

# **PERSONALISATION IN BLACK, ASIAN AND MINORITY ETHNIC COMMUNITIES**

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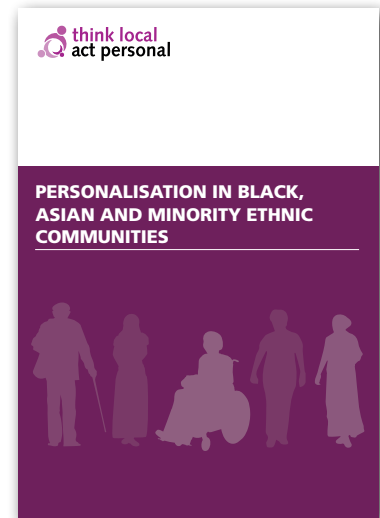
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## SUMMARY

TLAP commissioned this project to find examples of promising practice that demonstrate what good personalised community-based care and support looks like for people in ethnically diverse communities. Fourteen organisations across England feature in this report, offering a wide range of support and services in particular groups and communities.

Our examples demonstrate core aspects of what good personalised care and support can look like for people from Black, Asian and ethnic minority communities. This includes: focusing on the whole person: understanding and working with cultural complexity; providing flexible and creative responses; building capacity within the community; and being committed to supporting learning and development for the people supported and their wider networks – all underpinned by an understanding of and sensitivity to cultural diversity.

The report showcases examples of organisations and individuals' experience, and should serve as a useful resource for commissioners and funders to integrate some of these ideas into their own practice.

**FOREWORD****Foreword from Clenton Farquharson, MBE, Chair of Think Local Act Personal**

The Covid-19 pandemic has revealed systemic and structural problems of inequality that people from Black, Asian and ethnic minority communities experience; doubly so when disability and the need for care and support is taken into account. Our role at TLAP is to promote personalisation and to shine a light on what's not working. But we don't stop there. We always offer a contribution to making things better. We have undertaken this project to find good examples of personalised care and community based support for people from ethnically diverse communities. When we started out we were not sure what we would find. I am pleased to say that we found 14 organisations that are doing inspirational work, which we share here.

Three things stand out for me. Firstly, whilst the organisations and the communities they serve are diverse, they are all doing personalisation within a broad framework of promoting health and wellbeing as envisaged in the Care Act. They may not use these terms, but we found that the support was person-centred and highly sensitive to people's identities, background and beliefs, using staff and volunteers rooted in their communities. This came with a strong 'can do' ethos which stretched beyond only meeting people's needs for care and support. We use the term 'culturally competent' to explain this.

Secondly, most of the organisations are operating on the edge of mainstream commissioning and provision. This has some benefit in terms of flexibility and autonomy, but can mean a struggle to access sustainable funding and, whilst we heard that their views are sometimes sought by decision makers, there was a perceived lack of follow through in terms of support and investment.

Thirdly, whilst we don't want to over claim and this was a small study, my belief is that there are many more organisations providing great personalised and community-based support, but they may be 'hidden in plain sight'. I would urge local care and health decision makers to engage with organisations like these, in order that personalisation becomes more inclusive, more equal and better for everyone.

This project was commissioned by TLAP and undertaken by two consultants: Melanie Phillips and David Truswell. They undertook the call out for examples, conducted the field work, wrote up and analysed the findings, all of which provide the basis for the final report. The work was overseen by a project group which included three members of TLAP's National Co-Production Advisory Group. Any errors or inaccuracies in the interpretations we have placed on the information submitted are TLAP's.

# 1 | INTRODUCTION

**Think Local Act Personal (TLAP) is committed to ensuring personalisation works for all and addressing care inequalities.**

The Covid-19 pandemic has had a disproportionate impact on people from Black, Asian and minority ethnic communities and TLAP commissioned some specific work as a contribution to addressing this.

The aim of this project was to find examples of promising practice that demonstrate what good personalised community-based care and support looks like for people in ethnically diverse communities. This includes identifying the factors that support high quality care and support, and the barriers that stand in the way. The project was undertaken during the Covid-19 pandemic and so the work also highlights how organisations responded to this enormous challenge.

We were particularly interested in understanding the experience of those running organisations and the people supported by them, looked at through the lens of personalisation. As well as describing what the organisations do and for whom, we have tried to relate 'how' they do it to particular aspects of personalisation.

In addition to the 'what, who and how', additional analysis is put forward based on an understanding that the organisations face similar issues. Many of the projects had little support from mainstream commissioning, and a number of common approaches and responses are highlighted as a consequence of this.

An initial call out was made using TLAP's networks and those of our consultants. From this a number of projects were identified to follow up and in-depth interviews were carried out. A total of 14 organisations have been included in this report.

A note on terminology and scope: throughout the report we have used the term Black, Asian and ethnic minority, which is often abbreviated to BAME. We recognise that the term is a contested one, but have opted to use it in the absence of an agreed alternative. The report does not cover White minority groups.

In carrying out the work we were conscious of the need to be aware of intersectionality. This is a term now often used to describe the relationship between social identities such as race, gender, and disability, and how they overlap and interact with each other to affect people's experiences and outcomes, linked to systemic disadvantage and discrimination.

## What we found

Whilst the organisations differ in the support they provide and the groups they work with, they had much in common. The majority are small and local. Their services are, in the main, not commissioned to provide care and support by their local authority or other statutory organisations, although some do receive council and other statutory funding. There is one example of a council undertaking strategic work with Black, Asian and minority ethnic communities.

What shone through was a strong aspirational can-do focus and commitment to creative practice aimed at enhancing the vibrancy and quality of people's lives and the real benefits of innovative personalised care that is community-led. All of the organisations adopted a broad purpose that embraced a wide definition of promoting health and wellbeing, anchored and informed by the communities they were serving. In this way, most could be said to be operating within the spirit of the wellbeing contained in the Care Act 2014.

This was a small-scale project, and the findings cannot be over-generalised to make sweeping definitive statements about personalisation in relation to Black, Asian and minority ethnic communities. Not all ethnicities, places, or cohorts are covered, as to a very large extent we had to rely on what came to us from the call-out. We don't therefore make any claims for representativeness. However, what can be confidently said is that each of the participating organisations possessed an abundance of knowledge, experience, skills and – above all – dynamism and energy directed to working with and alongside the people they support. There is some valuable learning here.

The report showcases examples of organisations and individuals' experience, and is a useful springboard for commissioners and funders to integrate some of these ideas into their own practice. We also contend that there are organisations like those in this study in most places. The challenge and opportunity for the 'system' is to engage with them on equal terms.

## ② | ASPECTS OF PERSONALISATION

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Whilst the organisations profiled here did not necessarily talk in the language of personalisation, they more than demonstrated core aspects of what good personalised care and support looks like in the way that they work with, and alongside, people and communities.

**Focusing on the whole person** and holistic support rather than relying on diagnosis or narrow assessments of care needs. This allows care and support to be aspirational and creative, and to embrace what matters most to people including their cultural background, beliefs, and chosen way of living.

