



Danila Dilba

Health Service

Mr Russell Keith
Committee Secretary
Select Committee on Foetal Alcohol Spectrum Disorder
GPO Box 3721
DARWIN NT 0801

Dear Mr Keith

I am pleased to provide the attached submission to the Inquiry from Danila Dilba Health Service. I would be happy to provide further information to the Committee in any public hearings that are to be held.

Please contact me if you require any further information.

Yours sincerely

Olga Havnen
Chief Executive Officer

26th May 2014.



Submission to the Northern Territory Legislative Assembly Select Committee on Action to Prevent Foetal Alcohol Spectrum Disorder

Executive Summary

Danila Dilba Health Service welcomes the opportunity to make a submission to this important inquiry. This submission does not attempt to cover the full range of issues and actions relevant to Foetal Alcohol Spectrum Disorder (FASD). It is focused on issues where Danila Dilba has knowledge through our role as a provider of comprehensive primary health care services to the Aboriginal community of the Greater Darwin region.

Danila Dilba encourages the Committee to look beyond its terms of reference to ensure that critical issues are not neglected in the inquiry. In particular, the Committee should not ignore the wider effects of parental alcohol misuse on children, the social determinants of alcohol misuse, need for adequate services to diagnose FASD and support those with the condition and their families.

Simplistic responses to the issue of FASD, such as criminalization of drinking during pregnancy, will not work. Danila Dilba Health Service believes that reduction in the prevalence and impact of FASD will be achieved through:

- Broad population focused prevention strategies that encompass the reduction of demand, supply and harm across the community and among women in particular.
- Prevention efforts targeted at pregnant women as part of antenatal care; and
- Support for families, communities and individuals in dealing with a FASD diagnosis.

Danila Dilba Health Service also supports the detailed work done by the organisations cited in this submission and suggests that the Committee take note of the papers by the National Indigenous Drug and Alcohol Advisory Committee, Aboriginal Peak Organisations NT and the Peoples Alcohol Action Coalition.

Danila Dilba Health Service looks forward to the opportunity to provide further information to the Committee at a public hearing.

The following recommendations are contained in the submission:

Recommendation 1: Danila Dilba Health Service recommends that the Northern Territory Government support a review of existing diagnostic tools for FAS and FASD with a view to the uniform implementation of a valid diagnostic tool for FAS and FASD (validated for both Aboriginal and non-Aboriginal people) and the development of a standard data collection across

the Northern Territory to allow both accurate prevalence data and effective diagnosis and treatment/interventions for people with FASD.

Recommendation 2: Danila Dilba Health Service recommends that the Northern Territory and Australian Governments develop a performance measure for ante-natal care, relating to alcohol screening at first ante natal visit for inclusion in child and maternal health data sets. The measure should enable separation of Aboriginal and non-Aboriginal data. This would contribute to improving the knowledge base about alcohol consumption during pregnancy.

Recommendation 3: Danila Dilba Health Service recommends that the Northern Territory Government support targeted research by reputable research bodies to build on existing data in relation to risky alcohol use across the community and alcohol consumption by pregnant women.

Recommendation 4: Danila Dilba Health Service recommends that the Northern Territory Government recognise that a reduction in FASD requires broad population based efforts to reduce risky and harmful use of alcohol and implement a response to alcohol related harm that encompasses supply, demand and harm reduction. The response must be evidence based and comprehensive and not focus exclusively on pregnant women.

Recommendation 5: Danila Dilba Health Service recommends that the Northern Territory Government support the collaborative efforts of front line service providers in addressing primary prevention in relation to alcohol misuse in the NT. Support should take the form of funding or in-kind support for program development, serious consideration of collaborative proposals and funding for implementation.

Recommendation 6: Danila Dilba Health Service recommends that the Northern Territory Government support further impact in primary health care and child and maternal health services through the provision of:

- Funding for additional clinical positions (nurses and/or Aboriginal Health Practitioners) to develop and provide appropriate screening for alcohol use, brief interventions to support women (before, during and after pregnancy) in the cessation of alcohol use and referral pathways for women seeking support to cease alcohol use;
- Funding for additional support through family support workers to build relationships of trust and support with women both before and during pregnancy and their families;
- Increased outreach capacity across primary health care teams, and the child and maternal health services to take the services to the clients;
- Development and distribution of evidence-based tools and resources for brief interventions in the primary health care setting;
- Additional substance abuse treatment services suitable for pregnant women who identify as needing support for alcohol cessation, particularly those who already have children.

Recommendation 7: Danila Dilba Health Service recommends that the Northern Territory Government work with the Australian Government to ensure that the expanded Australian Family Nurse Partnerships Program includes an appropriate allocation to the Northern Territory and to ensure that the NT is included in the first stages of the expansion.

Recommendation 8: Danila Dilba Health Service recommends that the Northern Territory Government immediately commence a scoping exercise to explore the feasibility of a service like the Red Cross Young Parents Program appropriately tailored to the NT environment and service delivery sector. The study should involve all relevant sectors including primary health care, legal services, corrections, child protection, family support services, homelessness organisations and accommodation providers like Aboriginal Hostels Limited. The

implementation of our recommendation above regarding expansion of the Nurse Family Partnership Program would be an important input into such a service.

SUBMISSION

About Danila Dilba

Danila Dilba Health Service was established in 1991 as an Aboriginal community-controlled health organisation. Our mission is to improve the physical, mental, spiritual, cultural and social wellbeing of Biluru (Aboriginal people and Torres Strait Islander people) living in the Yilli Rreung (greater Darwin) region. We do this by providing innovative comprehensive primary health care programs that are based on the principles of equity, access, empowerment, community self-determination and inter-sectoral collaboration.

