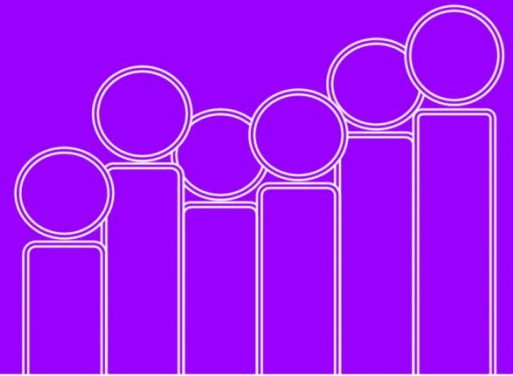




Making Reasonable Adjustments to Dentistry Services for People with Learning Disabilities

Sue Turner, Eric Emerson and Gyles Glover



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Sue Turner initially trained as a nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability teams. Sue was the Valuing People Lead for the South West Region for four and a half years, initially job sharing the role with Carol Robinson. During this time, Sue developed the health network in the South West and introduced the health self-assessment to the region. She later worked closely with the Strategic Health Authority on its implementation. Sue is now leading on the Improving Health and Lives project for the National Development Team for Inclusion.

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Acknowledgements: We would like to thank all those who contributed to this report by sending us examples of reasonable adjustments and good practice.



Introduction

The Learning Disabilities Public Health Observatory (LDPHO: www.ihal.org.uk) is one of the small number of specialist public health observatories that cover England. It was established by the Department of Health in April 2010 in response to a recommendation made by the *Michael's Inquiry* into access to health care for people with learning disabilities.¹ The LDPHO is a partnership between the North East Public Health Observatory (the contract holder), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion.

Learning disability refers to a significant general impairment in intellectual functioning (typically defined as having an IQ of less than 70) that is acquired during childhood.² In England approximately 1.2 million people have learning disabilities (300,000 children, 900,000 adults).³

People with learning disabilities have significantly higher rates of mortality and morbidity than their non-disabled peers,⁴⁻⁶ including having poorer dental health and facing significant barriers to accessing appropriate services.⁴ One in three adults with learning disabilities and four out of five adults with Down's syndrome have unhealthy teeth and gums,⁵ with adults living with families having more untreated decay and poorer oral hygiene and adults living in residential services having more missing teeth.⁶ Compared to older adults in the general population, older adult participants in the 2005 Special Olympics were less likely to have 21 or more teeth and gum inflammation was common.⁷

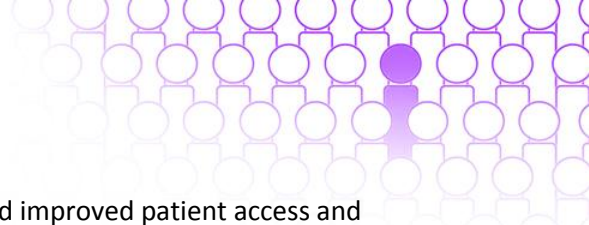
The importance of actively addressing the health inequalities experienced by people with learning disabilities has been highlighted by recent reports from: the Disability Rights Commission;⁸ Sir Jonathan Michael's independent inquiry into the healthcare of people with learning disabilities;¹ the Parliamentary, Health Services and Local Government Ombudsman;⁹ the House of Lords and House of Commons Joint Committee on Human Rights;¹⁰ the Department of Health;¹¹⁻¹⁵ Mencap.^{16 17}

It is a statutory requirement under the Equality Act 2010 and the NHS and Social Care Act 2008 that public sector agencies make 'reasonable adjustments' to their practice that will make them as accessible and effective as they would be for people without disabilities. Reasonable adjustments include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.¹⁸⁻²² A database of 'reasonable adjustments' made by health agencies is maintained by the LDPHO.^{23 a}

This legal duty for health services is 'anticipatory'. This means that health service organisations are required to consider in advance what adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities attempt to use health services to put reasonable adjustments into place.

