Research into the needs of learning-disabled adults from Black, Asian, and other ethnically diverse backgrounds

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EQUALITIES & INCLUSION

1. Introduction & Background

Funded by Brighton and Hove City Council, this research project sought to assist the Council's development of a plan/strategy for the City's adults with learning disabilities from Black, Asian, and other ethnically and culturally diverse backgrounds.

The Council wish to ensure they are aware of areas of concern, and matters considered important for adults with learning disabilities and their families. Armed with this knowledge the Council can take them into consideration in developing the plan. The plan is being produced with support from other organisations in the city whose remit includes supporting adults with learning disabilities.

2. Research Methodology

Time and resources do not allow for a long qualitative or quantitative consultation methodology. Therefore, the methodology maximised achieving the consultation objectives within the context of a focused qualitative methodology.

Due to time and budgetary limitations, it was not possible to conduct a demographic stratification for the research sample. It was decided to conduct nine, one-to-one qualitative interviews with adults with a learning disability. The final sample was as follows:

Age:
7 = 18 – 24
2 = 25 – 35

Gender
5 = Female
4 = Male

Ethnicity
5 = Asian (Indian, Pakistani Bangladeshi, other)
2 = Black (Caribbean, African, other)
2 = Ethnic Arab (Middle Eastern: Syrian Iranian, Iraqi, Egyptian)

With the exception of two interviews, all the respondents had carers accompanying them when conducting these interviews.

In addition to the nine learning disabled respondents, three interviews were conducted with senior representatives from voluntary sector providers of services to adults with learning disabilities. None of the three organisations provided culturally or ethnical diverse focused

or specialist services, but all were well established in the City and well regarded for the services they provided. The three organisations were:

- Grace Eyre
- Stay Up Late
- Speak Out.

Service providers were included in the consultation to obtain their organisational perceptions of support and service need for learning-disabled adults who are from Black, Asian or another ethnically or culturally diverse background.

The interviews were conducted by four experienced members of the Trust for Developing Communities' Equalities team and took place between 19 December 2020 - February 5th. 2021. The research was conducted during the COVID-19 national lockdown of winter 2020-21. Due to social distance restrictions all interviews took place using video calling technology. It should be noted that the increase in the COVID-19 transmission during this period and the heightened general concern it prompted had an impact on the extent the project was able to engage respondents. Recruitment took longer than had been initially anticipated. Further as the pandemic was dominating many aspects of collective and individual life, for some respondents there was a slight reluctance to express certainty about what types of services they can expect or might be possible in the future. Such was the importance of and strict adherence to the most recent national lockdown, for some respondents thinking about and discussing past experiences or future hopes was challenging.

3. Summary and Recommendations

Perhaps not surprisingly the findings from this short consultation have highlighted a number of complexities as well as contradictions.

3.1. Consultation process

Although the consultation has provided highly useful information and insights it is perhaps the case that in-depth consultations with people with learning disabilities might benefit from an alternative approach - one that seeks, over time to get to know them and their lives better, building trust and a broader awareness of their lives and circumstances. The customary consultations like this, with objectives of establishing awareness, answers and solutions from a singular consultation process may not be the most effective with this cohort. Instead, a more gradual, on-going, socially engaging approach could yield improved outcomes. This is as opposed to asking a set of generic questions in a one-off exercise.

3.2. Awareness of services

Amongst respondents there was low awareness of the range of services available to learning-disabled adults. Naturally, this represents a significant problem for them in assessing need as well as opinions. Therefore, consideration should be given to how methods of marketing, promotion and communicating to these groups can be improved and made more effective. A more targeted approach may yield results. This might include community advocates for services, word-of-mouth techniques and use of diverse people/faces in advertising materials. It is understood that some service providers have already begun to research and undertake new approaches to marketing to attract ethnically and culturally diverse service users.

Consideration should also be given to working with a range of providers throughout the city who share the same aim of seeking to attract to their services learning disabled adults from ethnically and culturally diverse backgrounds. By pooling resources, ideas and initiatives and then pulling together common objectives it is possible that overall, the impact may be greater. Further, it is likely that producing some basic information in other popular languages would also contribute to increasing awareness.

