her mental health and wellbeing is constantly being tested due to lack of adequate services within the Borough. The commissioned service not meeting Fiona's identified needs and inadequate support led to self-harming. Despite the service provider being aware of this, nothing has changed.

Support: After years of waiting for individual therapy Fiona was assigned to a male Therapist, a lot of Fiona's traumas had been caused by men in her past and she would have been more comfortable with a female Therapist. She tried to explain this, but he was very abrupt with her giving no other choice but to proceed with him or leave the service.

Their relationship was strained as she felt judged by him and then she was unfairly removed from the service due to not attending an appointment, despite a prior arrangement to call before her appointment to make sure she was physically able to attend.



When a complaint was made by Fiona, she arranged a meeting with the service provider to discuss the complaint, she required support for this meeting from her enablement worker. This was declined. Fiona later uncovered this support should have been provided. A service that should have been supporting Fiona, caused her mental distress and led to self-harming. Since being unfairly discharged, Fiona is still waiting to be seen by a therapist 6 years later.

Housing: Fiona told us of her experience of living in temporary accommodation that did not meet housing standards (infested with mice and damp) and she did not feel safe (living in close proximity to abusers and drug addicts). The stress of fighting to be moved to better accommodation for 5 years, resulted in her being hospitalised.

Fiona was frustrated and felt she had no choice but to inform her local Councillor, she was going to go to the newspapers. As a result of this conversation a housing manager and mental health manager apologised for not looking at her case correctly. Fiona was allocated the support of a Social Enabler and moved to a property within 4 weeks.

The property needed over 50 repairs. The main concern currently is the sinking garden which creates damp in the walls of the flat. With the rising cost of living and fuel prices up by 50%. Fiona is struggling to afford to keep on top of her efforts to prevent the damp and mould from getting worse. She must regularly wash and dry clean her clothes due to the damp in the built-in wardrobe.



Housing agreed her kitchen would be redone if Fiona would cover the cost. Despite raising the funds and the need for an accessible kitchen to be fitted, this is still yet to happen. There is a need for an accessible communal door as the current door is too heavy for residents with mobility issues to open. The door also lets in the cold, rain and vermin. This leaves Fiona isolated in a cold flat worrying about the cost of gas bills.

Case study Thandi Matthews: Under housing, we will also look at a further case study that highlights the experience of a Disabled parent and her disabled child of living in unsuitable temporary accommodation since 2013.

Thandi explained that no consideration was given to the fact that the house they were moved to wasn't suitable due to her disability. On bad health days Thandi is unable manage the stairs, making accessing the toilet located on a different level of the house difficult and on occasion impossible resulting in unnecessary soiling.



This has a negative effect on her physical and mental health, and wellbeing. She feels stripped of her dignity and quality of life, despite housing, her local MPs and the Deputy Mayor being made aware of this situation, nothing has been done in the last 9 years to move her to a suitable home.

Thandi now faces a new challenge, as she is currently under threat of being moved to a different temporary accommodation at very short notice, with no guarantee it will meet her needs and she fears the lack of understanding or communication from Housing staff, there is a strong possibility the next home may be worse than the one she is in.

With little choice over the location of the next property, she also runs the risk of being moved outside of her daughter's school catchment area, meaning her disabled daughter would experience the upheaval of changing schools. This would entail the battle to making sure her daughter gets the right support to meet her needs within her education provision. The next case study in 3.4 outline's what that prospect could look like for Thandi's daughter.

RUF Findings

Support and Commissioned Services:

Statutory bodies need to do more to make sure commissioned services are delivering the service they are contracted to, with consequences if they don't.

There needs to be a shift in attitudes that recognise the value of service user's voices. They give commissioners a window into whether a service is working or not. Service reviews should be done by third party organisations to avoid bias feedback.

Inadequate services are a direct barrier to independence and recovery, as they have a negative effect on resident's mental health and well-being leading to hospital admissions, issues around drug and alcohol dependency and in some cases homelessness.

Under the care act, it is important to remember that disabled residents have a right to receive a level of care that meets their needs and it must promote individual well-being

This also relates to receiving inadequate commissioned services that effect their well-being.