The recent NHS Equality Delivery System provides a framework of questions for all parts of the health service in relation to all protected groups. Its recently published 'Grades Manual' sets out four overarching goals and invites NHS organisations to identify evidence about their progress in

^a <http://www.improvinghealthandlives.org.uk/adjustments/>



relation to these.²⁴ The first two (better health outcomes for all, and improved patient access and experience) ask healthcare organisations to look for evidence of how members of protected groups (the term used in the Equality Act) are faring in terms of their health and their use of health services. Answering these questions comprehensively, systematically and regularly requires that health service information systems identify people in the protected groups so comparisons can be made. In addition to exploring substantive questions that should be asked, the Equality Delivery System also discusses the need to discuss the ways arrangements are made to do this for members of all the protected groups, with the people in those groups, themselves.

More generally, the importance of strategies to reduce health inequalities taking account of the specific situation and characteristics of high risk and marginal groups (such as people with learning disabilities) has been highlighted by Health Select Committee, NICE and The Marmot Review.²⁵⁻²⁷ The UK has entered into international obligations to progressively realise the right to health of people with disabilities and to take specific measures to address the health inequalities faced by vulnerable groups such as people with learning disabilities.^{28 29}

In future, community and specialist dental services will be commissioned by the NHS Commissioning Board, but locally, enabling improved access to dental services often involves partnership working between specialist learning disability services, families and dental services. This report sets out some of the reasonable adjustments that have been put in place to enable people with learning disabilities to access dental services, with the aim of sharing resources and good practice which can be used and adapted for local implementation.

Oral healthcare and services for people with learning disabilities


Good oral health can promote better communication and nutrition, and improve self-esteem and confidence, whereas poor oral health, in addition to detrimental effects on the above, can lead to pain and discomfort that people with learning disabilities may struggle to communicate.⁴ In extreme cases, this can lead to unnecessary and expensive interventions or services:

A psychiatrist from (an assessment and treatment unit) gave an example of someone being admitted with behaviour that had become very challenging, but within hours they found he had six deep cavities in his teeth, causing him extreme pain. Following treatment for this, he was back to his old self.³⁰

Oral health is not just the dentist's problem; people with learning disabilities, family carers, support workers and providers, social care and health staff including specialist learning disability staff and GPs all have a part to play. Oral health is everyone's business.⁴

The British Society of Disability and Oral Health [BSDH] has produced comprehensive clinical guidelines on oral health care for people with learning disabilities and how it can be improved.³¹ The guidelines are aimed at everyone involved in the support of people with learning disabilities, and cover:

- Barriers to Oral Health;
- Improving oral health through clinical guidelines and integrated care;
- Practical oral health information for service users, parents and carers;

- 
- Commissioning of oral health care services for people with learning disabilities;
 - Education and training;
 - Consent to treatment and clinical holding;
 - Role of voluntary organisations.

For further information see:

http://www.bsdh.org.uk/guidelines/BSDH_Clinical_Guidelines_PwaLD_2012.pdf

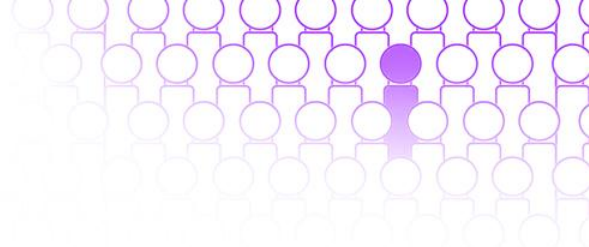
People with learning disabilities should be enabled to access dental services in the same way as anyone else. Local Salaried Primary Care Dental Services/Community dental services are available across the country, although special care dentistry services are also available. Anyone having problems accessing appropriate care should contact the British Society of Disability and Oral Health (BSDH) for help. See: http://www.bsdh.org.uk/public_information.html

For example:

Lancashire Care Dental Services has a dedicated Special Care Dental Service that can be accessed on referral from any health or social care professional, on behalf of the person with learning disability. The service is commissioned separately from the general dental service which allows additional time and resources to provide a patient centred service for those with learning disabilities and other groups meeting the referral criteria. Service users are recalled in accordance with NICE recall guidance which allows the dentist to assess whether more frequent visits are necessary to monitor oral health. Preventative regimes are also discussed with service users and care givers. The relevant history is documented on an electronic dental record which is networked to allow other dental professionals within the service to be made aware of a service user's learning disability status. Referral pathways exist that allow onward referral to secondary and tertiary care services and for sedation to allow completion of dental interventions where appropriate. An out of hours emergency dental service operates across central and east Lancashire which can be accessed by service users with a learning disability or care givers. Onward referrals to the Special Care Dental Service will be offered for routine care where appropriate. Domiciliary care can be provided where a risk assessment identifies that a person with a learning disabilities requires a home visit.

For further information please contact: Sarah.Procter@lancashirecare.nhs.uk

The BSDH is also trying to improve undergraduate training to give future dentists more exposure to treating people with learning disabilities. The example below demonstrates how people with learning disabilities can be involved in the training of dental students.



Plymouth People First (PPF) worked with a team of eight second year dental students from the Peninsula Dental School on a community engagement project. The project is part of the dental students' formal curriculum and helps students to develop a better understanding of some of the issues and factors that influence and impact on oral health and dental wellbeing.

The students first visited in November 2011 to discuss the role of a dentist, which personal attributes are needed and why they had chosen dentistry as a career.

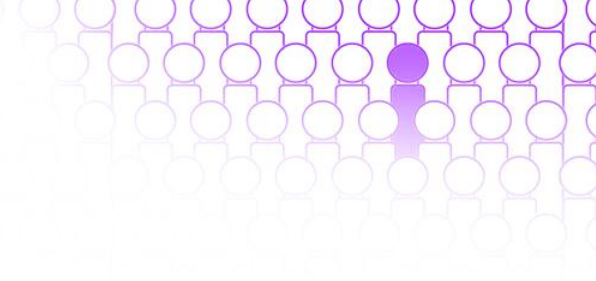
The students returned in December to give information to self-advocates on oral hygiene instruction, how to clean teeth properly. During these sessions they showed self-advocates different types of accessible information, but quickly realised that information they thought was clear was confusing. For example, 'spit don't rinse' caused upset as people had been told spitting was bad.

In February self-advocates were given a tour of the Peninsula Dental School in Devonport, and some consented to be filmed in a play with the students enacting a typical visit to the dentist. Self-advocates were then able to explore the equipment and sit in the chair. This was a very 'hands on' experience; the self-advocates were encouraged to feel and touch equipment, they could hear the sounds different pieces of equipment made, they were able to ask dental students and staff questions and discuss some of their previous experiences of visiting a dental surgery.

The students came back once more time to show us the completed film, leave us an information pack they had collated and to check to see how much the self-advocates had remembered (a huge amount!). We were invited to attend the dental symposium in June to support our students as they fed back on their work with PPF. Our students won the 'Rayna DiModic Contribution to Society Award' which recognises the group of students who have made a difference with their project and who have delivered an interesting and innovative project. PPF have already been asked if we would be willing to have another group of students, and have accepted.

The information pack we were given is being developed so centres and residential homes in Plymouth can all have a copy. We are planning a big health event and the next lot of students have been asked to come and participate. The film we were part of is being played daily in the Devonport centre as an acclimatisation film for new patients. Everyone involved in the project was offered free dental treatment by the students; one person has had a crown fitted; another is having dentures made.

The Peninsula Dental School noted that one of the major benefits to this project was the increase in knowledge for the students. They learnt a huge amount themselves as individuals and health professionals, their communication and interpersonal skills were improved and they understood more about the benefits of multi-agency working. They have been keen to share this knowledge with their colleagues across the School which will influence dental clinicians of the future.



Hospitalisation for dental treatment

Dental care is one of the areas of treatment where hospitalisation is not usually necessary; for most people, most dental procedures can be carried out on an out-patient basis. A notably high proportion of admissions under dental specialties are of people who have a learning disability. This probably reflects the difficulty of providing dental examinations or treatments, which may be distressing or painful, when the person receiving them does not fully understand what is happening and why. However some services seem to be better at doing this than others. Hospital Episode Statistics (the records of all NHS funded hospital care) give some impression of this.