3.3. Ethnically and culturally specific services

The study was not conclusive on the extent to which respondents felt there should be dedicated services for learning disabled adults from ethically and culturally diverse backgrounds. Nevertheless, there clearly is a view that culturally and ethnically sensitive factors should be assessed when services are being planned and considered. Moreover, provisions should exist that allows a person to receive ethnically and culturally sensitive support should they request it.

3.4.　　　Race and ethnicity: Learning disability

There was a belief among most respondents that in society there is a lack of understanding of the overall needs of people with learning disabilities. This lack of understanding can translate into narrow attitudes and perceptions and ultimately discriminatory behaviour. These circumstances caused many to feel that there was a stigma attached to having a learning disability. This in turn made some believe it was better for them not to venture too far into wider society. Further, many who did go out socially where consciously choosing to engage in areas where they would not feel different. Therefore, they socialised with other learning-disabled adults. Interestingly, race and ethnicity were not primary factors for many of those who sought to socialise. It did not appear to be the case that these respondents were seeking ethnically and culturally specific social engagement and activities. Instead, being amongst people they considered to be more like them and accepting of their learning disability appeared to be more important than the race or ethnicity of the people they socialised with. Therefore, as services are planned to engage more with learning disabled adults from ethnically and culturally diverse background, the messages should be more focused on learning disability than race/ethnicity.

3.5.　　　Families and carers

This consultation also found that amongst some respondents they felt that their family had difficulty in understanding and dealing with them and their learning disability. One respondent said their parents struggled to find a balance that reflected their concerns for their safety and well-being but also allowed the opportunity for them to go out, socialise and live the life they wanted. However, for some parents an additional concern for them was that race and ethnicity could compound the problems and discrimination experienced. Thus, their actions were a reflection of a desire to protect their child.

Some parents had felt concerned once their child became an adult and no longer had routine support from social services. When support from social services was expected to be minimal, some family carers were initially concerned they would find it difficult to meet all the needs of their now adult child. In a few cases this was still an ongoing concern. They felt alternative options and availability for support appeared to be in short supply.

Whilst many recognise the necessity of the reduction in social services support, it was also felt that efforts could be made to increase awareness and understanding about how they can identify suitable opportunities for support. This would create engaging and fulfilling lives as their children move into adulthood. Consideration should be given to ensure parents and young adults with a learning disability are supported to identify and devise personal goals and objectives that will contribute towards leading active and fulfilling lives.

There were a couple of cases amongst respondents where is it was clear that the family of the person with a learning disability had struggled to identify the best to support them. In these instances it would be prudent to ensure that all are aware of the services that are available to support individuals and the carers.

Those with learning disabled adults and children whose first language is not English are likely to require additional support. Unlike those who can understand and comprehend the processes and services available, those whose first language is not English will need to rely on others to ensure they have access to the information they need. However, as this condition is one that causes some degree of stigma in certain cultures, parents may not always be forthcoming in seeking help. A danger could be they do not seek to get help or receive support/advice from poor (e.g. inaccurate) sources. Therefore, efforts should be made to ensure that there are no language barriers that inhibit an accurate understanding of the range of services that exist to support adults with learning disabilities

3.6. Complex and profound needs

The issue regarding the needs of those with complex needs have been well documented. Nevertheless, it appears that there still exists a perception that more can be done to ensure there is a suitable range of services to meet the needs of this particular group. One respondent had complex needs and felt they had minimal contact with support services. No doubt this area represents an on-going area of concern for all stakeholders and one that requires further specific research and resources.

4. Main Findings

4.1.   Personal life and activities

Respondents were asked to give examples of how they typically spent their time, including examples of the things they enjoyed doing.

In discussing how they use their free time there was roughly a 50:50 split between those who had minimal socially active lives outside their immediate circle of family or friends, and those who routinely use one or range of a provider services offering social activities and wellbeing support.