Mental Health clients should be given choice and control of which therapist they see. Especially if like Fiona there are not exceptional circumstances. These services are there to support a mental health clients recovery.

Statutory Bodies Policy and Strategy

Newham Well 50 steps to a Healthier Borough, Health and Well-being Strategy 2020-2023 - placing health, well-being and happiness at the centre of our vision for residents. This is now reflected at the heart of how the council measures its performance. **Step 21** of the Strategy says, *'Support our most vulnerable residents to achieve and maintain relative good health, including mental health and overall well-being'*.

Care Act 2014 - Promoting individual well-being

1) The general duty of a local authority... is to promote that individual's well-being.

2) "Well-being", in relation to an individual...

- a) personal dignity (including treatment of the individual with respect);
- b) physical and mental health and emotional well-being;
- c) protection from abuse and neglect;
- d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided);
- f) social and economic well-being;
- h) suitability of living accommodation;
- i) the individual's contribution to society.

3)... a local authority must have regard to the following

- a) the importance of beginning with the assumption that the individual is best-placed to judge the individual's well-being;
- b) the individual's views, wishes, feelings and beliefs;
- c) the importance of preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist; d) the need to ensure that decisions about the individual are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or any condition of the individual's or aspect of the individual's behaviour which might lead others to make unjustified assumptions about the individual's well-being)

RUF Findings

Housing: This report highlights a real need for better housing standards. To improve living situations for Newham residents.

Long waiting times in temporary accommodation that is not suitable, leaving disabled people stripped of their dignity and quality of life.

Need for better communication between housing and disabled residents to make sure any move is going to be an improvement does not create further problems (moving a disabled child out of their school catchment area or move to worse property that further disables a person)

The impact the cost of living will have on people like Fiona if they are unable to heat their home in winter. Black mould can lead to physical health issues if not addressed.

Statutory Bodies Policy and Strategy

Newham Council have identified the need for 'Better housing for Disabled people' in the **Newham Well 50 steps to a Healthier Borough, Health and Well-being Strategy 2020-2023** in Step 46: Reduce the numbers of children living in temporary accommodation (family homelessness) on page 79.

How will we do this:

- Establish baseline through housing health needs assessment and identify vulnerable groups
- Develop a Health Impact Assessment Guide for new developments
- Work in partnership to promote broadband connectivity (digital inclusion) in social housing
- Maximise funding opportunities including S106 to enhance existing environments and create health promoting neighbourhoods
- Develop home safety plan and campaign to reduce falls, fires and accidents

3.4 Exclusion and Isolation

In Newham, we were one of the first boroughs to put in place inclusive education. Sadly, this has moved backward, with more funding being spend on segregated education facilities and Pupil Referral Units, that could be spent on inclusion.

The Timpson Report findings, mention the rising numbers of children that will require Special Educational Needs (SEN) support and how 1 in 8 boys with mental health conditions are being excluded from education. This has been shown to have a negative effect on disabled people's life chances and reaching their full potential.

Case study 'Manmeet's needs aren't met by education provider, he is labelled the problem': Manmeet is a Sikh child with autism and has communication difficulties. During COVID 19 lockdown, he did not get the right level of support during transition from primary to secondary school. As a result, he did not get Special Educational Needs (SEN) support and no reasonable adjustments were made to meet his needs for the start of secondary school. When Manmeet's needs were not met, he became frustrated, having a negative effect on his behaviour. Sadly, this would become a patten throughout his educational experience.

An Education Health and Care Plan (EHCP) was put in place but the education provider gave less support than identified to meet his needs, due to being 'short staffed'. This caused further frustration and angry outbursts. Rather than the school putting measures in place to meet his EHCP. Manmeet was labelled by the school as having 'behaviour issues and a safeguarding risk'. He was excluded from education and transferred to a Pupil Referral Unit, without being consulted with.



Not having the support needed and the negative turn of events has left Manmeet with post-traumatic stress disorder. All this could have been avoided had his EHCP been met and the education provider held to account when it wasn't.

RUF FINDINGS

Exclusion and isolation – the barriers to inclusive education
 Case study of Manmeet: Raising awareness of the detrimental affect labelling a child or young person as the problem and not address the route cause of the 'behaviour issues'.