This is made easier through straightforward and non-bureaucratic ways of accessing support and the absence of restrictive eligibility criteria or cumbersome assessment processes. The processes that are used were seen to be very person-centred and flexible.

In keeping with this, there was often real **choice over how support is provided**, often from a small team who get to know the person well. This includes assisting family and community members with information, advice and training to support personalised care. This partnership approach between the service and family and/or community member allows for a shared understanding of how to best support the person, which is highly sensitive to their needs and preferences and based on knowledge of the community they originate from.

**Flexibility of provision and creative responses** to the meet the needs of an individual within the context of their life experience. This requires a detailed understanding of what culture, religion and ethnic identity mean to the individual, and how these factors shape their everyday life choices, rather than making generalisations based on stereotypical views of communities' needs. It is greatly helped by having staff and volunteers who speak the person's language. The organisations are a trusted source of information where people feel their experiences are understood, and their aspirations met.

**Cultural complexity and competency** are issues that specifically relate to supporting people from Black, Asian and ethnic minority communities. In terms of complexity, this is a recognition that when it comes to care and support (as in other areas of life) there are frequent stereotypes and assumptions made about individuals and communities, such as 'they look after their own' and therefore do not require formal social care; this impedes needs being properly identified and limits the provision of culturally appropriate support.

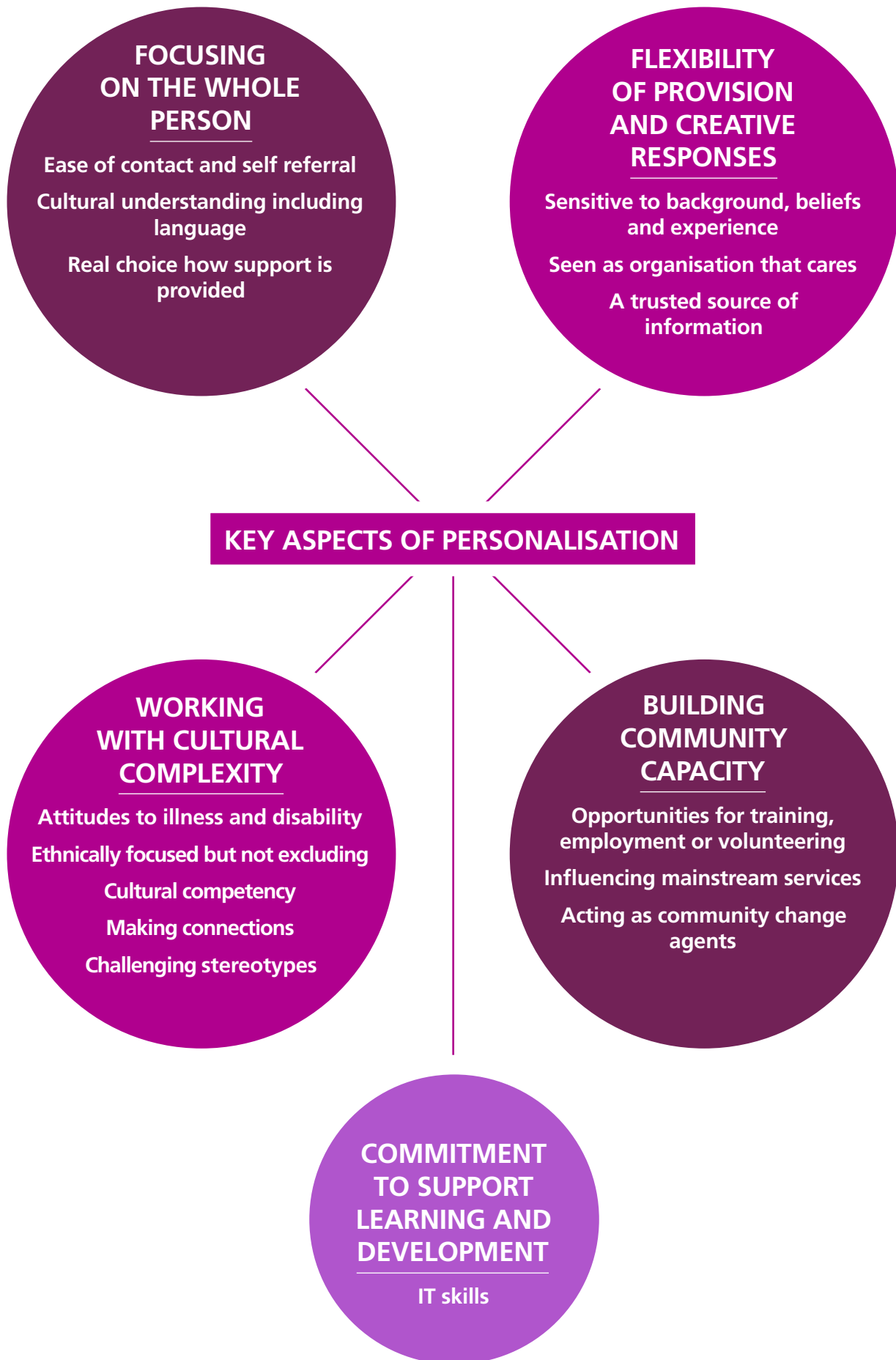
There can also be issues within communities around attitudes to illness and disability. A number of the projects work with issues such as mental health and dementia that may not be well understood in some communities. The communities benefit from being informed and educated about these health issues and assistance given to family carers to acknowledge their challenges, so they feel better able to seek help.

The projects also demonstrated high levels of **cultural competency**, whereby organisations and their staff (including volunteers) are highly sensitive to people's cultural identity and heritage. They are alert and responsive to people's beliefs, conventions, and ways of living that supports positive and respectful relationships, the cornerstone of personalisation.

A further dimension is that some projects were **ethnically focused but not excluding**, meaning that whilst they were aimed at specific ethnic groups and communities they also worked with people from other communities. Some had started out with a very specific group and over time had broadened out to meet the identified needs of local communities other than their own.

**Building community capacity** by mobilising and drawing on the strengths of the people being supported, their families, and their communities. A notable feature of some of the projects was how they acted as **community change agents**. At the individual level, there were examples of people (those drawing on the care and support, staff and volunteers) being assisted to find opportunities for volunteering, training and employment. This was often a new experience for people who had not previously had these opportunities, particularly as a result of barriers due to language or life chances. At the wider system level some of the organisations exercise an information and advocacy type role aimed at influencing mainstream care and health decision making.

