RESEARCH

Evaluation of the Social Services and Well-being (Wales) Act 2014: expectations and experiences of Black, Asian and Minority Ethnic service users and carers

The purpose of this report is to pull together the key guiding principles and activities of the Act, and understand and demonstrate the complex context in which it sits.

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Introduction and background

The Social Services and Well-being (Wales) Act 2014 sets out a vision to produce ‘transformative changes’ in social service public policy, regulations and delivery arrangements across Wales. It has 11 parts and is informed by five principles that set out a vision to produce transformative changes in public policy, regulations and service delivery. Aligned to it are structures, processes and codes of practice.

In Autumn 2018, the Welsh Government commissioned a partnership of academics across four universities in Wales and expert advisers to deliver the evaluation of the Act. The independent national evaluation, known as the IMPACT study, examines the implementation and outcomes of the Act through its five principles:

1. wellbeing
2. prevention and early intervention
3. co-production

4. multi-agency working
5. voice and control

The study does this by considering where the principles of the Act interact with the people or organisations for whom the Act should be having an impact; primarily, for individuals in need of care and support, for their carers and family members, and for the communities in which they live.

As part of the overall evaluation, extensive research was undertaken with service users and carers on their expectations and experiences of the Act. **Evaluation of the Social Services and Well-being (Wales) Act 2014: expectations and experiences**

This short report based on a sample of ten people contains a number of very powerful and challenging reflections on people's experiences within the social care system. It is not possible to draw general conclusions based on these experiences, but it is important to recognise the heartfelt messages contained within the perspectives that now follow.[footnote 1]

The aim of this document is to provide a focus on their lived experiences to ensure that their voices are heard within the overall study.

Research with Service Users and Carers from Black, Asian and Minority Ethnic Backgrounds

Detailed information on the methodological approach for the qualitative research undertaken with service users and carers on their expectations and experiences of the Act is available in the main report. The research used purposeful sampling, a technique which involves identifying and selecting individuals or groups of individuals who have in-depth knowledge and/or experience of the phenomenon of interest (Creswell and Plano Clark, 2018), participants were recruited via a range of gatekeeper organisations (Singh and Wassenaar, 2016). These gatekeeper organisations were pivotal in the data collection process and ensuring the voices of those receiving care and support were heard.

In this instance, we worked closely with EYST Wales (http://eyst.org.uk/). Ethnic

Minorities and Youth Support Team (EYST) is the leading Welsh charity that supports Black, Asian and Minority Ethnic young people, families, individuals and community groups living in Wales to contribute to, participate in and be valued members of Welsh society. EYST provides a range of services to achieve this aim, including one-to-one support; family support; advice and support for refugees, asylum seekers and EU migrants; volunteering opportunities; supported employment; and capacity-building. It also challenges and counters negative stereotypes about racial diversity, and increases awareness and understanding about the diverse communities that live in Wales.

EYST brought together an online focus group of 10 Black, Asian and Minority Ethnic older people and carers of older people, and facilitated the session. Evidence on the experiences of care and support was sought from these key informants which when brought together highlighted key characteristic patterns. It is important to note that the data collection took place during the COVID-19 pandemic, in September 2021. The session was structured around three key questions, but the discussion flowed very freely and naturally, and was certainly not limited to these:

- Can you tell us about the care and support you receive / the person you care for receives?
- Over the past 12 months, can you tell us whether there have been any changes in the care and support you receive / the person you care for received?
- What impact (if any) have these changes had on you as an individual / carer / family member?

We had hoped to explore people’s experiences over time, and to try to understand whether the implementation of the Act (from April 2016 onwards) had a material influence on people’s well-being. It would be fair to say that we were not able to explore these issues during this group. Principally that was because participants remained very clearly focused on their recent encounters and experiences of the care and support system.

This report provides an account of the discussion structured around the principal themes that emerged during the focus group. These key themes are supported by comments made from participants, but in a way that will not identify any of the people who took part. It is important to say that these are the perspectives of the people who contributed to the discussion, we make no claims about whether these are in any way ‘representative’ of others. What they are, and they should be understood as such, are the lived experiences of carers and service users. They are accounts of their interactions with the system, and their responses to that system.

