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**Royal College of Occupational Therapists submission to adaptations for autistic children and young adults with behaviours that challenge consultation**

This submission is made on behalf of the Royal College of Occupational Therapists (RCOT), the professional body for occupational therapists across the UK.

The submission is made in response to consultation on adaptations for autistic children and young adults with behaviours that challenge.

Further information on any aspect of this response can be gained by contacting the College.

**Submission**

Please see below for comments regarding the consultation paper:

1. This paper is a timely and important resource.  It can often be difficult for occupational therapists to gain agreement for adaptations that support behavioural, cognitive and sensory needs, rather than purely physical needs; this is often very disabling for young people, their families and carers.
2. It is preferable, and less judgemental, to refer to ‘behaviours that challenge’ rather than ‘challenging behaviours’.  This makes it clear that it is the perception of the behaviour that is deemed to be challenging, rather than the intention of the behaviour itself.  This is subsequently less stigmatising.  It is important to make this distinction explicit within the document.
3. Regarding the above comment, the title could be changed to 'Adaptations to improve quality of life for autistic children and young adults' and their families’.
4. The document would benefit from adapting the tone and language used within to reflect the child or young person's voice and to highlight that behaviour often comes from low well-being and a lack of skills to express their needs in a conventional way.
5. The document would benefit from focussing more on how adaptations can enable occupational performance, independence and productivity, rather than simply focusing on reducing ‘challenging behaviours’.
6. It is positive that Adaptations without delay <https://www.rcot.co.uk/adaptations-without-delay> is referred to along with the specialist role of occupational therapists in specifying necessary and appropriate adaptations for young people with complex needs.
7. It would be really helpful to include a discussion and case studies around the use of door and window locks to ensure a person’s safety.  Several occupational therapists who have contacted RCOT have reported working with young people for whom escaping from home or climbing out of windows has been a significant risk.  The wording of the DFG ‘purposes’ is about enabling access to the home, so adaptations that seek to restrict movement can be contentious – even if they are felt to be necessary to keep a person safe.  RCOT have also been informed about objections being made regarding proposed changes to door and window opening/locking mechanisms which were deemed to interfere with a building’s security and fire safety.  It would be very useful to include a statement about the importance of personalised risk assessments in these cases; also, a recognition of the need to balance the likelihood and severity of risks to the individual/household if proposed adaptations are completed, versus the likelihood and severity of risks if the adaptations aren’t completed.  It is not person-centred if there are blanket decisions made on the basis of security, fire safety and restricted movement only.  Also, the need to consider if less restrictive interventions / adaptations might be able to resolve the presenting issues should be included.
8. Overall, this document could be seen to portray children with Autism negatively. This consultation is an opportunity to start to reframe the language used by some people/organisations to describe the difficulties for children and young people with Autism.
9. It is important to state that some children/young people spend much of their time in a highly distressed or anxious state and they learn to use maladaptive physical and sensory behaviours to communicate this. These behaviours often challenge the adults working with them if they are not supported effectively.
10. The terminology ‘hurting others’ suggests that the function of this behaviour is to hurt others - this is very rarely the case. This term could be replaced with "Injury to others".
11. It would be useful to add another section entitled ‘Flight behaviours’ (e.g. absconding, climbing, hiding, withdrawal).
12. Pica should be referenced in the document along with an acknowledgement that this is a separate diagnosis and condition that needs to be carefully monitored so it is considered seriously by anyone reading the guidance (particularly given recent deaths).
13. ‘Distress behaviours’ (screaming, grounding, stripping, urinating, defecating, vomiting, spitting, repetitive behaviours) should be included.
14. Sensory differences are part of the diagnostic criteria for Autism. This should be acknowledged.
15. Some children do not bang their heads to gain sensory input, as this behaviour is often to block out pain or to communicate high levels of distress.
16. Multi-disciplinary/multi-agency assessment and intervention planning is often required to ensure the children and young peoples’ needs and rights are fully understood and that the adaptations are appropriate and proportionate to meeting their needs.
17. Early intervention is paramount to ensure the environment is adapted before the child/young person or their family members are at significant risk of harm.
18. It would be important to acknowledge that often adaptations to the home involve some aspect of DoLS/ convention of human rights. There needs to be a link to safeguarding and a multi-disciplinary assessment and consideration of the child/young person’s best interests if their independent movement and choices are being restricted.
19. Any reference to a safe space or other adaptation that limits freedom of movement should reference to Deprivation of Liberty Safeguards (DoLS).
20. Assessments for adaptations for a young person with Autism should be holistic and involve multi-disciplinary professional input in addition to contributions from the young person wherever possible and those who know the young person best.
21. A behavioural approach is not always considered (by many professionals with expertise in autism) to be appropriate, sufficiently evidence-based or robust. Functional assessment of behaviour is not a tool used by many professionals. The term "behaviour modification" is therefore somewhat outdated.
22. Additional examples of adaptations which could be used to reduce other unsafe seeking behaviours would be useful e.g. installing a swing.
23. The ‘Provision of wet room and wash/dry toilet’ case study could be improved/adapted as the adaptations appear to be linked to the young person’s physical needs rather than directly related to his Autism.

**Summary**

In summary, the College is broadly supportive of the document as it can often be difficult for occupational therapists to gain agreement for adaptations that support behavioural, cognitive and sensory needs, rather than purely physical needs which is often very disabling for young people, their families and carers.

**About the College**

The Royal College of Occupational Therapists (RCOT) is pleased to provide a response to this inquiry. RCOT is the professional body for occupational therapists and represents over 33,000 occupational therapists, support workers and students from across the United Kingdom. Occupational therapists work in the NHS, Local Authority social care services, housing, schools, prisons, care homes, voluntary and independent sectors, and vocational and employment rehabilitation services.

**Contact**

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