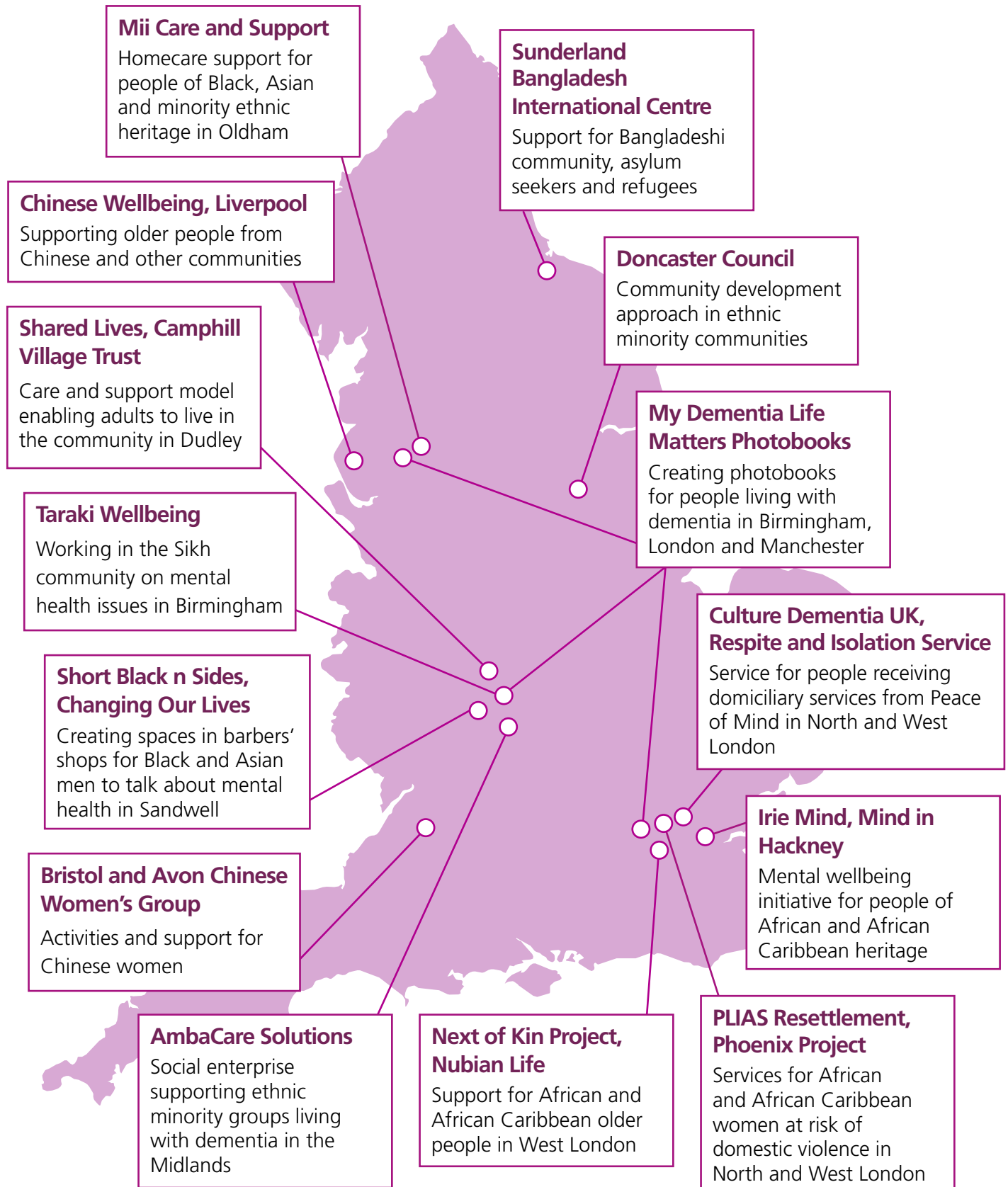
**Commitment to support learning and development** so that care and support is not seen as only about maintenance and keeping people going, but is also about creating opportunities for people to learn and develop. This was most clearly shown in relation to empowering people through learning IT skills. Training in IT can reduce isolation for people who can often be disconnected from others, as a result of language barriers and physical isolation from their communities which the pandemic exacerbated for many people in ethnic minority communities.





# ③ ORGANISATIONS AND PROJECTS

Fourteen organisations and projects are included in the report. Fuller descriptions are in Annex 1.



## 4 | EXAMPLES FROM ORGANISATIONS

Here we illustrate how the organisations and projects in the study corresponded to the aspects of personalisation described in section 2 and highlight the common approaches between the different organisations and projects. They are not mutually exclusive and there is a considerable degree of overlap<sup>1</sup>

### 4.1 Focusing on the whole person

Personalisation feels real to people because they are treated as individuals where support is focused on the whole person and holistic provision, rather than relying on a narrow assessment of care needs. The projects provide easy access and contact points that do not require complex referral processes. Care and support is based on a rounded view of the person's health and wellbeing, informed by cultural understanding on the part of those providing support, and often by having people who speak the person's language, when English is not their first language.

**AmbaCare** believe that the people living with dementia who they assist need to feel that they are being thought of as a person, rather than seen through the lens of their diagnosis. They ensure a personalised approach by taking the time to get to know people and exploring their strengths and aspirations. This enables them to be more creative in the way in which they provide personalised care. Some specific tools have been developed to support this approach such as 'Uniquely Me' a Plain English paper-based questionnaire for volunteers and befrienders that records preferences for those they support such as 'This is what I like to eat' and 'These are places I like to go'. This can be translated as needed in individual circumstances for those who have limited use of English.

The **Chinese Wellbeing Service** undertakes its own assessments to find out what people want and the detail of their circumstances, as council led assessments are felt to be overly task focused. The Wellbeing Service has an aspirational approach to care, based on a holistic view of need, which is also informed by their cultural beliefs about what being in good health looks like. This incorporates the physical, mental and spiritual dimensions of wellbeing and enables them to achieve health benefits that have far more impact on peoples' quality of life than just focusing on care needs being met. This way of working helps to keep the older people they support connected, including the provision of language specific help and advice as well as cultural support. Many people fear going into a care home and the organisation is important in keeping them living at home and enabling them to keep connected their families and community.

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<sup>1</sup>The interviews and information provided by the projects were not measured against these categories as a preconceived checklist.

**Irie Mind** intentionally does not have a set way to access its support, as a historic problem for the people it works with is a lack of accessibility to mental health services. The service makes it as easy as possible for people to ask for help and get a response when they do so. They work with the person to find out what is going on in their life and what support will work best for them. Feedback from people who use the service is that they feel what they say is valued, and the service recognises that they have something to contribute. Even feeling able to attend daily is important as some of the people they work with do not find that traditional services offer them this connection.

People drawing on support from Irie Mind are involved in aspects of its development and attend regular visioning sessions on developing the service. People see the service as a place where they will be understood culturally. They are involved in the recruitment process and have been at the heart of the job development discussions in recruiting a therapist and identifying the key qualities the candidate will need.

**Next of Kin Nubian Life** does not have a formal referral process for the service and responds by informal discussions that usually arise through its existing advocacy or day service activities. They have a general problem-solving brief and at initial contact will explore what solution is possible for the individual. The service starts from the premise: What problem do you need solving and what would a solution look like? Nubian Life takes this approach from the outset and their strengths-based approach enables them to explore what personalisation means for that individual.

The **Culture Dementia UK Respite and Isolation Service, run by Peace of Mind** takes the time to sit down with a person to find out what they want rather than going through a formal assessment process. The person is seen as an expert in their own needs rather than a passive recipient of support. The organisation recognises the importance of responding to different everyday things that contribute to people feeling better about themselves and their lives. This might be cleaning the curtains, doing some shopping, reading out the newspaper, or simply chatting for a while.