When education providers are not meeting the identified needs in the Education, Health and Care Plan (EHCP). Resulting in exclusion from education

Statutory Bodies Policy and Strategy

Children and families act, Part 3

31 Co-operating in specific cases: local authority functions

(1) This section applies where a local authority in England requests the co-operation of any of the following persons and bodies in the exercise of a function under this Part—

- a) another local authority; b) a youth offending team;
- c) the person in charge of any relevant youth accommodation;
- d) the National Health Service Commissioning Board;
- e) a clinical commissioning group;
- f) a Local Health Board; g) an NHS trust or NHS foundation trust...

(4) Regulations may provide that, where a person or body is under a duty to comply with a request to co-operate with a local authority in securing an EHC needs assessment, a detained person's EHC needs assessment or the preparation of an EHC plan, the person or body must comply with the request within a prescribed period, unless a prescribed exception applies.

Care Act - Promoting individual well-being

3) In exercising a function promoting individual well-being... a local authority must have regard to the following matters in particular—

- a) the individual's views, wishes, feelings and beliefs; b) the importance of preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist;
- c) the need to ensure that decisions about the individual are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or any condition of the individual's or aspect of the individual's behaviour which might lead others to make unjustified assumptions about the individual's well-being)

RUF FINDINGS

Identified that the demand for the Advocacy service SENDIASS needs to be increased to meet current demand

Statutory Bodies Policy and Strategy**Children and Families Act**

32. Advice and information

1) A local authority in England must arrange for children and young people... and the parents... to be provided with advice and information about matters relating to the special educational needs of the children or young people concerned.

2) A local authority in England must arrange for children and young people in... and the parents... to be provided with advice and information about matters relating to the disabilities of the children or young people concerned.

3) The authority must take such steps as it thinks appropriate for making the services provided under subsections (1) and (2) known to children, young people and parents

RUF FINDINGS

Some education providers are not providing adequate Special Educational Needs and Disabilities support to be educated

Statutory Bodies Policy and Strategy**Children and Families Act**

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2) A local authority in England must arrange for children and young people in... and the parents... to be provided with advice and information about matters relating to the disabilities of the children or young people concerned.

3) The authority must take such steps as it thinks appropriate for making the services provided under subsections (1) and (2) known to children, young people and parents



3.5 Independent Living and Advocacy

When a resident's Mental Health improves, they are moved from supported living into independent living. This means living in the community with the right level of care and support to meet their needs.

We were told that Evan should have received at least 6 weeks support, access to a Enablement Worker to help with transition and should have been monitored regularly.

The events that follow: by not giving the right level of advocacy at the beginning meant Evan was not given a voice and by not putting the right level of support in at this stage, the disabled person was is being set up to fail as this case study explains.

Case study of Evan Brown 'set up to fail': Evan Brown has mental health issues and has lived in supported housing for a vast number of years. During COVID -19 Lockdown Evan was told he would be moved to his own property.

However, Evan had anxiety about moving and voiced his concerns on many occasions. No support was given to talk him through the process and find out his true wishes around what support and accommodation was best for Evan.

Due to his uncertainty and insecurities he became withdrawn and did not move out as planned for 3 months. He was completely unaware he was falling deeper into debt, as while he remained in supported living his care package only paid for supported housing rent, this meant the rent on the flat was not being paid.

Housing and support: Evan moved out into the flat, he was not given any support to ease him into a new way of life and manage the responsibilities of paying bills, taking medication, eating healthy and how to deal with the unexpected debt of 3 month rent arrears. He did not have the right level of support to function in society, as he did in supported living.

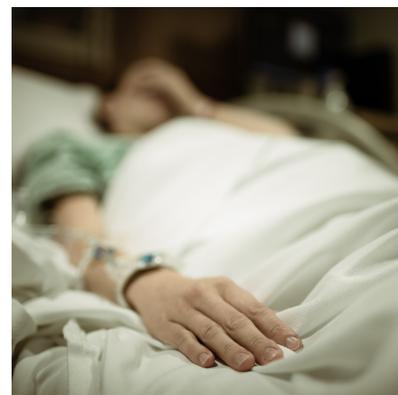
The property he was moved into was in disrepair (doors that did not meet standard requirements, damp in the bathroom and no kitchen cupboards). He was unable to address the number of maintenance issues.