In a recent year (2008/9), out of 119,764 NHS hospital in-patient spells for which the main diagnosis was a dental condition (using NHS definitions for ambulatory care sensitive conditions), 2,172 were of patients known to have a definite learning disability, 746 patients with conditions commonly associated with learning disability (most commonly cerebral palsy or hydrocephalus) and 356 were of patients recorded as having autism. Overall, these made up just under 3% of dental admissions. This figure can be compared to the proportion of people known to their GP to have a learning disability, which is 0.43%. The proportion varied considerably between PCTs. The median proportion of episodes for patients with a learning disability was 2.4%, the inter-quartile range 1.3% to 4.3%.

We have not shown figures for individual PCTs as interpreting them is not simple and cannot be done without further local information. A PCT may show a low rate of hospitalisation for dental conditions because primary prevention of caries is good, because community dentistry services are skilled at helping people with learning disabilities tolerate examinations and treatments, or because patients do not receive care, they need. Local sources are likely to be able to interpret local figures.

Consent and capacity

Consent must be sought prior to any dental investigation or treatment. Some of the resources detailed below are designed to enable people with learning disabilities to make informed decisions about their dental care. The Mental Capacity Act 2005 sets out the law regarding capacity and consent and is underpinned by five key principles which must be considered when assessing capacity:

- A person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision.
- An act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.

- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Where an individual is not considered to have capacity to consent, staff involved would need to decide if it is in the individual's best interests to undergo dental investigation and treatment.

Unlocking barriers to care includes detailed guidance on consent and 'Clinical Holding' in relation to dentistry as well as a Best Interests flow chart.³² See:

http://www.bsdh.org.uk/guidelines/BSDH_Clinical_Holding_Guideline_Jan_2010.pdf

Resources

The following sub-sections include some examples from practice, and links to easy read resources, many of which can be found on the Easyhealth site: www.easyhealth.org.uk the picture of health site: www.apictureofhealth.southwest.nhs.uk and the LDPHO reasonable adjustments database www.ihal.org.uk/adjustments/

Please note, some resources may be available from more than one site, but we have only included one link per resource, and we have only included resources that are free to download, although the Easyhealth site includes resources you can buy.

Reasonable adjustments regarding oral hygiene

Good oral health care can improve comfort, function and self-esteem. It can also reduce the need for fillings and extractions which can be difficult for people with learning disabilities to tolerate.

Resources

Information for carers	<p>Oral health care advice for carers: www.easyhealth.org.uk/sites/default/files/oral%20healthcare%20leaflet%201%20general%20advice.pdf</p> <p>Oral health care advice for carers (for people who have dentures or few teeth): www.easyhealth.org.uk/sites/default/files/oral%20healthcare%20leaflet%203%20DENTURES.pdf</p> <p>The good teeth guide for parents and carers of children with extra needs: www.easyhealth.org.uk/sites/default/files/The%20good%20teeth%20guide%20for%20parents%20and%20carers%20of%20children%20with%20extra%20needs.pdf</p> <p>Oral health care for people with profound and multiple learning disabilities: http://pamis.org.uk/cms/files/oral_health_leaflet.pdf</p>
Information for people with learning disabilities.	<p>Keeping my mouth healthy – check list: www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Keeping_My_Mouth_Healthy_Checklist.pdf</p> <p>Keeping my mouth healthy - action plan: www.easyhealth.org.uk/sites/default/files/Keeping%20my%20mouth%20healthy-%20action%20plan.pdf</p> <p>My teeth and gums: www.surreyhealthaction.org/assets/files/Looking%20after%20your%20teeth%20-%20easyread%20guide.pdf</p> <p>Film – Your way to a healthy mouth: http://www.apictureofhealth.southwest.nhs.uk/primary-care/teeth/films/</p>
Information to take to the dentist	<p>Keeping my mouth healthy checklist: www.easyhealth.org.uk/sites/default/files/keeping%20my%20mouth%20healthy%20checklist.pdf</p>

