

LONDON BOROUGH OF CAMDEN	WARDS: All
REPORT TITLE Reducing structural inequalities for disabled and autistic people through increased participation – Report of September Cabinet 2022	
REPORT OF Cabinet Member for Health, Wellbeing and Adult Social Care	
FOR SUBMISSION TO Disability Oversight Panel	DATE 10 January 2023
SUMMARY OF REPORT This report was previously considered and agreed by the Cabinet of Camden Council in September 2022. It is being brought to the Disability Oversight Panel in their first meeting of the 2022/23 civic year to reflect its relevance to the Panel's terms of reference. This report sets out plans for a whole Council approach to tackle structural inequalities for Disabled adults through partnership grant funding to two 'user-led' organisations, Camden Disability Action and The Autism Hub. The grants will provide the sustainable infrastructure needed to empower Disabled residents to reduce societal barriers and co-produce services to deliver better Adult Social Care outcomes. Local Government Act 1972 – Access to Information No documents that require listing were used in the preparation of this report. Contact Officer: Tim Rising – Strategic Commissioner 5 Pancras Square, N1C 4AG 020 7974 2224 Tim.rising@camden.gov.uk	
RECOMMENDATIONS The Disability Oversight Panel is asked to discuss and note the report.	



Signed:

Jess McGregor, Director of Adult Social Care

Date: 03.01.2022

1. CONTEXT AND BACKGROUND

- 1.1. The Social Model of Disability, developed by Disabled people, states that people have impairments but that the oppression, exclusion and discrimination people with impairments face, is not an inevitable consequence of having an impairment, but is caused instead by the way society is run and organised. Such impairments will include physical, learning and sensory differences as well as 'hidden' differences, such as autism. Autism is a lifelong developmental disability which affects how people communicate and interact with the world. Autism is a spectrum condition and affects people in different ways.
- 1.2. People with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them. Such barriers include:
 - **Attitudinal barriers** – such as assumptions that people with certain impairments can't work, can't be independent, can't have sex, shouldn't have children and need protecting.
 - **Physical barriers** – a huge range of barriers that prevent equal access, such as stairs, inaccessible toilets, poor lighting, noise and poorly managed public spaces.
 - **Information and communication barriers** – such as the lack of interpreters for d/Deaf people, lack of information in different accessible formats such as Easy Read and a complete lack of understanding of people's communication needs.
- 1.3. Language is an important part of the Social Model of Disability as this reflects people's identity and the assumptions and thinking of society around them. In this report, the term 'Disabled person' will be used to describe anyone with a difference or impairment who is discriminated against in society as a result of this. How people describe themselves is a personal choice and this report acknowledges that not all people who are linked with the organisations in this report will describe themselves as Disabled. Some autistic people identify as being Disabled but not all autistic people will. There isn't a single term which is preferred by everyone.
- 1.4. The Covid-19 pandemic exposed structural and systemic inequalities that disproportionately impacted residents with a range of protected characteristics, including disabilities. The Office for National Statistics reported that Disabled people in the UK have been more likely to die as a result of Covid-19 and that outcomes for Disabled people remain significantly below those of non-disabled people, for example:
 - Disabled people had 16% lower life satisfaction than non-disabled people and felt less happy by almost 20% compared to non-disabled people.
 - Anxiety levels were 50% higher than non-disabled people.
 - The proportion of Disabled people in England who reported feeling lonely "often or always" was over four times that of non-disabled people.
 - Around 50% of Disabled people aged 16 to 64 years in the UK were in employment compared with around 80% of non-disabled people.
 - 13% of Disabled people had no qualifications compared with only 5% of non-disabled people.