Those who said they tended not to socialise much outside immediate family and friends gave a range of reasons, which included:
- Confidence levels
- Fearful of experiencing discriminatory attitudes or hostile behaviour towards them
- Preference and strong attachment to focusing on immediate family
- Receives guidance and support from a social prescribing service as well as a mentor
- Unsure of what services were safe and available to them
- Lack of services that reflect their (complex) needs

Also included in this response was a perception that their learning disability was not strictly speaking an obstacle to the extent to which they might want to socialise. Reluctance to socialise, reflected the fears, restrictions and barriers imposed by family members on them. In these cases, it was easier to succumb to the wishes and preferences of their family.

The respondents from the service providers when considering the extent to which they engaged with learning disabled adults from Black, Asian, and other diverse communities all stated that naturally they did. Nevertheless, each to varying degrees felt the relative low number of people from these backgrounds who used their services was for them a cause of concern. A survey conducted by one of the service provider respondents estimated the proportion of people from Black, Asian, and other minority ethnic backgrounds that there were in Brighton with a learning disability. They acknowledged the actual number of people from these backgrounds who used their service was substantially lower than the local percentage.

All three stated they were considering actions and initiatives that they hoped would raise awareness and attract services users from these backgrounds to their provisions. However, there was a degree of uncertainty of how successful these interventions might be, and a perception that significant increases in ethnically and culturally diverse services users could take time to achieve.

The respondents who were more socially active in their lives also listed a range of reasons why and gave example of what they liked to do. Also, there were mentions for each of the three service providers amongst those who liked to socialise. Activities respondents enjoyed included:

- Becoming involved and associated with different community groups and organisations (culturally specific and non-culturally specific).
- Meeting friends (usually others with a learning disability)
- Shopping, usually with friends
- Attending day and activity centres

A common factor in all those who expressed a desire and willingness to socialise appeared to be a determination not to overtly let the label of learning disability heavily restrict what they wished to do. Interestingly many in this category tended to avoid using or describing themselves as learning disabled. Although many carefully chose which activities and services they used to socialise, their rational was as much about what the activity offered as it was a service designed specifically for learning disabled adults. Nevertheless, it was noted most did not socialise widely with people who were not learning disabled.

All service provides spoke of and acknowledged the importance of providing quality and responsive services for learning disabled adults. Further, all felt it was important to take a holistic approach. They acknowledged the importance of health and social well-being, ensuring access to leisure, good accommodation, opportunities for employment, and to pursue interests as all essential considerations in meeting their needs.

4.2.   Services

Again, there was a mixed response to the extent to which the respondents stated they were using the learning-disabled specific services. Respondents mentioned only a limited number of specific services overall. They included Grace Eyre, Beach House, and unspecified day centres. The extent to which respondents appeared to lack significant knowledge of the range of services that are targeted specifically towards adults with learning disabilities was interesting to note. In some cases respondents were aware of the three service providers who took part in the study. However most had limited awareness and knowledge of the full range of services each provided. Perhaps not surprisingly, two or three respondents said they had no knowledge at all of the any of the three service providers who took part in this study.

Most respondents were unable to say whether the services they used were delivered by the City Council or other providers. Nevertheless, most who access services appear to be largely

satisfied with the services they used. It is worth stating that overall, the level of use across these respondents to the range of services appeared to be relatively small. A point made by two or three respondents was the perception that the services available were primarily targeted at those with mild to moderate learning disabilities. One or two respondents with more complex needs felt there were few if any suitable services that offered opportunities for interesting or engaging activities or broad social engagement.

In contrast, the service providers to the study collectively offered a comprehensive range of activities. These included arts activity, sports events, leisure pursuits, friendship and buddying opportunities, employment, volunteering opportunities and options to engage in special interest groups. Overall, the three service providers were focused on supporting greater autonomy and options for a more varied lifestyle for all learning-disabled adults. However, except for supported living services, the service provider respondents also acknowledged there were too few services for learning disabled adults with complex or profound needs.