At **Phoenix Project**, the approach is based on working with the person to help them to think about their needs and what they want to happen to improve the quality of their lives and free them of the harm they are experiencing. Women and girls who contact the service directly themselves do not need to fill out a referral form. The support package built up for every woman is different. The project often challenges the traditional fragmentation of services by thinking about the woman's needs holistically. Through their experience of providing services to Black, Asian and minority ethnic communities they understand that individual women have different experiences and have had different journeys. This, combined with having support workers from these communities, enables them to have a greater insight into and empathy for the needs of the women who they support.

## Stories of experience – being the best I could be

Ronald Amanze is a former music producer of Jamaican heritage living with dementia. As founder of Talk Dementia, he is working with The Photobook Project to develop photobooks that are a creative record and expression of his own and others' everyday lives. He says:

“The Photobook project gave me a chance to be involved with something and it's important to be involved with something when you are coming to terms with feeling so irrelevant to everything, when people are being defined by their mental health issues and not their potential or their ability. The Photobook Project for me was therapy, meaningful involvement in a situation where I could explore being the best person I could be and where I was reminded that this was something we should all do, and it was something that was still relevant to me. Try to be the best person you can be despite the diagnosis and despite the circumstances.

It was a chance to take on a challenge that was enjoyable and also it refreshed my mind about working with people and being involved in a situation creatively where I could start exploring things with my imagination. It was an example of what should be. When you are doing something that's relevant to your life, you want it to be relevant to what you are doing, you don't want other people to be setting your agenda for you, painting your picture of life for you and then managing to persuade you to think that this is what you really wanted.

Taking photographs made me think and when you start using your brain after your brain has been almost dormant for such a long period of time you start to realise things, even little things. When it started to rain, I'd look out of my window and I'd look at the rain. I'd see it on my windowpane, and I'd be tempted to take a picture of that to see what I could do with it. I started to look at the trees, nature. I started to search for things that intrigued me. It made me start to notice my environment again.”

## Stories of experience – getting to know you

Mii Care & Support shared a story on behalf of a person they are supporting.

“We are supporting a young man who had a traditional support package for several years before he came over to us on a direct payment, which gave him more choice and control. He was involved in choosing and creating his own consistent staff team, building trust and rapport.

Other positive outcomes were achieved such as reconnecting with his neighbours and community, re-establishing contact with his mother and sisters, and gave his first Eid gift. He now attends Friday prayers and participates in his faith; spirituality is a very personal thing, and everyone has their own way of practicing, however minor it may appear to others.

He didn't eat chapatti for many years, relying mainly on ready meals. Now he is eating food he enjoys and eats a variety of freshly prepared cultural food that is Crohn's disease friendly, resulting in weight gain.”

### 4.2 Flexibility of provision and creative responses

The projects address aspirations and wants rather than just focusing solely on needs. Support and services are not rigidly prescribed, but are closely matched to individuals, allowing room for flexibility, creativity and innovation to meet needs, all rooted in a strong understanding and sensitivity to the cultural background, beliefs and experience of the people and communities being supported.

The **Bristol and Avon Chinese Women's Group** has developed a freephone helpline – The Chinese Lantern Project, which provides help, support and advice to Chinese communities in the Bristol area. This was developed in response to a recognised need that many organisations in the area had closed down due to lack of funding, which had created a gap in the services available to the Chinese community. Through signposting and word of mouth this has developed into a trusted resource in a space where no other resources exist.

**Mii Care and Support** take a holistic approach which considers what support the person wants and how they would like it provided which means looking at peoples' wishes and preferences and not only at their physical needs. This includes matching people with their preferred support workers who are then continuously involved in their care, rather than have different workers coming along. Support is therefore provided by creating a team of people around the individual.

It was clear that the people who were supported by **Peace of Mind** did not want strangers coming into their homes to provide the additional support from the **Respite and Isolation service**, commissioned by **Culture Dementia UK**. To address this the organisation works hard to create a team around the person which allows for much stronger and more personalised relationships to develop, which in turn builds trust in the project.

**Short Black n Sides** was intended to create a safe space in the community where Black men could have conversations about their mental health. The aim was to normalise these conversations and help people to stay well in the community. It was developed in this way because barbers were already engaged in those conversations with men who came to the barbers, and also having conversations with families who were going along.

The barbers taking part were helped to understand mental health issues. The original idea was to bring them together for a group training session, which was abandoned early on. Instead the project team adopted an individualised approach, visiting each of the barber shops and tailoring the information and support provided so each barber felt confident to have these conversations and could signpost appropriately to other sources of assistance. The project also engaged with a local college and photography project to broaden awareness of the project in the local community.

The importance of getting permission to speak in an ordinary setting about mental health issues cannot be underestimated, and Short Black n Sides has shown an effective way of achieving this.

Back in 2007 the **Sunderland Bangladesh International Centre** identified that Bangladeshi people in the area were not accessing appropriate care and support services. This was due to a number of factors:

- a lack of community knowledge and understanding about what services were available
- an inability to access services because they were not available in Bengali
- a misunderstanding of the needs of Bangladeshi older people by mainstream services
- assumptions made by services, and sometimes by the families themselves, that care would/should be provided by the family themselves.

As a response the centre worked with a national organisation to train 12 personal assistants from the Bangladeshi community to provide care for adults who were disabled or had specific health conditions that meant they needed personal care. These carers facilitated an understanding of the personal care needs of the person that social workers had not been able to identify because of language issues and how questions about care needs were asked. The carers provided personal one to one care based specifically on the needs of the person where the personal assistant understood both their language and cultural needs.

**Taraki Wellbeing** started out with the mainstream mental health first aid model, but quickly decided that this did not work with Punjabi communities, so they have developed their own model of peer support which is supported by the Sikh faith.

It works by creating a safe and dedicated space through relaxation techniques, open discussion and mutual support. People's faith and culture is drawn on as a resource and dialogues are opened up about male/female identity, sexuality and what support looks like for different individuals within the Sikh community.

## Stories of experience - taking control, the value of direct payments

This is the experience of **Mohammed Patel** who responded to the call out for examples of good personalised practice and told us his story about having a direct payment.

“Because of religious needs, food requirements, access to religious places and having family and friends around whom share these beliefs, direct payments make all the difference when it comes to having the care and help that meets my needs. It allows me to get that help from different sources. But I also work as an advocate for other people on direct payments so I think there still is a lot that needs to be done by commissioners to think in a more innovative way about how these payments could be used. This would save money for those commissioners as well as make those us using direct payments much more confident and help our wellbeing even more.

There is still a sense within the Black, Asian and minority ethnic communities that ‘independence’ might be too much of an expectation for someone with disabilities, and that can lead to hesitancy about people looking into direct payments for support. You can also find professionals in the health and care services who think that people with disabilities in these communities don’t need direct payments because they are more likely to have family carers. So, both of these attitudes are likely to be contributing to limiting the number of Black, Asian and minority ethnic people using direct payments.

For those using direct payments we are still left with the commissioners having a hard time of letting go of the ‘control’ aspect of the ‘choice, independence and control’ that is the cornerstone of the concept of personalisation in care. For example, in my area several of us receiving personal care would like to set up some form of consortium to collectively meet our care needs through a provider of our choice. We can’t do this because local commissioners will only consider each of us in isolation.