- 1.5. These inequalities cannot be ignored and addressing them is a core principle of the Adult Social Care strategy for living and ageing well in Camden, “*Supporting People, Connecting Communities*”.
- 1.6. The 2011 census found that around one in seven Camden residents (14%) had a ‘long-term health problem or disability’ that limited their day-to-day-activities in some way. Of these, over 11,000 people reported that their health was, ‘bad or very bad’.
- 1.7. There is a shortage of accurate local or national data for autistic adults (who do not have an accompanying learning disability). Not all autistic people are known to statutory services or have a diagnosis, and there is a known undercount when it comes to national autism prevalence estimates. Whilst some sources suggest prevalence estimates are 1.1%, it is widely acknowledged that this is an underestimate, with some studies suggesting the prevalence rate is 2% to 2.5%. Based on this, the autism prevalence in Camden could be up to 7,000 residents, of whom two-thirds will be without an accompanying learning disability. The likely underestimation of autism prevalence from under diagnosis is supported by Camden data which shows that there has been a 56% increase in the number of pupils diagnosed with autism in 2021 compared to 2017.
- 1.8. The All-Party Parliamentary Group on Autism (2019) notes autistic people experience inequalities that include:
 - Unacceptable health inequalities
 - Risk of falling into mental health crisis
 - Risk of social isolation and underemployment
 - Risk of dying early.
- 1.9. This group also emphasise that support for autistic adults has got worse, particularly for those who need social care, over the last 10 years. They found high levels of unmet need, with 71% of autistic adults saying that they are living without the support they need. In particular, those who need ‘preventative’ support are not getting it because the services all too often are not available.
- 1.10. When autistic adults have experienced a system that they feel is not equipped to support them, we have been told that they can feel left behind, misunderstood, unheard or abandoned. Autistic residents tell us that when there is not ‘a place’ where they and their families or carers feel they can go to get the right support at the right time (in an autism informed way), smaller problems can escalate unnecessarily, causing distress and trauma.
- 1.11. To dismantle these barriers in Camden will take a whole Council approach so that any Disabled adult has equal access to health, care, housing, employment, leisure, education, and everything in their community. In line with *We Make Camden*, this report sets out proposals to work in partnership with two user-led organisations to share power with our Disabled residents to take the actions needed to address these structural inequalities. The approach will embed the action from the Council’s *Building Equal Foundation*’s plan to

encourage residents to work with us and our partners to shape and deliver the actions in our plan.

- 1.12. The first organisation that this report recommends grant funding is Camden Disability Action (CDA). CDA is a user-led organisation which aims to promote the equality of d/Deaf and Disabled adults living or working in Camden. CDA is a pan-disability organisation, and as such it is the only disability organisation in the borough that is open to all people with any impairment, health condition or difference. This includes people with learning disabilities, mental health issues, long term health conditions, those with a physical or sensory impairment and people from the neurodiversity community (such as autistic adults).
- 1.13. In 2017, CDA was awarded Council seed funding to deliver Camden's first Centre for Independent Living (CIL) and to work towards future financial sustainability using the income from the conference and meeting rooms in Greenwood. This was a new commissioning model for the Council and CDA was the only organisation who bid to run the CIL.
- 1.14. The CIL opened in February 2019 within the newly built Greenwood Centre in Kentish Town. The original vision for the CIL, co-designed with Disabled people, was for a community resource run by Disabled people, that any Disabled person can go to for information and support so that, whatever their level of impairment, they can find out the choices open to them, decide how to live, and make it a reality. The vision aligns with the Council's "Supporting People, Connecting Communities" strategy by enabling the CIL to act as a 'connector' to the services and information needed to support independence.
- 1.15. There have been a significant number of internal and external challenges that CDA has faced since the creation of the CIL. The greatest of these challenges was the impact of Covid as this completely undermined the income generation model through room bookings, whilst hugely increasing demand for support for Disabled residents.
- 1.16. With additional short-term financial support from the Council and other funders, CDA has successfully delivered a range of projects despite these challenges. CDA has coproduced a new vision and mission statement with local residents, embedding into its governance its identity as an organisation for social change.

CDA Vision: "We believe in a radically inclusive world where people with differences are never disabled by the society in which they live."

CDA Mission: "We exist to enable the Disabled community and those most marginalised within it, to lead the way in building a Camden that works for everyone."