Reasonable adjustments in dental surgeries

Resources

Information about dental services	<p>What does your dentist do? www.easyhealth.org.uk/sites/default/files/what%20does%20your%20dentist%20do.pdf</p> <p>Do you have a dentist poster: www.improvinghealthandlives.org.uk/adjustments/?adjustment=216</p> <p>Dental care for adults with learning disabilities in Surrey: www.surreyhealthaction.org/assets/files/dental%20services%20in%20Surrey%20.pdf</p>
Invitation letters	<p>Dental appointment letter: www.improvinghealthandlives.org.uk/adjustments/?adjustment=214</p> <p>Dental appointment letter: www.improvinghealthandlives.org.uk/adjustments/?adjustment=215</p> <p>Creating an easy read dentist appointment letter and reminder letter www.surreyhealthaction.org/health-services-in-surrey-made-easy/going-to-the-dentists-surgery</p> <p>Invite to dental hygienist: www.improvinghealthandlives.org.uk/adjustments/?adjustment=217</p>
Having a check up	<p>Coming to have your teeth checked: www.easyhealth.org.uk/sites/default/files/Coming%20to%20have%20your%20teeth%20checked.pdf</p> <p>Going to the dentist: www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Going_To_The_Dentist.pdf</p> <p>Film – A visit to the dentist: http://www.easyhealth.org.uk/content/visit-dentist</p> <p>Film – Dentist (includes 6 monthly check up, having a filling, having a scale and polish and cleaning your teeth: www.my-healthvision.co.uk/My_HealthVision/See_the_Films/Entries/2011/6/13_Dentist.html</p>
Having an injection	<p>Having an injection at the dentist: www.easyhealth.org.uk/sites/default/files/having_an_injection_at_the_dentist_0.pdf</p>
Having sedation	<p>Going to the dentist for sedation: www.easyhealth.org.uk/sites/default/files/going%20to%20the%20dentist%20for%20sedation.pdf</p>
Having teeth taken out	<p>When you have your teeth out: www.easyhealth.org.uk/sites/default/files/when_you_have_teeth_out_0.pdf</p>

Making dental services more accessible for people with learning disabilities

My son has learning disabilities and autism and hated being touched. He was always sedated for check-ups and had general anaesthetic in hospital for treatment. Now that he is older we have been using his personal budget for the last 18 months to pay for a 30 minute massage every fortnight.

It started with a hand massage, progressed to his head and enabled him to tolerate someone touching his face and cheeks and having their face close to his face. The dentist loaned the protective specs a patient wears and we got him used to the close proximity the dentist needed.

My son no longer has a general anesthetic for treatment. He has check-ups with no sedation and treatment including injections, drilling and X-rays. A brilliant result.

Making dental services more accessible to people with learning disabilities

My daughter has very complex needs and uses a specially adapted wheelchair. Before they were known as reasonable adjustments our local dentist in Bristol came to the house to check my daughter's teeth. He was an ordinary dentist, but his surgery was upstairs and at the time they had no lift. He would bring his basic kit and a dental nurse. He could not have been more helpful. The problems began when my daughter needed dental work and the involvement of the dental hospital, and the long waits.

However this year in Torquay, my daughter has had excellent service from her local specialist dentistry service. They have a piece of kit that allows them to tip my daughter in her wheelchair, thus stopping them having to tilt her head back, which she hates, and allowing her the reassurance of her chair. They listened to us and even when they could not see much they respected that we knew her best and she was not right. The resulting treatment at Torbay hospital was great. The Anaesthetist came to see her/us beforehand and listened to what we suggested and acted on it. The anaesthetist came back after the treatment to check on her. The dental surgeon again came to see her/us beforehand, listened to our suggestions and came back afterwards as well. They had to remove all 4 wisdom teeth as they were impacted, but they also checked over everything and even cleaned up her front tooth which she broke off years ago to give her a lovely smile again.