I have muscular dystrophy and before I received a direct payment I was in and out of hospital on a monthly basis. Now my hospital stays have been reduced to zero. Beyond getting people’s basic needs met we need to bring together the wealth of knowledge and experience that people receiving direct payments can bring to innovative and enterprising thinking in providing care and support. That would build our self-confidence and our wellbeing even more, as well as saving money for services and would stimulate innovation. Commissioners making more use of our expertise on local or regional basis could be taking personalised care up to an even more innovative level.”



### 4.3 Working with cultural complexity

Projects often face having to address challenging stereotypes and assumptions about people from Black, Asian and minority ethnic communities whilst at the same time they demonstrate the willingness to connect with other groups and communities, and exercise a high degree of cultural competency in the way they support people.

The **Chinese Wellbeing Service** supports Chinese elders living alone who don't have close family members. A common stereotype of the Chinese community is the myth of 'close knit family support' that does not reflect many of Liverpool's Chinese people's experience in later life. The service understands that this stereotype means that many older people can be left isolated with their needs not addressed by mainstream services.

Black, Asian and minority ethnic groups often have to defend their communities from racism and negative judgments about their faith and culture. When **Taraki** started out providing support to Punjabi men it opened up conversations about masculinity and mental health within the community. The group developed a strong bond of trust with those who attended and, as they were all from the same community, this enabled a much fuller engagement with debates about taboos in relation to gender and sexuality and for group members to debate and challenge their own perceptions and those of others. They have evolved the model to provide peer support to women, LGTB+ and non-binary people. They run workshops in faith centres.

**Irie Mind** is building working partnerships with other organisations in the community, such as faith organisations, in order to build community alliances in areas of shared work.

**Phoenix Project** is part of the London Violence against Women and Girls Consortium who have campaigned for greater recognition of abuse in Black, Asian and minority ethnic communities and the need to tackle it. The Phoenix Project project initially focused on African-Caribbean and African communities, but discussions with community partners combined with evidence from referral enquiries, identified that there was a need for the service in the South Asian community who did not want to approach support organisations in their own community because of stigma. As a result, they extended their service to respond to this need. A more granular understanding of local community needs can evolve through wider community engagement with different communities if organisations are flexible enough to hear and respond to these voices.

Having Black therapists employed by the Phoenix Project has been important in creating an atmosphere that challenges cultural stereotypes, such as the one that Black women have to be strong, independent and can look after themselves, which lead to reluctance to look for or take up support because of fear of being seen as dependent and weak.



Although the **Bristol and Avon Chinese Women's Group** predominantly supports older Chinese women, using the 'Bristol meets the World' and 'Ageing Better' initiatives, the project set up a small group for Asian, Caribbean and Chinese women. The aim was to increase awareness across different communities and the group shared stories, recipes and foods from their communities. This not only benefited the Chinese women who participated, but enabled stories of migration, identity and culture to be shared. Despite the different narratives, languages and faiths, commonalities of experience enabled all who participated in to learn from this initiative.

**Dudley Shared Lives** scheme's local community is primarily white, as were the cohort of Shared Lives carers and people referred to the scheme. In 2018 the project took a conscious decision to challenge themselves to become more inclusive and change the profile of their service. As a consequence, they now have six Black, Asian and minority ethnic households who are Shared Lives carers. To achieve this, they made significant use of the local press and national black press to publicise Shared Lives within the local community and the Black, Asian and ethnic minority carers recruited have acted as informal ambassadors to publicise the service within their own local communities. This has changed the narrative about who provides care and how it is provided. It has involved white carers thinking about how they might meet the needs of a more diverse group of people in terms of faith, culture and ethnicity. It also provided Black, Asian and minority ethnic carers with the opportunity to change stereotypical thinking about who provides care, and to challenge the myth that Black carers do not come forward to provide this type of care. As a result, the scheme is better able to serve the needs of the local community.

**Sunderland Bangladesh International Centre** is open to different Black Asian and minority ethnic groups. Although originally set up to provide a service to the Bangladeshi community in Sunderland, the project has re-evaluated its service provision with changing needs and a growing African, refugee and asylum-seeking community. The service focuses on the commonalities of migrated and migrating peoples and has sought to help communities understand the similarities in their experiences and histories, rather than focusing on division and difference.

## Stories of Experience - challenging stereotypes

Denzel is originally from the Caribbean and has lived in the UK for a long time, where he successfully worked for a number of years. Following a breakdown in his marriage and excessive use of cannabis, he had his first 'breakdown' aged 47 and was later diagnosed with a severe mental illness. He has experienced bouts of depression and anxiety over the years and has accessed the Irie Mind service for one-to-one support, therapy and psychosocial groups.

Prior to the March 2020 lockdown Denzel's mother became unwell, and he had planned to visit her, but the sudden lockdown made that impossible. He became frustrated and irritable, as the activities and support services he previously used to give him structure and support had now moved online.

This became more of an issue as Denzel lacked the necessary equipment and IT skills and was unable to access online services. Collectively, Irie Mind provided a workaround, where they conference-dialled him into their groups so that they could come together and support him. Denzel seem to enjoy that, participated frequently and was optimistic about the potential changes for the future as a result of life being paused, and people in the groups reflecting on what they really valued. Irie Mind also helped Denzel to get a smart phone. As things began to open up again, Denzel seemed to need fewer services. Thanks to the group interaction, he managed to stay well, bounce back and started to do odd jobs in his community.

Later in 2020 Denzel's mother passed away. This led to a decline in Denzel's mental health, and he began to show early warning signs of a relapse. Irie Mind supported him and he is now regularly taking his medication, staying active and meeting online with others. Irie Mind continues to be a point of contact for his GP if they are unable to reach Denzel and he continues to have regular MOTs with the team. Without this support, Denzel could have easily been another Black person characterised as 'difficult to engage' by mainstream services.

### 4.4 Building community capacity

Projects in the study demonstrated the commitment and ways of working that reflect that, at its best, personalisation builds on the resources, talents and gifts that people and communities have to help create natural supports to go alongside formal care. This can lead to creating the expertise and momentum to influence wider change and development for individuals and collectively at a local level.

**AmbaCare** was set up to find out from communities that typically have not had much influence on the development of support for people with dementia to identify what help and support they wanted. The first stage was to gather information about what was available and put this onto their website. A second phase has been to develop the role of community researchers, utilising the experience and knowledge of volunteers, befrienders and family carers who value the opportunity to share their experience to assist and educate

others and raise awareness about dementia. Some provision is targeted by language, for example supporting people speaking Hindi or Gujarati.

In Liverpool, the **Chinese Wellbeing Service** was initially set up to train carers and as a befriending service for carers, but it gave many people from the Chinese community the opportunity to move into the care sector. Many people of the generation who migrated to the area in the 1960's and 1970's never expected to work in anything other than the catering trade, and for them it has been a gateway to creating alternative opportunities for work. Community organisations can be an important bridge to wider employment opportunities for some community volunteers.