- 1.17. This vision and mission statement have been showcased through a number of recent CDA projects that have started to shift power to our Disabled residents as part of the journey towards a more fully inclusive Camden.
 - **Inclusive economy** – an innovative approach to codesign work for Good Work Camden's Inclusive Economy project. Disabled adults with lived

experience of systemic labour market barriers were at the heart of the work including interviewing employers and employees and designing new service models with Council officers.

- **Community journalism** - A collaboration with 'tech savvy' journalists enabled CDA to set up a new model for engagement. Local Disabled people were trained to become community reporters, and to use a digital platform to tell stories which effectively highlight disabling barriers – [Camden Disabled People's Voice](#).
- **Leadership programme** – 12 local Disabled adults have been trained and supported to lead their own change projects addressing systemic barriers in Camden. One example was a project set up by six d/Deaf residents focused on barriers for d/Deaf people communicating with the Council. Initially, Council managers received d/Deaf equality training, designed, and delivered by a group member. Secondly, there was a live experiment where the Council managers directly observed the group trying to use online Council systems such as housing repair requests or trying to contact a department using Sign Video. The Council managers were encouraged to use “empathy maps” to think deeply about what they were observing. The managers observed some of the common barriers and frustrations experienced by D/deaf residents. D/deaf residents were also invited to think about the experience of Council staff to empathise with pressures and restrictions for them. This approach was effective in increasing Council managers' understanding of the problem and motivating them to find solutions. It also changed the power relationship with D/deaf residents moving from being viewed as “complainers” and from viewing themselves as unable to have any control over change, to the Council staff and residents seeing themselves as working collaboratively to solve a mutually unsatisfactory problem. This piece of work resulted in some immediate changes in the way D/deaf residents are responded to, with an understanding that written English is not necessarily accessible for BSL users, but also deeper system change, with the group now being actively consulted as the Council decides on new IT and communication systems.

- 1.18. The second organisation that are recommended for funding is the Autism Hub. The Autism Hub are autistic-led, formed mostly by autistic adults who provide support to other autistic adults (who do not have an accompanying learning disability) and who live in Camden and Islington. They are a small organisation that responds to a high level of need in the borough. Over the last 2 years, the Autism Hub have received a number of small short-term grants (some relating to Covid) from the Council and North Central London (NCL) NHS Clinical Commissioning Group (now the NCL Integrated Care Board (ICB)). While these have sustained the organisation to deliver significant support to autistic residents, they have not supported the long-term planning or viability of the organisation.
- 1.19. The Autism Hub play a crucial role in supporting autistic adults (who do not have a learning disability) living in Camden including coproduction and promoting resident led change. They provide peer support, case work, advocacy, information and advice, and autism specific counselling. Many statutory and voluntary services refer to them and reach out to the Autism Hub for support and consultation. The Autism Hub require urgent support to build

infrastructure and develop a sustainable model that has the potential to grow over time. Currently the Autism Hub's funding is fragile. The impact is that some staff are on a rolling 3-month agreement. The risk is that staff will need to seek alternative employment if more sustainable funding is not in place.

- 1.20. There are long waiting lists across services and the pandemic has, for some, exacerbated need. Often autistic adults turn to the Autism Hub as a place they can trust when poor experiences of services may have led to feelings of distrust. Autistic residents tell us that they are falling through gaps in the system and that they are entering crisis that they feel is avoidable.
- 1.21. The work that the Autism Hub has achieved locally is rooted in the principles set out in the Autism Act, National Autism Strategy and NHS Long Term plan. This work has supported individuals when barriers have presented as well as supporting the wider systemic transformational change to improve care and support for autistic people. Achievements have included:
 - An autistic-led training and reflective workshops for Camden staff. The training programme includes basic autism awareness for employees across all services and specifically supporting Adult Social Care practitioners. This is part of the Autism Hub's work to support the wider system to ensure that identity is at the heart of practice with a focus on autism and intersectionality.
 - Co-production by autistic people of statutory advocacy services to ensure these are autism informed.
 - A high level of intensive support to autistic residents with positive impacts. This has involved the Autism Hub spending hundreds of hours supporting individuals to navigate community and inpatient mental health services, to access health care, housing and other support to avoid crisis. The Autism Hub are championing autism informed practice, influencing a better understanding of autism amongst services and promoting better outcomes for residents.
 - Tailored information webinars to give autistic residents crucial information from health and care professionals, for example Covid vaccinations.
 - Examples where support to autistic residents and practitioners have ensured that autism informed care needs assessments were completed with expert support from the Autism Hub. For some people this has transformed their experience of care and support through rebuilding trust in services and experiencing placements that have been carefully matched in an autism informed way with individuals' strengths, needs, interests and personality.