Main issues emerging from the discussion

This section identifies four key issues that were part of the discussion. Under each is a series of sub-themes using the voice and the words of participants, providing detail on their experience and how they had responded to the interactions they were having with the social care system (the headings of these sub-themes are derived from quotations from participants and denoted by statements which are in bold and italics). It is quite deliberate that this section focuses heavily on what individual participants said, we have not overlaid interpretations or analyses to allow their voices to resonate.

Overall sense of being let down by social services

There was an overall sense that people had been let down by social services, and these feelings were especially acute given that people had often tried to avoid needing to use social services. The disappointment that is evident from the following quotations, is evidence of the disconnect between the expectations that people had of the support they wanted to receive, and what they actually received.

> “ “When I needed support after years of coping without, it [the support I needed] wasn't there for me.”
>
> “ “I said ‘I never asked you anything about carer support, but now I need it’ because she [mum] had a broken hip four months ago and one month ago she had a fractured arm and she needed support when she sat and lay

> down. I always help her and now my back is aching. So I called and I said I needed help for 24 hours, but they said sorry we can’t help at the moment with what you need, we’ll put her name down and we’ve been on a waiting list since.”
>
> “ “There is a lack of communication regarding whether we were speaking to the right people. I've been able to do this caring role for years but now things have changed and I need support, and I'm coming to social workers but I'm not getting the support I need. There's an assumption that family members will continue with support I'm not can't always be the case.”
>
> “ “When I was raising those concerns, social services were saying there is nothing that we can do and we’ll wait and see.” ”

> “ “We only get in touch with them when we really need them, when we need them the most, where are they?”
>
> “ “Another sad, well I don’t know what to call it, frustrating, sad example. I myself am disabled, my young son is a carer, unpaid carer for me. When I tried to get in touch with social services when he was admitted into hospital, social services ignored my requests for help. They also refused other professionals’ request that I needed extra help at home because they realised my son wasn’t able to care for me because he was in hospital. They didn’t even contact me then.” ”

Lack of time for caring within the care system

People acknowledged that the social services system is under significant pressure and there are challenges everywhere when it comes to having enough staff. What was difficult for participants to reconcile was the lack of compassion and empathy that they experienced, from a system ostensibly designed to support and care for people in need. They did not place this criticism at the feet of individual workers as they recognised how ‘time-poor’ they were, but did want a better response from the care system which had not shown care towards them.

> “ There is insufficient capacity or resource in the system to show compassion
>
> “ We are not seen as equal partners. We’re caring for our loved one at their most vulnerable time in their life and, and I sometimes feel there is no empathy because I, there is, the social worker was saying that they are under resourced, they haven’t got the funding resolved and they are over stretched, but you’re caring for a loved one at that time and you need someone to be compassionate, to show empathy, to give you that time for you to understand the process, but it’s not there, it’s not available. ”

> “ “There is a massive lack of responsiveness to simple requests”
>
> “ “It takes very many months for the most simple requests to be heard and listened to and acted upon.”
>
> “ “Despite having professionals who are familiar with the social care system in our family we struggle to work through the system when we needed to.” ”

People’s voices are not heard, and they have no control

There were many concerns raised over the fact that people feel that they have no ‘voice’ in the system, and they are not listened to in any meaningful way. A number of consequences of this were identified: that this lack of response leads to a feeling of having to ‘battle’ to be heard; that there are concerns that raising complaints will lead no-where or will result in worse care and support for their loved ones; and that people feel disillusioned about what will happen to their family members.

> “ “I needed to battle to have my voice heard but it wasn't and I had no

> control”
>
> “ “We plod on and it comes to this and we can’t manage and she asked me but why, why it took an email from the professional for them to take an action? She was asking them, asking them for a year and a half before she completely gave up because no one was listening.”
>
> “ “There was a battle, there was a battle to receive that support from social services.” ”

> “ “I've become very disillusioned, saddened and apathetic because no one listens to me”
>
> “ “I do want to echo my sadness really and my frustrations regarding social services not bothering to phone back when they say they will. To be honest it’s just tiring because nothing has changed, nothing has improved since I last gave my feedback a couple of years ago, you know I don’t see the point anymore, I really don’t.”
>
> “ “But as I said like nothing surprises me anymore and I just don’t bother contacting them. I keep things as they are because I know it would be a waste of my energy, my limited energy and my limited time.” ”

