



Core Capabilities Framework for Supporting Autistic People Consultation - June 2019

A Healthwatch South Tees Response

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Introduction

A new Autism Core Capabilities Framework is being developed to provide workforce training programmes aimed at improving the lives of children, young people and adults with autism. It is funded by Health Education England and is due for completion during summer 2019. Skills for Health is the lead organisation, requiring consultation feedback by 1 July 2019.

Local Response

Healthwatch South Tees (The operating name for Healthwatch Redcar & Cleveland and Healthwatch Middlesbrough) and Middlesbrough Voluntary Development Agency are offering the following comments on the Core Capabilities Framework for Supporting Autistic People*.

The contribution is based on recent and relevant work undertaken by Healthwatch South Tees as part of our ongoing programme of work.

Scope of the Framework

The voluntary and community sector acknowledges the excellent practice to co-produce the framework with autistic people and their families and recognises the requirement for capabilities to extend across the whole context of people's lives. This is very much in line with the values and principles across the sector, recognising the role of the community, in addressing issues such as isolation and increased vulnerability, and recognising the positive impact community engagement this has on people's lives.

A predominant factor within this approach is the grounding within the social model of disability. Community intelligence tells us the nature of autism is so diverse that having a choice to access community provision or activities (as well as specialist provision) is very important to autistic people. Adjustments and better awareness in creating autism friendly opportunities goes a long way to widen the scope and increase the quality of life for autistic people's engagement in community living.

It is encouraging that the framework recognises the increased vulnerability of undiagnosed people. A high ratio of those accessing a wide range of community and voluntary services could be described as some of the most vulnerable in society. It is likely that many individuals have undiagnosed ‘hidden’ disabilities that impact on their ability to cope effectively within everyday life. Many adults, historically, missed out on any form of diagnosis. By the time ‘autism’ was given more recognition, many developed coping strategies to ‘hide or mask’ typical traits but struggle with a diverse range of significant issues that severely impact on their quality of life. Our recent consultations have also revealed that getting a diagnosis for autism in children often remains a challenge and that assessment processes can take a very long time. We also now know that presentation of autism in girls is often misdiagnosed and/or missed and that many go undiagnosed. Going forward, identification, assessment and diagnosis of autism (and any comorbid conditions), early on, is key to meeting needs, promoting wellbeing and opening access to development and learning opportunities.

The impact of moving towards a more autism friendly society by increasing understanding and tolerance, as well as valuing and encouraging diversity, is likely to positively impact on the increasingly emerging issues around mental ill health. Poor mental health and related conditions such as depression and anxiety are impacting on more people accessing voluntary and community provision. Poor mental health can frequently co-exist with hidden disabilities both diagnosed and undiagnosed, not as a part of, but due to the challenges of everyday life. This has a knock-on effect for those in the caring role, who often feel as isolated and helpless as those with disabilities. The strong message from parents and carers during our recent NHS Long Term Plan focus groups was:

*“The **attitude** of those in contact with people with hidden disabilities, and their carers, can make a huge difference. People might not always get it right, but what matters is they want to get it right and make steps to do so.”*

Three-Tier Approach

The three-tier approach, building on and grouping core learning and capabilities makes much sense and is in line with intelligence from parents, carers and young people engaged in our work. Healthwatch Redcar & Cleveland undertook a study with parents and carers highlighting issues around children's unmet needs relating to none recognition or misinterpretation of behaviours and presentation of autistic children. Autism assessment had therefore not taken place or parents were told the "autism pathways were closed". Where assessments were proceeding, these were sometimes taking years and creating significant hardship for families. Parents told us that even with a diagnosis, this didn't guarantee people with a duty of care always effectively meet the child's needs. Those without a diagnosis were impacted the worst. One young man told us he didn't get diagnosed until his teens, he got picked on (bullied) at school and was scared most of the time. He had poor relationships with his parents because they didn't understand him. He has suffered badly with anxiety and getting a diagnosis earlier would have made things much easier for him and his family.

In relation to the links between the tiers, it is essential for professionals, specialists and any others working with autistic people, to work across the tiers to ensure consistency in providing a personalised and needs led approach. Parents expressed their concerns that once a specialist had identified specific needs and support strategies, these were not necessarily applied across the full contexts of the child's life. Education was a significant factor here and one of the key recommendations from parents was that professionals take more responsibility for working together to ensure core areas of help and support continue to impact on the overall wellbeing of the child. All partners should take equal responsibility where EHCPs are in place, but often fail to do so. The recommendation from Healthwatch South Tees to the NHS was for health and social care to work more closely with other providers, especially education.

Reasonable Adjustments

The framework has highlighted the needs to make reasonable adjustments to meet the needs of autistic people. Our consultation with parents and carers revealed that a common misconception was that reasonable adjustments didn't refer to policies and procedures and that 'treating everyone the same' meant equality compliance. This was often the case with school behaviour policies and parents described children having eight to 10 detentions pending and frequently spending days in isolation. In transition to adulthood, our work with 18 - 25's revealed DWP were consistently failing to make reasonable adjustments to Claimant Commitments for undiagnosed young people, rendering them unable to meet required expectations, often resulting in them being sanctioned. Those with a diagnosis were not expected to aspire to work and therefore nothing was required of them. Talent Match Middlesbrough, led by a panel of young people (diagnosed and undiagnosed members) have worked with DWP at the local job centre to create a local procedure to recognise and begin a conversation about consideration of a more personalised approach. The procedure is called Requesting Adjustments to Claimant Commitment, which highlights adjustments to individual commitments based on needs and personalised approaches. Monitoring of this work suggests it is working well and there could be opportunities to escalate this to adults as well as roll out regionally and nationally.

These examples highlighted how making reasonable adjustments to policies and procedures for hidden disabilities can be challenging when these are embedded in traditional institutional culture and ethos. Consideration of exploring how deep-seated beliefs associated with our cultural norms can impact on perceptions of what is a reasonable adjustment and how we move this to be person centred might be a useful way of changing thinking around this area.

Meaningful activity and independence

The voluntary and community sector offers a range of inclusive opportunities for meaningful involvement including volunteering, paid work, peer and group support, campaigning and driving positive change. This applies within the sector and across sectors in partnership working. Very often, the voluntary and community sector takes the lead in this, championing a bottom up approach by supporting autistic people, those with learning disabilities and their carers to come together and lead the change agendas that have the greatest impact.

Summary

The Core Capabilities Framework is an excellent piece of work providing an extremely comprehensive and detailed outline of competencies across three tiers. There is clear potential for improving the lives of people with autism/learning disabilities both diagnosed and undiagnosed, and their carers.

The framework is considered very ambitious, which isn't a criticism but an observation in terms of the extent to which it can be implemented.

From the perspective of the voluntary and community sector, there may be scope for implementation of all three tiers across a diverse range of provision, from commissioned health and well-being services to community groups, social and leisure activities. It is important therefore, to recognise how the ever-changing landscape of the voluntary and community sector impacts on the lives of autistic people and to ensure opportunities exist for the sector to develop in line with the framework specifications.

The sector is also unique in being able to develop close relationships as a foundation for better communication, open and honest conversations, based on lived experiences. It is these case studies and stories that have the greatest effect on wider communities to change attitudes and perspectives and cut through deep-seated beliefs to embrace positive change.

Please use the contact below for further discussion:

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