This whole situation was very stressful and overwhelming. Evan's mental health and well-being deteriorated, and no one was monitoring how he was doing.

As time went on things got worse, with family interactions becoming difficult and strained, with the police called several times, which resulted in Evan being arrested and detained under the mental health act for 28 days.

Hospital stay: Evan's told us that during his stay in hospital, he did not feel he was involved or informed about his care plan, medication was increased without his knowledge, staff attitudes and understanding around what is needed to care for someone going through a mental health crisis, were well below what is expected.



Evan stayed in his room isolated, as there were no activities provided for in patients. He did not feel safe to leave his room, as difficult patients took over the ward and communal areas.

Independent Living and Advocacy

Advocacy: Evan feels that he has been discriminated against because of his mental health issues, on more than one occasion his concerns have been dismissed by three different commissioners: Commissioned service provider, Newham Centre for Mental Health and Newham Council.

Evan is currently being supported by a voluntary group, who have supported him to raise his concerns around his support plan and the condition of the property.



A visit from the council housing department advised Evan that he has got a support worker, Evan was unaware of this as he had not had any contact from them at any point. Since this visit Evan is yet to hear from either the Enablement Worker or the housing repairs department.

RUF FINDINGS

Advocacy at an earlier stage could have helped Evan and made a huge impact on his stress levels

By not putting the right level of support in at this transition stage, the disabled person is being set up to fail

Evan's wishes were not taken into consideration

Statutory Bodies Policy and Strategy

In some situations you might be legally entitled to get the support of an advocate. This is called '**statutory advocacy**'. There are three types of statutory advocates in England and Wales. These are: **Independent Mental Health Advocates (IMHAs)**. These are specially trained advocates who can support certain patients under the Mental Health Act 1983. The law regarding IMHAs is different in England and Wales.

IMHAs (England) and IMHAs (Wales) Independent Mental Capacity Advocates (IMCAs). These are specially trained advocates who can support certain people under the Mental Capacity Act 2005. For more information on whether you're entitled to an IMCA, and how to access one, see our page on IMCAs.

Statutory Bodies Policy and Strategy

Continued

Social care advocates. These can support certain people under the Care Act 2014 (in England) and the Social Services and Wellbeing (Wales) Act (in Wales).

Newham Council have identified the need for 'Independent Living' in the **Newham Well 50 steps to a Healthier Borough, Health and Well-being Strategy 2020-2023** Priority 5: Meeting the needs of those most vulnerable to the worst health outcomes

Care Act - Promoting individual well-being

3) In exercising a function promoting individual well-being... a local authority must have regard to the following matters in particular—

b) the individual's views, wishes, feelings and beliefs;

c) the importance of preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist...

d) the need to ensure that decisions about the individual are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or any condition of the individual's or aspect of the individual's behaviour which might lead others to make unjustified assumptions about the individual's well-being);

h) the need to ensure that any restriction on the individual's rights or freedom of action that is involved in the exercise of the function is kept to the minimum necessary for achieving the purpose for which the function is being exercised



3.6 Attitudes and better understanding

The carers we spoke to told us: Disabled people and carers need a supportive service that are supportive when they raise concerns or complaints on service provision, that recognise the role carers play in supporting disabled people.

“Carers are tired and stretched, things need to change as we are too tired to have to fight the services that should be working with us to care for our loved ones. Every day begins with a new battle, fighting with a different service. If it is not the social workers, it is the GP or the service providers. It is a constant battle to get the support we need”.

Carers in Newham also mentioned the lack of support around carers assessments, lack of information, lack of support to fill in forms and no extra support is provided to take into account the cultural / language barriers.

When carers try to get support, they come up against negative attitudes from staff, “no regard is given for disabled carer’s health and need for respite or financial support, we are treated like criminals rather than allies”. There is a need for better attitudes towards carers and understanding of the important relationship between them and the disabled people they support.