> “ “Who stands up for the most vulnerable people?”
>
> “ “When you are at your most vulnerable and your complaint is not upheld, it is difficult and undermines you. These impacts ripple across families. There is no way to complain independently without professionals closing ranks. No one stands up for the most vulnerable people in these circumstances. Who are our advocates? Where does my voice go? Who hears me? Who safeguards vulnerable people? Everyone goes through challenging times, and this is exacerbated for vulnerable people from ethnic communities.”
>
> “ “It makes me feel that there is no point in contributing. No one listens. And

> if you are in any way assertive, they mark you down as a troublemaker.” ”

> “ “We have had to pretend to be less upset than we really are to secure the ongoing support of social services”
>
> “ “I had to assert my authority even though I didn’t feel I had any because if you are over-assertive the social worker won’t turn up, they won’t, they won’t come back, they won’t engage with you if you’re over assertive, you have to play down that in some way and almost become like a robot and don’t show emotion for them to provide support.”
>
> “ “It is when you are at your most vulnerable and you need the support from a professional and then they say you have to go through the complaints procedures and you’re still not listened to or actions followed it is very soul destroying. I’ve been a carer most of my life but with my mum knowing how proud she is and when no one listens to a vulnerable person the impact just ripples right across the family, not only for my mum but for my children, the grandchildren as well. There seems to be, there’s nowhere to complain and have those concerns listened to and acted upon it seems so that everybody closes ranks on you, and that’s it you can’t go any further than you making that complaint and that’s it.” ”

Impact of racial stereotyping on care and support

Many of the above themes shape and are shaped by the impact of racialisation faced by many of the participants. Participants reflected on more troubling experiences they had had which made them call into question some of the assumptions that were being made about them, their ethnicity, and their cultural background. There were real concerns that on too many occasions, the colour of their skin had been a consideration in their interactions with the system.

> “ “Stereotyping based on ethnicity has been part of my experience”

> “I believe that we do get alienated very often by certain organisations, because all they do is they just kind of judge you off how you look and like what colour your skin is and how you are able to articulate words. It’s never about what the actual problem is, cos I believe when we go to these organisations it should be about the support you can get from them and not who you are, where you come from, what your religion is and all of that and like this. This racism is everywhere but in organisations it becomes abundantly clear when other people are getting a lot more support and a lot more help and they actually benefit from these services whereas some people they are just left out, sort of left aside and they’ll kind of deal with us when they can, when they’ve got time, when they can do this, it’s always excuses when it comes to us and that’s just my opinion on it you know, everyone’s story is different but that’s just how I see things.”
>
> “I did ask my social worker one day whether the way that I’ve been treated has got anything to do with the colour of my skin and they just said to me ‘no, why would you think that?’ I was receiving, or not receiving the help that I needed, that my son needed and even complaining to higher up there is only one way, you know one or two ways to complain and even the managers there didn’t return phone calls. So it just seems like the whole, everybody was not doing what I thought social services were doing. And I did think it might be because of my name and the colour of my skin.”
>
> “I think we are judged as soon as we are seen. You can’t tell from my name or my mum’s name but as soon as the social worker turns up to my mum’s home there was like a fear on her face. And the way, when you live with racism all your life you can just pick it up from a nuance from the way that they look, from the way people look at you. From the tone in the voice, the way they ask, the way people ask you questions, because you’ve lived with it you can pick it up.”

> “Assumptions are made about Black, Asian and Minority Ethnic families

> which should not be made”
>
> “ “I’m one of ten children…so the first assumption the social worker made was that we would be able to manage because they said, ‘oh you’ve got a big family so you’ll be able to manage’. I said that wasn’t the case because there is only me, myself, I was an active carer, an unpaid carer.”
>
> “ “I think race has a big part to play in it because I often think that when it comes to bigger families, racialised families its assumed that they are self sufficient, that they don’t need help, that they can do everything, that they can fit these cultural social needs of this particular person. And the assumption that manpower equals care I think always detrimentally affects people of colour because we may come from big families but if only three or four people are working and supporting everyone else then that means that even just one extra person breaks down the very very tentative balance we had in place.” ”

Towards a conclusion

This short report contains a number of very powerful and challenging reflections on people’s experiences within the social care system. It is not possible nor sensible to draw general conclusions based on these experiences, but it is important to recognise the authenticity of the perspectives provided. There are four themes around which the main points converge.