**Doncaster council** is investing in a strategic and planned way to build engagement with and learn from local communities. The Link Coordinator works closely with the council's Minorities Partnership Board, which has developed an action plan to improve access to services and outcomes linked to Covid recovery, and with local community champions. The council is committed to being led by the community in this development process, rather than see the dialogue with the community as an add-on extra. The board aims to include some peer training and support work with up-skilling and empowering people from Black, Asian and minority ethnic communities. They have identified that mainstream services can support this by building mechanisms in their organisations to provide opportunities for community members to become influencers in local health and care decision making structures. Doncaster council recognise that this is long term work that needs to be integrated with community organisations.

Contrary to a common mainstream myth, many older African and African-Caribbean people live alone or are isolated from family support. Through written submissions to national and local consultations, and through public presentations of their work, **Next of Kin Nubian Life** have robustly championed and highlighted these issues and through these initiatives have helped to help educate and inform decision makers.

The **Short Black n Sides project** was part of **Changing Our Lives** work with local policy makers and services to look at a redesign of resources to influence the development of services and reduce risk. It involved creatively thinking outside the box to explore non-traditional avenues for providing support. Support from statutory organisations is needed to back the development of these innovative approaches to health and wellbeing and ensure feedback of information into local policy making and service redesign. In Sandwell, the issues highlighted by the project were fed into the local Health and Wellbeing Board via the People's Parliament.

The approach that the **Sunderland Bangladesh Centre** took to providing better and more culturally appropriate care and support for people from their community was to recruit and train local women from the surrounding Bangladeshi community. Most of these women did not have any formal education qualifications and some were isolated after their own children had grown up. The training allowed the carers to go on to qualify and take on care worker jobs in other services which changed their opportunities as well. The funding for this project was withdrawn but some of the workers continue to provide care through private arrangements or have gone to work for other care providers.

## Stories of experience - information and insight shared

Kanta is a volunteer with the AmbaCare Living Well with Dementia project in Slough. She became involved in the project as it had become increasingly stressful to care for her mother who had been diagnosed with vascular dementia. Since her mother passed away Kanta was determined to play her part in easing the burden for other carers with practical advice and support. At the time she was caring for her mother, she felt there was little support to help her cope with the practical aspects of caring for someone living with dementia in her community. She cited the lack of Gujarati speaking volunteers, which she said was essential because her mum was no longer able to speak or understand English.

To help Kanta and other volunteers spread the word among their family and friends a PowerPoint presentation with a soundtrack is being prepared. This idea came from the volunteers to have a greater impact in the community in terms of raising understanding and awareness of dementia. Kanta's lived experience of caring for her mother has been invaluable in being able to signpost individuals to local information and support services which can meet their personal needs as they respond in a culturally sensitive and responsive way.

### 4.5 Commitment to support learning and development

People drawing on care support are seen as having the potential to grow and develop rather than as passive recipients of care. This is exemplified through the empowering effect of learning IT skills which was heightened in response to the Covid-19 pandemic.

During the pandemic normal activities at the **Bristol and Avon Chinese Women's Group** centre had to stop and some members of the group became very isolated from their friends and family. Some members had previously relied on family members if they needed to use technology. In response the service quickly established an ongoing training programme on using IT, providing workshops and tutorials for using smart phones, video calling and using Zoom. Usually, the women would be visiting their families in Hong Kong and China, but using technology enabled them to keep in touch with friends and family and reduce their isolation, as well as taking part in the online activities and support. The shift has opened up new avenues for support and opportunities for personal development. Additionally, at the beginning of the pandemic the project developed a bi-weekly telephone support group for members with dementia with help to use a telephone conferencing service so that the group could call each other.

People living with dementia are often viewed as unable to be creative and the **Dementia Photobook** project is intended to challenge that stereotype. It demonstrates the ambition and realisation that organisations can adopt a different mindset by exploring the capabilities of people living with dementia. Through unlocking their hidden or unexplored talents rather than managing the limitations of their condition, people living with dementia can respond positively to being involved in creative projects.

**Mii Care and Support** is committed to ensuring that people who use the service live the lives they want to have and have the opportunity to contribute to their local community. They achieve this by helping people to acquire skills and develop new roles in their community. For example, one person with severe disabilities was supported to volunteer with a local organisation.

The **Phoenix project** has a very strong connection to those who use the service through their flexible and personalised approach. At the start of the pandemic, they provided laptops for home-schooling and taught people how to use Zoom and IT skills for employment. Developing IT skills is an important part of not only gaining self-confidence but also gaining independence from an abusive and controlling partner. With children being home-schooled during lockdown this was an additional burden faced by many. Phoenix's pragmatic and responsive approach to changing needs allowed those who accessed the service the opportunity to take back control over aspects of their lives that would not have occurred without this support.

## 5 | KEY MESSAGES

We must be careful to avoid simplifying and over-generalising what by its nature is a complex area. This study looked at 14 organisations, which constitutes a small slice of dedicated support and services available for people from Black, Asian and minority ethnic communities. With this caveat in mind, a number of commonalities were found, both in how the projects provide support and were regarded by the people they support and family carers, and in relation to some of the barriers experienced.

A stand out feature was that the organisations and projects are trusted by the people they support; people feel the organisation ‘has their back’. The people working in the projects have a deep understanding of people’s situations which comes from being **rooted in the community** they serve with less of a distinction between carer and cared for. This is the opposite of time and task care and support. They are **trusted organisations** who provide **trusted information** in ways which people can understand and is relevant to their situation.

The projects also provide **easy access to support** without the fuff and hindrance of hard to fathom eligibility criteria and assessment processes. The projects adopt a **broad definition of health and wellbeing** and use this to work with people and family carers to create support and services which are **person-centred, flexible, encourage learning and development** (both for people drawing on the care and support and those providing it), and **draw on the interests and strengths of people and their communities**. These are the hallmarks of what good personalisation looks like.

It was evident however from discussions with representatives from the organisations that they face a constant **challenge from stereotyping of diverse communities**. This often sees these communities as being both homogenous (pretty much all the same) and isolated primarily as a result of ‘cultural factors’, rather than excluded through systemic features such as under investment in appropriate support, mechanistic processes for accessing support, and lack of flexibility within mainstream provision.

While the representatives we spoke to did not refer directly to intersectional issues themselves, much of their work highlights **multiple and overlapping discriminatory challenges** faced by those they support; for example, being older and also from a Black, Asian and minority ethnic group; experiencing mental health issues and being a woman from a Black, Asian and minority ethnic group. This is compounded when so many people drawing on care and support are on low incomes or living in poverty, and by the scant resources available to the organisations providing them with support.

Despite these challenges many of the projects are **invested in improving understanding between and within communities**. They see changing minds in both the mainstream community and in Black Asian and minority ethnic communities themselves as an essential feature of the way they work with issues such as mental health and dementia that may be stigmatised. Communities can benefit from being educated and informed in these areas to enable better support.