Case study Qamari Jones: Disabled parent of a disabled son with physical and Mental Health issues. Qamari explained that she is his sole carer and he has no one else. He is no longer in contact with any other family members. Though her relationship with her son is turbulent, she has his best interests at heart and is desperately trying to get him the support he needs to live independently.

She said she was told by a Mental Health team in order to get help for her son's needs, she should file a 'domestic abuse' case against him. This is not only a barrier to service provision, but also a detrimental service pathway design that does more harm than good, destroying key relationships by betraying trust that may never be repaired again and in this case removing the only support network this disabled man has in his life. She does not feel as his carer, that her voice and concerns for his safety as a safeguarding risk are listen to or taken seriously.

RUF Findings

Told by the Mental Health team in order to get help for her son she should file a 'domestic abuse' case against him. This is not only a barrier to service provision, but also a detrimental service pathway design that does more harm than good, destroying key relationships by betraying trust that may never be repaired and in this case removing the only support network this disabled man has in his life

When a disabled parent asks for support with their disabled children from social services, they are told they can't be a carer to a disabled person if they themselves are disabled. With a shocking trend of disabled parents being reported to child protection by social services for being a disabled parent.

Statutory Bodies Policy and Strategy

Newham Well 50 steps to a Healthier Borough, Health and Well-being Strategy 2020-2023 - placing health, well-being and happiness at the centre of our vision for residents. This is now reflected at the heart of how the council measures its performance.

Priority 3: The Social Welfare Alliance offers a training programme and development pathway to enhance the skills of all frontline workers and create better connectivity between Newham Council and the Voluntary, Community and Faith sector. It has trained over 1,500 frontline workers and individuals in Newham on a range of topics from core conversations through to immigration law, welfare rights, mental well-being and domestic violence.

Care Act 2014 - Promoting individual well-being

- 1) The general duty of a local authority... is to promote that individual's well-being.
- 2) ...in relation to an individual...
 - a) personal dignity (including treatment of the individual with respect);
 - b) physical and mental health and emotional well-being...
 - g) domestic, family and personal relationships
- 3) ... a local authority must have regard to the following matters in particular—
 - d) the need to ensure that decisions about the individual are made having regard to all the individual's circumstances (and are not based only on the individual's age or appearance or any condition of the individual's or aspect of the individual's behaviour which might lead others to make unjustified assumptions about the individual's well-being);
 - f) the importance of achieving a balance between the individual's well-being and that of any friends or relatives who are involved in caring for the individual;
 - g) the need to protect people from abuse and neglect;

4. Recommendations Listen, understand and apply!

RUF is not alone in recognising the need for co-production within Newham. The Newham council strategies, reports and transformation programmes mention moving towards this as well. Decision makers have shown incentive and willingness by setting up the co-production board in 2016. The case studies show that currently in 2022, disabled residents and carers still feel their voices are not heard or valued, and issues raised were not followed with actions. This report recommendations will look at what can be done to build on existing work in the borough by moving it forward to true co-production.

The definition of co-production is:

“Co-production means that Disabled residents and decision makers are working together in an active way to plan, design and review policy and services that affect our lives, to get rid of the barriers we face.”

4.1 Aim: Make Newham an accessible and inclusive borough

RUF 's Objective is for Newham to be an inclusive and accessible borough for all. By Improving attitudes and working cultures that support and promote inclusion, where disabled resident's rights are upheld, eliminating all forms of racism, inequality and discrimination within Newham. RUF believe the change in approach involves removing societal barriers, such as making physical spaces accessible too.

Through true co-production we can strengthen working relationships and create better systems of communication between disabled residents and decision makers, shift attitudes towards 'change makers' to see us as allies and work together to make Newham an accessible borough for all

By decision makers actively listening and working with us, together, we can take action.

4.1 Aim: Make Newham an accessible and inclusive borough

Recommendation 1:

Newham Co-production board and key decision makers sign up to and adopt RUF's definition of co-production and agree to increase diverse representation of co-opted members on decision maker committees

Actions: Increase diverse representation of co-opted members: disabled people (Adults and young people), carers / parents and Voluntary sector (example: One Newham / Health watch) on the Newham Policy and development scrutiny committees for; adult health and social care, education, children and young people and education, as well as the regeneration, housing and environment.

