

Children and Young People Committee
COH19

Inquiry into Children's Oral Health

Evidence from Down's Syndrome Association



Consultation Response:
National Assembly for Wales review of
'Designed to Smile' Programme & The
Oral Health of Children in Wales.

**Submission by the Down's Syndrome
Association
September 2011**

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The Down's Syndrome Association (DSA) provides information and advice to an estimated 60,000 people with Down's syndrome, their families and professionals across the UK, 4,000 of whom live in Wales. We are a Registered Charity established in 1970 and have a membership of over 20,000, 1,750 in Wales. We are at the forefront of ensuring equitable access to all forms of health, education and social-care provision for children and adults with Down's syndrome.

Down's syndrome is a genetic condition which can affect a child in a variety of different ways and to varying degrees. In addition to an underlying learning disability (which can range from mild to more severe and complex), children with Down's syndrome are likely to experience a range of additional physiological and associated health conditions which may need additional, specialist, health input. Equally importantly, a generic primary health care service must be geared-up to meet their needs.

The Association is an information provider and signposting organisation and campaigns on behalf of people with Down's syndrome and their family carers, as such, we do not have first-hand knowledge of take-up of the various elements of the scheme on an area by area basis. However, we would wish to record the following support for the principles and aims of the Designed to Smile programme:

Early intervention is broadly recognised as being an effective use of resources. This is especially the case for children with Down's syndrome, where a generic early intervention programme can assess the needs of this population and identify those children who might require additional, specialist, input. Without this provision, children's needs may go unrecognised and require more costly and invasive remedial intervention at a later stage.

The routines of good oral health need to be established in babyhood / early childhood. Children with Down's syndrome, who may have a particular likelihood of developing oral

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sensitivity, need to be introduced to oral hygiene routines from a very early age, so that this becomes an established part of their daily lives. Parents may need additional advice and practical interventions that can help them overcome their child's additional learning needs and sensitivity to procedures that involve touching and accessing the mouth. A universal initiative such as the Designed to Smile programme, which is accessible to children with additional needs is therefore to be welcomed.

Children with Down's syndrome can present with a smaller mouth cavity which can pose certain additional challenges in ensuring all areas of the mouth, gums and teeth are kept healthy. Some children with Down's syndrome, due a suppressed immunity, may have susceptibility to developing infections, For others an underlying congenital heart defect, (which may or may not have been the subject of corrective surgery) may mean that their dental / oral health care needs a more tailored management. Again, good oral health and hygiene routines are especially important for these more vulnerable children.

Some children with Down's syndrome may have additional support needs connected to their history of i) being tube fed or ii) problems with eating, drinking and swallowing connected to oral hypersensitivity and subsequent psychological / behavioural issues.

Children with Down's syndrome are visual and kinaesthetic learners. Therefore an education approach that involves hands-on, practical, intervention is best suited to their learning needs. Children with additional needs also benefit from the reinforcement of repetition and so an aspect of the Designed to Smile programme that involves intervention which is repeated at regular intervals and in a child's usual environment is to be welcomed.

We would especially welcome a professional education component of the Designed to Smile programme that provides dentists and associated health and school-based professionals with practical skills and resources to make their provision as accessible to children with a learning disability as possible. We know from feedback to our helpline that many parents struggle to find a dentist that has the additional skills to meet the very specific support needs of some children with Down's syndrome who have complex needs. In some cases a child's anxiety / inability to cooperate with a dentist / hygienist necessitates the use of sedation / anaesthetic for even minor treatments. Understandably, measures that might reduce this reliance on sedation would be very much welcomed.

We particularly welcome the establishment of Consultant posts in special needs dentistry (e.g. within The Aneurin Bevan Health Board) although we note that this is not yet commonplace across Wales. Whilst some regions have demonstrably included their population of special needs children in the programme, we would propose that the expertise these specialist posts represent within Wales be used to refine the Designed to Smile programme, to ensure that it is delivered in an accessible way in every area across Wales.

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Given that the programme has had only a limited period of time to become imbedded across Wales (and its staggered implementation meaning that certain regions have had less time than others to develop local strategies to ensure its delivery) we would hope that continuing funding will be made available to ensure its longer-term objectives are met.

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