Some of the organisations we talked to felt disconnected from the mainstream care and health system in their area and face considerable **barriers**. Representatives of organisations frequently reported that whilst they were asked to be part of strategic consultation exercises these often felt one way; their expertise was sought but little support or few resources were then forthcoming to support the work they do. This was linked to a sense that commissioners and funders were too remote from the experience, needs and concerns of the groups of people supported by these organisations, which in turn meant that many of the organisations exist on small amounts of funding, often time limited, and struggle to achieve sustainability in competition with larger more visible organisations.

This is not to say that organisations in this report lack agency. The report contains many examples of where projects have sought to extend their influence and support change for and beyond their own immediate communities. In Doncaster, there is an example of a council that is deliberately engaged in reaching out to its Black, Asian and ethnic minority communities.

## 5.1 Conclusion

In terms of a way forward, attention should be directed to recognising and supporting the role that organisations like these in the report can play as community change agents; acting as a bridge so that local decision makers for care and health are exposed to the wealth of expertise that is available to support people from different backgrounds. There are opportunities to develop prevention and strengthen the resilience of people and communities. For this potential to be realised a robust outreach approach and proactive stance from care and health decision makers is required, which should look for ways to engage with grassroots organisations on an equal footing and build co-production from the ground up.

When we started this project, we were not sure what we would find. Asking organisations to come forward in the midst of a pandemic when they were directing pretty much all of their time and effort to doing the best they could for people they support was certainly a big ask. We were therefore pleased and very grateful that 14 organisations have trusted us to share their experience and insights. We hope this document does their contribution justice.

It is our hope that the report will contribute to raising the profile of the organisations that are featured, but also serves a bigger purpose of demonstrating what good personalised care and support for people from Black, Asian and minority ethnic groups looks like. There will be other organisations and projects across the country that are doing similar work. The challenge and opportunity for local decision makers is to engage with these organisations and invest in supporting the change they are exemplifying.



## ANNEX – ORGANISATION DESCRIPTIONS AND DETAILS

### AmbaCare Solutions, Living Well with Dementia

A social enterprise which works to ensure that people living with dementia from minority ethnic groups can access information and support which is culturally sensitive, individualised, and promotes whole wellbeing. They recruit and train volunteers to provide support with physical and emotional wellbeing; reduce loneliness and isolation through befriending services; and provide advice and support to find solutions for complex social needs. They are based in the Midlands, although Covid-19 has provided an opportunity to extend the project nationally.

 [dementiadiversity.org.uk/about-us](http://dementiadiversity.org.uk/about-us)    
  [www.facebook.com/DementiaDiversity/](https://www.facebook.com/DementiaDiversity/)  
 [ruth@amba-uk.org](mailto:ruth@amba-uk.org)    
  [@DD2020\\_Dementia](https://twitter.com/DD2020_Dementia)  
 07974 727223

### Bristol and Avon Chinese Women’s Group

The group provides assistance, advice, representation and support, for Chinese women of all ages and their families in Bristol and the surrounding area, who are socially or economically disadvantaged and/or disabled. The group also facilitates a wide range of social, cultural, recreational, and educational activities. Support for unpaid family carers is also provided.

 [bacwg.org.uk](http://bacwg.org.uk)    
  [admin.bacwg@btconnect.com](mailto:admin.bacwg@btconnect.com)    
  [business.facebook.com/bacwg89/](https://business.facebook.com/bacwg89/)

### Camphill Village Trust - Shared Lives Scheme West Midlands

Shared Lives is a model of care that enables adults with additional/complex needs to live in their chosen communities. Specially trained carers open up their home and informal family life to provide a more personalised form of support. The person is encouraged to connect to the wider community, so they can access local amenities and activities, whilst developing life skills, building new social circles and maintaining contact with other family and friends.

The person requiring support is carefully matched with their Shared Live Carer(s) on either a long-term, short-break or day session basis which provides a real alternative to traditional day services, supported living or residential care. This particular service is an independent Shared Lives Scheme covering Dudley Borough and the surrounding Black Country areas on behalf of the local council, and is managed by national charity, Camphill Village Trust.

 [www.camphillvillagetrust.org.uk/locations/shared-lives-west-midlands/](http://www.camphillvillagetrust.org.uk/locations/shared-lives-west-midlands/)  
 [sharedlives@cvt.org.uk](mailto:sharedlives@cvt.org.uk)    
  [www.facebook.com/cvtsharedlives](https://www.facebook.com/cvtsharedlives)    
  [@CVTSharedLives](https://twitter.com/CVTSharedLives)



### Chinese Wellbeing (Liverpool)

A well-established charity supporting older people from Chinese and other communities in Liverpool, Sefton and the Wirral. Their aim is to provide high quality, culturally appropriate, community-based services. Core to the support is a domiciliary service and wraparound day resource; the Evergreen Club. Services are designed to enable individuals to live independently in their own homes for as long as possible. They assist with everyday tasks, provide companionship and support to remain active within the community, and help carers seeking breaks.

Support is provided by a culturally diverse team of personal assistants, nearly all of whom are Chinese - many of whom are trilingual, speaking English, often Cantonese and one other Chinese language, such as Mandarin or Hakka. During the pandemic all of the group activities of the Evergreen Club moved online for 3 days per week. The activities include dancing, chair-based exercise, singing and arts and crafts. People unable to use online services were supported by telephone.

 [www.chinesewellbeing.co.uk](http://www.chinesewellbeing.co.uk)

 [info@chinesewellbeing.co.uk](mailto:info@chinesewellbeing.co.uk)

### Culture Dementia UK, Respite and Isolation Service

Peace of Mind Home Care Solutions is a home care service registered with the Care Quality Commission working in North West London, delivering services on behalf of Culture Dementia UK. The service is mainly with older adults from Black, Asian and minority ethnic communities. Many people accessing the service do not have any family or a local social network to support them. In response, the organisation has established a supplementary service targeted at those who are most isolated and at risk. A range of assistance is provided, including social support, befriending and help with household tasks. The focus is very much on quality of life and what makes people feel supported and happy.

 [www.peaceofmindhcs.co.uk](http://www.peaceofmindhcs.co.uk)

 [www.culturedementiauk.org](http://www.culturedementiauk.org)

## Dementia Photobook Project

“My Dementia Life Matters” is a creative partnership operating in London, Manchester and Birmingham between The Photobook Project and Talk Dementia. It uses photography and the written word as a vehicle for creative expression and confidence building for people living with dementia, prioritising people from Black, Asian and minority ethnic communities. The immediate product is a photobook created from the photographs taken over a one-month period by the person living with dementia. These images include objects and daily scenes of importance to the photographers. Embedded within the photobook is text written by the participant which reflects their experience of the important aspects of their lives. Each person has their own copy to keep.

Copies of the photobooks are intended for physical display, for example in a local library, housed in a bespoke box designed by Juniper Bespoke and made by the Wyvern Bindery. The project team have since launched a radio show titled Dementia Pirate Radio on Deepness Dementia Radio and a film titled AMANZE which focuses on Ronald Amanze’s experience of The Photobook Project.