There is an identified need for a local Mobility Forum to support and feed into co-production within Newham, addressing residents access needs in day to day living and inclusive design within the borough

Supporting data: Case study of Helen Smith - Identifies need for improvements around co-production and partnership working with residents at planning stage to avoid dangerous design that creates unnecessary risk or isolates residents from their community

Being involved from the idea stage, at the very beginning of consultations and projects, the forum provides added value of our lived experience and expertise around access and inclusion, supporting the local authority to make sure work done in Newham is accessible and inclusive for all. This can save money by avoiding costly circumstances where the design is not fit for purpose, with the need to spend the same money again to correct the design flaw.

Disabled people want to work with Newham Local Authority on re-development, to make public spaces accessible (public walkways, crossing points and highways, buildings, services, accessible toilets and bus stops).

4.2 Aim: Disabled people's voices are heard, listened to and acted on.

Recommendation 2: Commissioners commit to listening to concerns raised and acted on implementing change to improve service provision.

Decision maker attitudes and staff culture need to shift towards change makers, educating staff to see the voices of service users, carers and their families as allies.

Service users need to be at the heart of feedback. RUF, Co-production board, disabled residents and carers are more involved in contracted service consultations, reviews, in which service users can express their views openly and honestly to a non-bias third party Deaf and disabled people's organisation.

Concerns raised need to be listened to and acted on. Where it is identified, commissioning must hold service providers to account when they are found to be breaking a contractual agreement (Applies to case studies; 3.2, 3.3, 3.4, 3.5 and 3.6)

Actions: Make sure safeguarding policy, procedures and practices are followed to improve service user experience. Making it more person centred and improve lines of communication during this difficult time.

Commissioners hold services that do not meet their contractual agreement to account.

Supporting data: Case study 'Safeguarding Becky' Identifies the following issues:

Attitude shift needed: People who report safeguarding concerns are Change makers not trouble makers. Safeguarding is everyone's responsibility. It is our duty to speak up and be a 'change maker' if you think someone is at risk.

Supporting data continued...

Following policy: The Safeguarding processes and procedures in the policy are not equating to what is happening in practice and lessons need to be learnt. All decision makers should be following the safeguarding policy but this case study shows that reporting concerns to service providers is not always received well. There seems to be issues that need addressing to make sure the safeguarding processes and procedures are followed.

Value they bring: Helping (decision makers) statutory bodies 'Quality & Safeguarding Information Panels' to reduce the need for safeguarding through early warning systems, enhance the standards of care and support by sharing early warning signs with providers, target resources effectively to reduce duplication, support prevention strategies and continuous service improvements.

Commission services not meeting their contractual agreement
Support being given 1:6, was not what had been commissioned 1:3 and therefore not fit for purpose

It was unclear if the Local Authority continue to pay for the accommodation and support service Becky was unable to use for her own safety, since she left almost 3 months ago.

The commissioned service had clearly broken its contractual agreement to keep Becky safe whilst under their care.

Lack of communication between social worker and disabled resident and her family
Becky's experience was not person centred as she had no communication with her social worker, no feedback on what actions had been taken, no plan was discussed regarding her return to supported living accommodation

4.3 Aim: Disabled people are valued and treated with respect and dignity

Recommendation 3: Decision makers commit to improve housing standards for Newham residents and address the housing crisis

Action: All decision maker bodies need to look at the ways in which housing affects all these issues raised by this report. The Housing crisis with lack of available accessible or suitable housing and the need to improve housing standards

Supporting data:

Support and Commissioned Services: Statutory bodies need to do more to make sure commissioned services are delivering the service they are contracted to, with consequences if they don't.

There needs to be a shift in attitudes that recognise the value of service user's voices. They give commissioners a window into whether a service is working or not. Service reviews should be done by third party organisations to avoid bias feedback.

Inadequate services are a direct barrier to independence and recovery, as they have a negative effect on resident's mental health and well-being leading to hospital admissions, issues around drug and alcohol dependency and in some cases homelessness.

Under the care act, it is important to remember that disabled residents have a right to receive a level of care that meets their needs and it must promote individual well-being

This also relates to receiving inadequate commissioned services that effect their well-being

Housing: This report highlights a real need for better housing standards. To improve living situations for Newham residents.