2. PROPOSAL AND REASONS

- 2.1. Coproduction and the development of equal partnerships with Disabled adults is at the core of the ambition to achieve the transformational, systemic change that the Council is working towards. The Camden Health and Care Citizens' Assembly set a clear expectation that, "We expect citizens to be involved in the design of local services" and that there should be funding for groups who support people with protected characteristics. Coproduction has been the driving force in achieving all the developments set out above and it is therefore proposed to grant fund Camden Disability Action (CDA) and the Autism Hub over the next three years to embed the effective long-term partnerships needed to co-produce solutions to structural inequalities for

Disabled residents. There is still a long transformational, system wide journey ahead and a partnership approach with residents is needed to achieve the essential developments.

- 2.2. The proposed grants for both organisations will cover core costs as well as the delivery of a range of innovative projects and initiatives. For CDA the core costs will include rent and service charge paid to the Council (c. £100,000 per year). Both grants will provide funding from 1st October 2022 and will be awarded at the following levels:

	2022-23	2023-24	2024-25
Autism Hub	£141,000	£231,000	£231,000
Camden Disability Action	£150,000	£265,000	£130,000

- 2.3. The nature and reasons for the funding for each organisation is set out below. For each area of funding, the grant agreements will include clear deliverables, targets and measures.

CDA funding

- 2.4. As set out above, the financial sustainability of CDA and the Centre for Independent Living was hugely impacted by Covid and the drastic reduction in income from Greenwood meeting room hire. With the gradual return to pre-pandemic activity, the hire of conference and meeting rooms will become a significant source of income for CDA again and CDA have undertaken work over the last year to have the marketing skills, tools and systems in place to maximise the opportunity. CDA have developed an income generation plan to reduce reliance on Council funding within 4-years with income coming from three sources:

- Rental income from room bookings within Greenwood.
- Delivering training e.g. Disability awareness, to the public and private sector
- External grant funding.

- 2.5. As the income generated from the above strategies increases, the dependency on Council grant funding will reduce, potentially to zero if economic conditions allow. The combined self-generated and Council income will allow CDA to take forward the following key objectives:

Objective	Summary
1. Significantly increase the activity in Greenwood and income generation	To turn the CDA mission and vision into business products, unleashing the Greenwood Centre for Independent Living's vast potential to deliver activities for Disabled residents and to generate income
2. Develop CDA's Engagement and Coproduction	Provide leadership to the Council, building on CDAs current engagement and coproduction work to embed coproduction throughout the Council's services
3. Develop CDA's signposting/information	To recruit and train local Disabled people to become Disability Advice and Benefit Volunteers

Autism Hub funding

- 2.6. The three-year grant funding will allow the Autism Hub to maintain their core offer of autism specific counselling, peer support, case work and information webinars and events for autistic residents. The funding will also allow the Autism Hub to build capacity to expand and develop an autistic-led peer support offer at a rate that is manageable and led by the peer support facilitators and mentors' needs. In addition, the Autism Hub will be able to further support coproduction work with Camden autistic adults to influence autism informed service delivery.
- 2.7. Finally, funding for clinical supervision will embed autism informed clinical supervision in both individual and group settings for Autism Hub paid staff and voluntary staff. This will ensure safe and reflective spaces to think about the emotional components of the work to reduce stress and anxiety for staff and to improve the quality of service delivery to residents. From 2023/24, building on the core offer outlined above, the Autism Hub will build infrastructure through developing core roles that have a wider reach in connecting with Camden autistic residents and support the Autism Hub's involvement in transformational, across system developments to integrate with the wider work taking place.