 [ellierobinson-carter.com](http://ellierobinson-carter.com)  [ellierobinson-carter@gmail.com](mailto:ellierobinson-carter@gmail.com)  [@EllieGraceRC](https://twitter.com/EllieGraceRC) [@arts\\_dementia](https://twitter.com/arts_dementia)

## Doncaster Council - Covid Community Link Workers

The council has recruited a Covid Community Link coordinator to address inequalities and the health needs of less affluent communities in the city, including Black, Asian and ethnic minority communities. The coordinator, together with four link workers recruited from local communities, works closely with commissioners, people who use services from all walks of life, hard to reach groups, and carer and provider organisations to work together to build an understanding of care and support needs.

During the start up the emphasis was on responding to the Covid-19 pandemic with the provision of information, advice and support to local community groups and individuals. Information was disseminated via community leaders on the council’s Minorities Partnership Board and through social media, for example, a Facebook page dedicated to Covid. Information also went out directly to community organisations via Community Teams. The coordinator developed the first Black, Asian and minority ethnic newsletter for Doncaster and the Covid link officers were recruited via the newsletter.

 [doncaster.gov.uk](http://doncaster.gov.uk)  [stacey.chaplin@doncaster.gov.uk](mailto:stacey.chaplin@doncaster.gov.uk)

## Irie Mind

A mental health initiative, run by and for the African-Caribbean community in Hackney, led by Mind in the City, Hackney and Waltham Forest and launched in 2019. Irie stands for 'inclusion, respect, integration and empowerment'. Irie Mind is a service designed to help and support marginalised and at-risk residents of Hackney. They provide easy to access advice, information and support through a walk-in centre, one to one support sessions, therapeutic groups, crisis intervention and prevention work, and practical support and referrals to facilitate greater access to meaningful participation in the wider community.

 [www.mindchwf.org.uk/our-services/irie-mind/](http://www.mindchwf.org.uk/our-services/irie-mind/)

 @IrieMindE9

## Mii Care and Support

A recently established homecare provider registered with the Care Quality Commission, Mii Care primarily supports people in Oldham providing inclusive services to people from Black, Asian and minority ethnic communities to make personalisation work for them and to have more choice and control over their lives. The service has a holistic approach, looking at what support people want and how they would like it delivered.

 07738 549752

## Next of Kin Service, Nubian Life

An advocacy service operating in the London Borough of Hammersmith & Fulham and surrounding boroughs that provides African and African-Caribbean older people who do not have family or friends with a voice, skills and support to manage their affairs. Next of Kin (NOK) ensures that vulnerable older people attending Nubian Life's day care service do not slip through the net of adult social care or health services, or face disempowering statutory intervention. Support includes advocacy, support to attend medical appointments and emergency admissions, liaison with medical teams to ensure that the older person understands their condition and treatment options, and practical tasks ensuring that their faith, cultural needs and end of life wishes are made known and incorporated within treatment/care plans.

 [www.nubianlife.org.uk](http://www.nubianlife.org.uk)

 [www.facebook.com/NubianMatters](http://www.facebook.com/NubianMatters)

 020 8749 801

 @NubianMatters

### Short Black n Sides, Changing Our Lives

Changing Our Lives is a rights-based organisation based in the West Midlands that operates across England. They work with disabled people and people with lived experience of mental health difficulties, in particular those who are experiencing multiple disadvantages, such as discrimination through being from a Black, Asian and minority ethnic community or living in institutionalised settings. The organisation focuses on finding solutions and achieving outcomes that result in equality and social justice and works through tailored community-level projects that influence local decision-making structures and commissioning decisions. This can be through community action, practice development, rights-based advocacy, Quality of Life review work or highlighting issues through recording local stories.

One project they have co-produced is Short Black n Sides which developed from conversations with Sandwell’s Mental Health People’s Parliament, made up of local people with lived experience of mental health difficulties. The project aimed to address inequalities in the mental health system faced by Black and Asian men by creating safe spaces in barber’s shops where men could have conversations about their mental health.

 [www.changingourlives.org/short-black-n-sides](http://www.changingourlives.org/short-black-n-sides)

 [www.facebook.com/ChangingOurLives/](https://www.facebook.com/ChangingOurLives/)

 [@Positive\\_Lives](https://twitter.com/Positive_Lives)

### Sunderland Bangladesh International Centre

The centre was purpose built in 1999 and opened in 2000 to act as focal point for support for the Bangladeshi and wider Black, Asian and minority ethnic communities in Sunderland. It provides a range of services including, activities, training, advice, information and welfare support services. They have now extended their support and services to asylum seekers and refugees.

 [facebook.com/Sunderland-Bangladesh-International-Centre-214258638686529/](https://facebook.com/Sunderland-Bangladesh-International-Centre-214258638686529/)

 [info@sb-international.org.uk](mailto:info@sb-international.org.uk)

## Taraki Wellbeing

Originating in Birmingham, Taraki Wellbeing works with Punjabi communities to improve access to mental health awareness, education, social support, and research through activities to benefit individual and community-level care. Within Punjabi communities, those living with mental health difficulties can face stigma from family and friends, wider society, as well as within health care settings, which can sometimes lead to increased isolation and a lack of support.

Taraki was started in 2017 by a Punjabi Sikh man in response to his personal experience with mental health challenges as a student when he had found it difficult to access support that worked for him. They have developed their own approach to mental health awareness, care and support, informed by the Punjabi Sikh faith and culture. This model has been used to change the perception of mental health care and support; group facilitators have developed skills in using this approach and have extended its use to other Asian communities

 [www.taraki.co.uk](http://www.taraki.co.uk)

 [info@taraki.co.uk](mailto:info@taraki.co.uk) [shuranjeet@taraki.co.uk](mailto:shuranjeet@taraki.co.uk)

 [www.facebook.com/taraki1](https://www.facebook.com/taraki1)

 [@\\_taraki\\_](https://twitter.com/_taraki_)

## The Phoenix (P&ACT) Project @ PLIAS Resettlement

A free confidential service for Black, Asian and minority ethnic women and girls in North and West London who have or are experiencing domestic violence or other harmful practices. The service includes dedicated case workers providing intensive support, one to one emotional support and assistance with accessing advice on legal rights, housing and benefits matters, advocacy support, training and presentations on the impact of domestic and sexual violence. Although the project does not provide social care, they have been included in this report because of their ability to provide personalised and flexible help and illustrate good practice in this respect.

 [www.pliasresettlement.co.uk/services/pact-project/](http://www.pliasresettlement.co.uk/services/pact-project/)

 [@PLIAS01](https://twitter.com/PLIAS01)



Think Local Act Personal would like to thank all the organisations and individuals for their willingness to take part in this study and who gave their time so freely.

Think Local Act Personal (TLAP) is an alliance of over 50 national social care, health and housing partners committed to improving the delivery of personalised, community-based care and support. It brings together people who use services and family carers, central and local government, provider bodies and other key groups to work together to ensure people live better lives.

Relevant TLAP resources:

**[Making It Real](#)**

**[Personalisation and mental health](#)**

**[Directory of Innovations in Community-Centred Support](#)**

**[thinklocalactpersonal.org.uk](http://thinklocalactpersonal.org.uk)**

**[info@tlap.org.uk](mailto:info@tlap.org.uk) [@tlap1](#)**

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