They only had her in on the day of surgery, respecting that her home would do what was required, they gave her a side ward and we her parents and one staff member were treated as partners in her care and everything went well.

Reasonable adjustments to hospital dental services

We were sent very few examples of reasonable adjustments to hospital dental services. This possibly reflects the need to make bespoke resources for individuals that suit them and the specific hospital environment or process.

Resources

Tooth x-ray	Having an x-ray on your teeth: www.improvinghealthandlives.org.uk/adjustments/?adjustment=170
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Making hospital services more accessible for people with learning disabilities

In Nottingham, the acute liaison nurses have become involved in working with the specialist dentistry services to put in place reasonable adjustments when people need to come to hospital for dental treatment. Reasonable adjustments include:

- Desensitisation work/visits;
- Arranging for the provision of side rooms;
- Shorter booking in times/ alternative routes into the area;
- Car parking for carers/families;
- Use of pre-med for people who are very anxious;
- Longer consultation slots;
- Liaising with community learning disability teams and health facilitators to make admissions and procedures as successful as possible.

For further information please contact the Acute Learning Disability Liaison Team on:

QMC and City Hospitals Nottingham.0115 9691169 ext. 56568 or City, 0115 9249924 ext. 62562

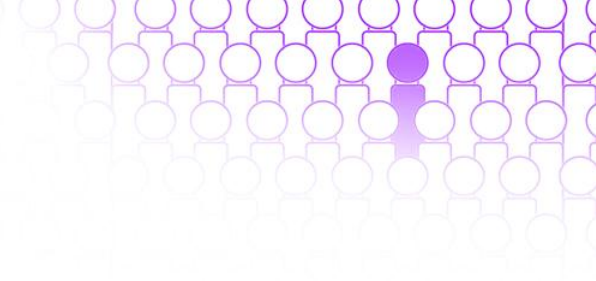
Making hospital dental services more accessible for people with learning disabilities

John (not his real name) is eight years old, and has a diagnosis of severe learning disability and autism. He becomes extremely anxious and agitated if he goes anywhere new and to environments that are strange to him. In these situations he will become very upset, scream and shout, become aggressive, and it is generally very difficult to support him to calm.

He has never been able to tolerate a toothbrush in his mouth and the family struggle to clean his teeth.

The family had to access the Dentistry Service at Alder Hey Hospital, and through a long process of discussions between the dentist and Mum, using pictures/symbols, rewards, de-sensitisation, and general calm approaches from the staff, he will now attend his appointments with little sign of any anxiety. They have also accommodated his visits to reduce waiting times.

He will now go to the hospital, into the dentist's room, (still sitting in his buggy), will take the dentists light and shine it in to his mouth whilst she puts the mirror in to look around.



Reasonable adjustments - other

Audit	Dental surgery inspection questions: www.improvinghealthandlives.org.uk/adjustments/?adjustment=190
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Checking the quality of dental services

My Life My Choice (MLMC), a self-advocacy organisation, worked with Oxfordshire Primary Dental Care Services to raise awareness about issues for people with learning disabilities.

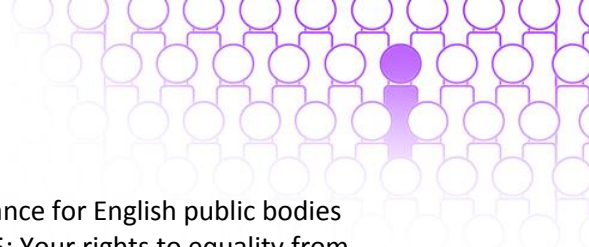
Initially a 'Tooth Day' was held, attended by nearly 90 people with learning disabilities, which included a number of activities and games to inform people about oral/dental health and where the views of patients were collected about their dental service.

Secondly, the dental service held an away day for over 100 practitioners on the theme of learning disability. The MLMC user-led training team, working with a Ridgeway Partnership Community Nurse and conducted presentations, role-plays, and exercises for those who attended.

Finally, the MLMC "Experts by Experience" carried out inspections of six dental surgeries and delivered their report to the dental service for them to consider.

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