Long waiting times in temporary accommodation that is not suitable.

The impact the cost of living will have on people like Fiona if they are unable to heat their home in winter. Black mould can lead to physical health issues if not addressed.

4.4 Aim: Disabled people can make their own decisions, lead fulfilled and independent lives. With accessible information, support and services when needed

Recommendation 4: Decision makers commit to improving communication across the board. Better understand and to have empathy for residents. Better access and understanding of their right to an advocate

Actions: Need for a Mental Health and well-being hub that provides support and information.

Support from Community Psychiatric Nurse / Housing and social care worker to assist with transition. Providing support, to understand transition plan / process, make sure home is suitable, go through housing tenancy agreement, give copies, make sure support is in place.

More information is needed around the right to an advocate. The way someone is treated drastically changes with an advocate present and some of the further abuses of power could have been avoided.

Mental health awareness training must be led or co-produced with people with lived experience of Mental distress

Supporting data: Client should have received an advocate to support him to have his wishes heard, when moving client should have had support when leaving supported living. The only support he had was a voluntary providing peer support, if it wasn't for this support, he would be stuck in a cycle of being discharged from hospital, without support, mental health deteriorates, reaches crisis point and re admitted to hospital. It is important to get the right level of support in place if we want to set disabled residents up to succeed on living independently.

All 3 providers should have been liaising together to enable a smooth transition

Council property should have been up to living standards

Staff attitudes in all services need to be investigated, especially towards vulnerable clients/residents

4.5 Aim: Disabled people are empowered & not discriminated against, Inclusive education where disabled children are given the level of support to meet their needs

Recommendation 5: Commit to Increasing the SENDIASS service to reflect and meet current demand for this support

Action: Hold education provider to account when they do not meet a child's needs under the Children and Families Act & the Care Act.

Supporting data: *Rising numbers of children require SEN support. 1 in 8 of 5 to 19 year-olds have a mental disorder and, looking across a 3 year period, over a million children were classed as in need. We also know that many of these children are more likely to be excluded. In particular, new analysis of a cohort of children with a mental health condition shows the rate of exclusion was also higher in this group: 1 in 10 boys with a mental health condition has been issued with some form of exclusion from school.*

Exclusion and isolation – the barriers to inclusive education

Case study Manmeet: Raising awareness of the detrimental affect labelling a child or young person as the problem and not addressing the route cause of the 'behaviour issues', when education providers are not meeting the identified needs in the Education, Health and Care Plan (EHCP)

Identified that the demand for the Advocacy service SENDIASS needs to be increased to meet current demand

Children and young people with SEND need to stop being punished with exclusion and isolation due to the failing of the education provider to meet their EHCP.

This label will be carried with the child through their time in education and limit their choice and control over their education. With little to no mention of the responsibility taken by the education providers failure to give adequate support which contributed to this outcome.

Around behavioural issues there is a need for more training for staff to support young people like Manmeet, by providing the required level of support, recognising the signs and supporting them before they reach frustration and outbursts by changing their environment to a quieter one.

4.6 Aim: Create a fair and just complaints system for disabled People and their carers. Making sure they have access to advocacy services, understand their rights and are supported to exercise them. Better understanding that Disabled people and carers are working with staff to move towards the best outcome for the disabled person

Recommendation 6: Change attitudes towards 'change makers'. Commit to improving the way in which disabled residents and carers are treated when raising and during the complaints procedure. It is imperative that people have a fair and just complaints system given their needs and that are safe to use it to create meaningful change.

Action: We want to be involved in the change to processes and want decision makers to produce key aims, objectives and an action plan on how they will make these changes.

Supporting evidence:

Reporting a complaint across all case studies, these residents were treated as trouble makers, concerns were not acted on, poor communication, badly treated by staff and not treated fairly.