3. OPTIONS APPRAISAL

- 3.1 **Do nothing** – do not award grant funding to either CDA or the Autism Hub. This will risk the financial viability of both organisations and would significantly impact the Council's ability to reduce the structural inequalities faced by Disabled residents.
- 3.2 **Award a reduced level of grant funding** – funding could be awarded over a shorter period of time, or for a reduced level. While both organisations have benefited from lower levels of funding over recent years and still delivered a number of achievements, neither has been able to develop and implement a longer-term sustainable strategy that can address the current inequality gaps at the pace needed.
- 3.3 **Award the recommended grants** – this is the recommended option as set out above. CDA and the Autism Hub are uniquely placed to take on the role to deliver citizen-led change for Disabled residents. CDA are Camden's only pan-disability user-led organisation and deliver the Centre for Independent Living. The Autism Hub are the only autism-led organisation in Camden and have championed the current work to highlight the many significant gaps in services for autistic adults.

4 WHAT ARE THE KEY IMPACTS / RISKS? HOW WILL THEY BE ADDRESSED?

- 4.1 There are two main risks associated with the proposal set out in this report. Firstly, the funding level awarded to either organisation may be insufficient to meet future demand, or guarantee sustainability, if the need for services increases, or if income projections are not achieved (e.g., due to changes in the wider economy). While it is not possible to fully mitigate this risk, officers will work closely with both organisations in an 'open-book accounting' approach to get early warning of any potential issues. Part of the funding to be awarded to both organisations will be used for them to seek additional income

from external funders, or to consider other social investment opportunities. Ultimately, if funding is insufficient and extra income cannot be raised, then the ambition for change, and services delivered, may need to be reduced.

- 4.2 The second risk is that due to the current systemic inequalities for Disabled residents, there is a huge desire for quick action and impact and this may not match the pace of change that is possible. While both CDA and the Autism Hub have ambitious resident-led plans for change, these will undoubtedly take time to bring about observable change for residents.

5 CONSULTATION/ENGAGEMENT

- 5.1 No formal consultation is required in relation to the proposals in this report. As user-led organisations, both CDA and the Autism Hub are made up of and governed by a majority of D/deaf and Disabled people. As such, the plans for future developments of both organisations are embedded in the views and needs of Camden residents and all future projects and activity will continue to be co-produced with these residents.
- 5.2 The importance of this engagement and lead from Disabled residents was highlighted in a recent report from the Local Government and Social Care Ombudsman, "Equal access: Getting it right for people with disabilities". This made clear the necessity of involving residents to ensure we can meet our duties under the Equalities Act, "*The most important learning point we highlight in this report is the duty for local services to anticipate the needs of people with disabilities in their area. This means putting the needs of people with disabilities at the heart of everything the service does, designing services with them in mind, so that their needs can be met before they even come through the door, pick up the phone or write a letter.*"
- 5.3 An Equalities Impact Assessment has been completed, which shows that the proposals will have a positive impact on our duty to eliminate discrimination and advance equality of opportunity for Disabled residents of Camden.

6 LEGAL IMPLICATIONS

- 6.1 Decision makers must take into account in coming to any decision the Council's equality duties and have due regard to them. In summary these legal obligations require the Council, when exercising its functions, to have 'due regard' to the need to:
- a) eliminate discrimination, harassment and victimisation and other conduct prohibited under the Act (the protected characteristic of marriage and civil partnership is also relevant);
 - b) advance equality of opportunity between people who share a relevant protected characteristic and those who don't; and
 - c) foster good relations between people who share a relevant protected characteristic and those who don't (which involves tackling prejudice and promoting understanding).
- 6.2 Under the Duty the relevant protected characteristics are: Age, Disability, Gender reassignment, Pregnancy and maternity, Race, Religion, Sex, Sexual orientation. In this case the EIA concludes that there is no potential for

discrimination and all appropriate opportunities to advance equality and foster good relations have been taken.