1. There was an overall sense that people had been let down by social services, and these feelings were especially acute given that people had often tried to avoid needing to use social services.
2. People acknowledged that the social services system is under significant pressure and there are challenges everywhere when it comes to having enough staff. What was difficult for participants to reconcile was the lack of compassion and empathy that they experienced, from a system ostensibly designed to support and care for people in need.
3. There were many concerns raised over the fact that people feel that they

have no ‘voice’ in the system, and they are not listened to in any meaningful way.

4. Participants reflected on troubling experiences they had had which made them call into questions some of the assumptions that were being made about them, their ethnicity, and their cultural background.

We recognise that these reflect only the perspective of the individuals we heard from. We amplify these voices here because they provide important insights into where the system may be most challenged in being able to respond to people in a culturally sensitive and appropriate way.

It is important to recognise the resonances and alignment between this report and the broader document exploring service user and carer perspectives, alongside the differences. The points below are made in conclusion to that report, and those that are re-presented here to demonstrate that many of the issues raised in this document cross over with the main report.

- Service users and carers feel there is still a distance to travel before the aspirations of the Act are fully realised.
- It is important to recognise the value of hearing directly about the lived experiences of others as one of the key foundations for improvement which is at the heart of the Act.
- The ‘journey’ towards the full implementation of the Act is not yet complete, and the system clearly needs to work more effectively to fully realise the potential of all of the principles working together in harmony.
- For some people during the pandemic, the principles have never felt further away from their day-to-day experience of social services. Moving these closer to people will be difficult to achieve, but there has never been a more important time to do this than now.
- Some service users and carers, however, are growing increasingly impatient for change. Recognising and valuing this is now key to the work to further embed the Act and its principles.

However, it must be noted that they very specific experiences of Black, Asian, and Minority Ethnic service users and carers are different in one obvious respect, that the ethnic stereotyping and prejudice they have reported through their own experiences is unique to them.

We want to finish with the thoughts of one of the participants. Towards the end of the discussion, the conversation turned to what would happen next with the information that people had provided. One participant in particular reflected on the tension between their story being told or not. They were initially worried that they may be identified from the narrative and were concerned about that. In the next moment though, they came to recognise that in in order to bring about a different set of experiences for others, their story had to be told and their voice had to be heard. It is in that spirit that this report concludes:

> “ “I do want it to be used actually, use it. Use it you know because I haven’t had good treatment from social services. Use it, use it…things need to change. Sorry I just as I’m talking I’m reflecting and I’m thinking this is what I didn’t want, I didn’t want to be identified, and as I’m talking I’m saying if that’s what needs to happen for change, yes then tell my story, use my words. I think it makes sense, I think that’s the right thing to do…” ”

Footnote

[1] It is axiomatic that minority ethnic populations are heterogeneous, with differences both within and between groups, and as Saltus (2020) states, attempts at categorising such populations has and will always be problematic (**Holding On to the Gains**). Similarly, Welsh Government’s draft Race Equality Action Plan states: “The terminology used to describe a very diverse group of people that often share very little in common other than the discrimination they encounter is often a contentious issue. There were several debates on the terminology that should be used in this Action Plan. There was little agreement on what the most appropriate terminology should be. Therefore, in keeping with EYST’s usage and in line with Welsh’s Government’s draft Plan, the term ‘Black, Asian and Minority Ethnic’ (to describe people, populations and groups) will be used in this summary. EYST notes: ‘We recognise that this is a contested term and that others prefer to use “BME”, “Black” or “Ethnic Minority/ Minority Ethnic” or “POC”/ People of Colour”. We will discuss and review the preferred terms to be used within our practice on an ongoing basis, and also note that EYST team

members, participants and partners may not all agree on their preferred terminology.’

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Views expressed in this report are those of the researchers and not necessarily those of the Welsh Government.

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