RUF Recommendations

1. Newham Co-production board and key decision makers sign up to and adopt RUF's definition of co-production and agree to increase diverse representation of co-opted members on decision maker committees
2. Commissioners commit to listening to concerns raised and acted on implementing change to improve service provision.
3. Decision makers commit to improve housing standards for Newham residents and address the housing crisis
4. Decision makers commit to improving communication across the board. Better understanding and to have empathy for residents
5. Decision makers commit to increasing the SENDIASS service to reflect and meet current demand for this support
6. Change attitudes towards 'change makers'. Commit to improving the way in which disabled residents and carers are treated when raising and during the complaints procedure. It is imperative that people have a fair and just complaints system given their needs and that are safe to use it to create meaningful change.

5. Conclusion

Speaking up has never been more important as the Inclusion London report '**Abandoned, forgotten and ignored - The impact of Covid-19 on Disabled people**' details, with issues disabled people face being compounded by the pandemic. The frustration and struggle to be heard at a decision maker level has resulted in many disabled residents and carers reaching crisis point with negative effects on their physical and mental health.

RUF sees this as an important opportunity and wants Newham Council to fully support it with our recommendations. We hope this report gives insight into the current barriers for local Disabled residents. We are very excited about the plans to turn the recommendations into action so that creative co-production can really take off. Through shared decision-making Disabled residents will start to see their daily lives get better.



Thank you to; our funders GLA Roots Incubator Grant for funding this report, the RUF Chairperson and founding RUF Trustees, all the disabled residents and carers who shared their experiences, Ruth Bravery at One Newham and to Justine Jones (Disabled and Neurodivergent Campaigner) who wrote this report on RUF's behalf.

6. Glossary - Definitions used in this report

6.1 What do we mean by Disabled People?

By Disabled People we include 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.

6.2 What do we mean by Carer?

Carers are people who are carers, allies and advocates to disabled people of all ages, they support them to have their voices heard. Carers provide unpaid support to family members, friends or members of their community.

6.3 Disabled Carers and parents.

We mean disabled people who are parents to disabled children or are carers for a disabled person within their family or community.

6.4 Statutory Bodies – ‘The Decision Makers’.

We are referring to Newham services across all areas including: Clinical Commissioning Group, Nation Health Service, Health Watch, Newham Local Authority, North / East London Foundation Trust, Education and services providers commissioned by Newham Local Authority. These are the Statutory bodies that make decisions about services disabled residents and carers use.

6.5 Speaking up – ‘The Change Makers’

We are talking about Disabled residents or carers who have the confidence and courage to speak up about the barriers faced in Newham and share their lived experience at a decision maker level (with statutory bodies / service providers). With the aim of; raising awareness to issues and working as allies with statutory bodies to improving service provision for all.

6.6 Co-production.

Co-production (working together) means that Disabled residents and decision makers are working together in an active way to plan, design and review policy and services that affect our lives, to actively remove the barriers we face.

6.7 Safeguarding.

When we are talking about Safeguarding, we are referring to disabled people who are considered 'valuable children, young people or adults at risk' in the Newham Safeguarding policy. Adult safeguarding means protecting a person's right to live in safety, free from abuse and neglect. This is a person aged 18 or over who needs care and support (whether or not those needs are being met), who is experiencing or at risk of abuse or neglect, and because of those needs is unable to protect themselves against the abuse or neglect or the risk of it. The Equality Act 2010 legally protects people from discrimination. It sets out the different ways in which it is unlawful to treat someone.

6.8 Inclusive education

Inclusive education – also called inclusion – is education that includes everyone, with non-disabled and Disabled people (including those with “special educational needs”) learning together in mainstream schools, colleges, and universities.

7. Resources

<https://www.inclusionlondon.org.uk/disability-in-london/coronavirus-updates-and-information/campaigns-news-during-coronavirus-crisis/abandoned-forgotten-and-ignored-the-impact-of-covid-19-on-disabled-people/>

<https://www.newham.gov.uk/downloads/file/2870/social-integration-strategy>

<https://www.allfie.org.uk/definitions/what-is-inclusive-education/>

https://www.preparingforadulthood.org.uk/SiteAssets/Files/pfa_care_act_factsheet.pdf

<https://www.legislation.gov.uk/ukpga/2014/6/part/3/enacted>

<https://www.legislation.gov.uk/ukpga/2014/23/section/1/enacted>

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

<https://www.newham.gov.uk/council/policies-plans>



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