- 6.3 Contract Standing Orders (which form part of the Council's Constitution) specifically refer to award of grants being outside their scope. This reflects the fact that grant awards are not subject to the procurement regime as set out in Public Contracts Regulations (PCR) 2015 and supporting legislation. Nevertheless, any decision to award a grant must be taken having regard to relevant public law considerations including (i) is value for money being achieved (ii) is the award the most effective means of achieving the Council's objectives and (iii) are measures in place to monitor performance and delivery of objectives.

7 RESOURCE IMPLICATIONS

- 7.1 The Autism Hub is seeking funding to enable it to continue its work within the community. This is an annual grant award with the amounts as specified in section 2.2 above. It is expected that this project will be funded via the Better Care Fund (BCF) for 2022/23. As the BCF is subject to annual agreement, this funding is contingent on the continuation of the BCF being agreed annually. Should BCF not continue, the Council is not expected to continue the grant funding arrangement. It is not expected that the Autism Hub will be self-sustaining when the 3-year period covered in this report has come to an end. There will likely be an ongoing form of financial support required from the Council if this initiative is to continue.
- 7.2 The grant will be managed by Asperger London Area Group (ALAG) (the umbrella charity) who have the capacity and ability to manage the funding on behalf of the Autism Hub. The Council while providing this grant will not be the only source of funding available for the Autism Hub. It is expected that the Autism Hub will continue to seek other funding source from other external partners such as the NCL ICB, Camden Giving and Camden and Islington NHS Mental Trust. It will also seek to enhance its fund-raising capacity. This funding will enable the Autism Hub to have sustainability while it continues planning for impending growth as demand on the service is expected to continue to rise.
- 7.3 To enable adequate governance, the grant will be monitored quarterly. This will include a review of finance and activity data alongside the use of KPI's to determine its effectiveness.
- 7.4 Camden Disability Action is seeking funding for development and continued operation of the Centre for Independent Living. This is intended to be an annual grant award as specified in section 2.2 above. Funding for 22-23 is on top of the seed funding of £81,499 already approved. It is expected that three different strands of funding are used to fund this additional allocation. £78,727 underutilised budget transferred from Commissioning Development Fund across all three years, additional Transformation Funding allocated for year 1 & 2 of £43,773 and year 3 £51,273. As well as drawing down from the Community Investment Fund reserve £27,500 in year 1 and £142,500 in year 2, this funding is already set aside for the Centre for Independent living and utilises these funds.

7.5 Whilst the CDA plan aims to reduce reliance on Council funding and become more self-sustaining it should be noted that around 30% of room booking income is projected from public sector and the majority of which is expected to be Camden. As such overall sustainability could be over reliant on Camden.

7.6 These plans have been challenged and adjusted; however, it should also be noted that whilst robust and prudent, with further operational decisions that could be taken around cost, should income not materialise that there is still risk that this level of additional investment could prove insufficient for sustainability. There is also potential should performance be better than projected that CDA require less grant funding, this has been evidence in previous years where CDA have requested lower levels of funding than Camden has set aside.

8 ENVIRONMENTAL IMPLICATIONS

8.1 There are no direct environmental implications arising from this report.

9 TIMETABLE FOR IMPLEMENTATION

9.1 Following approval of the recommended grant funding, formal agreements will be finalised and signed by CDA and the Autism Hub prior to the commencement of funding from 1st October 2022. The agreements will include the Council's standard conditions of grant and co-produced outputs, outcomes and targets that each organisation will deliver in partnership with the Council. The agreements will also set out the 'open-book' accounting approach that will ensure financial transparency to manage the risks for both the Council and the organisations themselves. A monitoring framework will be finalised with CDA and the Autism Hub to capture and monitor the work undertaken over the period of the grants and the expenditure incurred. Quarterly monitoring meetings will take place and will include quantitative and qualitative data (including case studies).

10 APPENDICES

Appendix 1 – Equalities Impact Assessment

REPORT ENDS