For the service provider respondents whose core provision was care and support for independent living/housing most of their service users were said to be referrals from social services. However, collectively this group also stated their service users could typically be self-referrals – especially those with direct payments, they had come to them via word-of-mouth recommendation and the respective marketing and promotions of the providers. At this point, these respondents acknowledged that the marketing was not attracting adults from ethnically and culturally diverse communities to their services at the levels they would expect given the population size of these communities in Brighton.

4.3.   Ethnically and culturally specific services

When asked 'Should services be made available that specifically reflects the needs of people from an ethnic or culturally diverse backgrounds?' most were reluctant to give a definitive answer. The interviews explored the extent to which areas of discussion, experiences and circumstances of the respondents were related to their race and ethnicity as opposed to the main barriers in their lives being caused by their learning disability. When asked directly, most respondents were ambivalent or unambiguous. For many there seemed to be a reluctance or uncertainty that problems they experienced in their lives tended to be because of their race/ethnicity. The nature of the ambivalence was not easy to determine. However, there was amongst some respondents a definite sense of not wishing to add to their complexities of their lives by expressly bringing in issues concerning race and racism. Where perhaps this differed was amongst the respondents whose first language was not English. Moreover, the concern regarding race and ethnicity appeared to be more of an issue with the parents of these adults than the adults themselves. However, many

respondents expressly stated that they did not feel their race or ethnicity had any impact on the services they accessed or were offered and available to them.

Nevertheless, there was agreement amongst all respondents that when services are being planned, decision makers should take into consideration cultural factors and sensitivities of people from ethnically diverse backgrounds. It was felt that there should be options for all adults from ethnically and culturally diverse backgrounds to access services and support that specifically reflects their cultural needs and sensitivities. Again, this view was more pronounced when it was related to those families whose first language was not English.

The service provider respondents also expressed the view that consideration should be given to the needs of ethnically and culturally diverse people with learning disabilities. However, given the relatively low numbers of people from these backgrounds accessing their services, they currently did not have specific services that reflected ethnic or cultural factors or sensitivities.

The relative absence of adults with learning disabilities from Black, Asian and other ethnically diverse backgrounds was a concern for all service provider respondents. Most were unclear why there were so few people from diverse communities using their services. However, there was a strong feeling that low levels of awareness were more of a factor than specific decisions based on race and ethnicity. Although, this was not to conclude race and ethnicity was in no way a factor in low engagement. One or two of the service provider respondents felt addressing the issues of low engagement of ethnically and culturally diverse learning-disabled adults with services would require support and initiatives from the City Council.

4.4. Perceptions of future services

When asked what services respondents wished to see in the future, not all respondents felt they could give an answer. Many were unaccustomed to being asked for their opinion on matters that they are used to others being responsible for. For some their limited awareness and use of existing services prompted general and unspecific responses. They included,

- Create greater awareness and understanding of learning-disabled people amongst the public to foster a more inclusive society.
- Group activities and more engagement opportunities with other learning-disabled people.
- Guidance to understand the services and the social care system specially from the perspective of Black, Asian, and diverse communities.
- Parents' groups supporting those with young children.
- Information on services available in other languages.

- Services that support mental health wellbeing.
- Access to support and (support) workers who are able to speak the different language of learning-disabled service users and their families/carers.
- Reduce risk of social isolation by having more interventionist services, that put the rights and the needs of the person with learning disabilities ahead of all other consideration.
- Greater more effective work between schools and social services to ensure needs are assessed and understood early.
- Provide more services for people with profound and multiple needs. There are far few services for this group of people.

As stated earlier for some respondents the impact of COVID-19 lockdowns, specifically the restrictions placed on socialising made it difficult for some respondents to consider how they might be able to socialise in the near future.

Overall, learning disabled adults from Black, Asian and ethnically diverse background appear to have accepted the availability and access to services and support. The consultation did not uncover substantive areas of dissatisfaction with services. However, this is possibly because these respondents have a limited approach to the range of services they use, access and are aware of. Largely, the services appear to meet their immediate (but not all) needs. However, their lack of awareness of what other support and services exist for them negates their ability to make significant critical assessments of services and their needs. For most of these respondents, their race and ethnicity do not appear to be at the forefront of their concerns on matters of care and support.

End.
February 2020.