Danila Dilba is primarily funded by the Australian Government through the Department of Health.

In 2012-13, we employed 140 people and provided 40,000 episodes of care to some 6,000 active clients. Demand for our services is growing, with the total episodes of care almost doubling between 2008 and 2013. Around 30 per cent of the Northern Territory population identifies as either Aboriginal and/or Torres Strait Islander, and this includes approximately 12,000 people living in the Yilli Rreung region. We also provide services to Indigenous people visiting our region. Danila Dilba has a majority Biluru Board of Directors that governs the organisation and whose members are chosen by the community..

Danila Dilba Health Service aims to provide culturally-appropriate primary health care services and all our activities are underpinned by core values of:

- providing of and advocating for services that are equitable, accessible, professional, high quality and responsive to local needs
- working with our community to ensure a culturally-appropriate environment that promotes safety, trust and respect
- supporting a workplace culture based on honesty, integrity, fairness, transparency and accountability.

Introduction

While Danila Dilba Health Service welcomes this inquiry into important aspects of the issues related to Foetal Alcohol Spectrum Disorder (FASD), it is important to note that the terms of reference for the inquiry have the potential to be too narrow to address the issues that both contribute to and arise from the prevalence of FASD in the Northern Territory. To develop effective responses, the Committee must ensure that the inquiry addresses:

- Deficiencies in prevalence data, including probable under-diagnosis of FASD and the importance of separately identifying prevalence of Foetal Alcohol Syndrome (FAS) and the broader range of conditions encompassed by FASD;
- Deficiencies in data relating to maternal consumption of alcohol in pregnancy for the whole population and specifically for Aboriginal women in the NT;
- The effects of FASD, not only on sufferers but on their families and communities, as well the broader social impacts including on crime and justice

systems, education, mental health services, child protection and out of home care and disability services;

- The fact that the impact of parental alcohol abuse on infants and children extends well beyond ante-natal exposure. In considering ways to reduce FASD in the NT, the Committee should consider approaches that will also address the broader impact of parental drinking on early years development;
- The social determinants of alcohol abuse that contribute to FASD and responses that address these determinants
 - In this context the broader culture of alcohol consumption in the NT is important
 - The need to address the determinants of alcohol abuse through a three pronged approach to reduce supply, demand and harm as recommended by NIDAC (National Indigenous Drug and Alcohol Committee, 2009);
- The role of primary health care in preventing and diagnosing FASD and supporting people with FASD and their families;
- The importance of addressing the health and related needs of the existing population of people affected by FASD in the NT community – noting that the terms of reference for this inquiry do not touch on this issue.

Danila Dilba data relevant to FASD

Danila Dilba Health Service (DDHS) provides a comprehensive primary health care service, including a targeted child and maternal health service through the Gumilebirra women's clinic. Key data of interest include:

- In 2012-13, DDHS provided ante natal care to 145 women.
- Of those women, 30% had their first visit in the first trimester and further 21% had their first visit before 20 weeks
 - Screening for alcohol use is part of the standard first antenatal visit.
- More broadly, DDHS conducted just over 1,000 screenings for alcohol related risks for men and women as part of the adult health checks using the Indigenous Risk Impact Screening tool.
- DDHS currently has nine clients with a recorded diagnosis of Foetal Alcohol Syndrome.

Comments in relation to the Terms of Reference

1. The prevalence in the Northern Territory of Foetal Alcohol Spectrum Disorder (FASD)

The data in relation to the prevalence of FASD in Australia are limited, which makes it unlikely that an accurate prevalence for the Northern Territory (NT) can be gleaned from existing data sources. The House of Representatives Standing Committee on Social Policy and Legal Affairs concluded in 2012 that there is a need for a standard diagnostic tool for the detection of FASD and the collection of data on prevalence from the use of such a tool.

The Committee cited evidence from many submissions to its inquiry and other sources that led to widely varied estimates of the prevalence of FASD in the general Australian population and in the Aboriginal and Torres Strait Islander population specifically (House of Representatives Standing Committee on Social Policy and Legal Affairs, 2012).

Similarly, the National Indigenous Drug and Alcohol Committee (NIDAC) noted in 2012 that FASD is not well known or understood in Australia and that most prevalence data comes from overseas studies. NIDAC quoted international prevalence estimates of FASD at one to three per 1,000 live births in the general population, and as high as 9.1 per 1,000 live births in high risk populations. In the Australian context NIDAC concluded that current data on prevalence of FASD and FAS are likely to be greatly underestimated. (National Indigenous Drug and Alcohol Committee. & Stokes, 2012).

For the NT specifically, one study has estimated that the overall rate of Foetal Alcohol Syndrome is between 0.68 and 1.7 per 1,000 live births across the population, and for the Aboriginal and Torres Strait Islander population between 1.87 and 4.7 per 1000 live births (Harris, 2003). The wide span of the estimates is due to the uncertainty of whether all cases of alcohol related disorders are in fact FAS or not. The higher estimates might be seen to be closer to an indication of prevalence of FASD.

Patterns of alcohol consumption can be a useful indicator of the likely prevalence of FAS and FASD. While the overall picture regarding alcohol consumption in the NT, and among Aboriginal and Torres Strait Islander people in the NT, is well known, a more detailed level of information is necessary to give useful indicators in relation to risks of FASD. At the broader level, it is known that the NT has the highest rate of risky alcohol assumption, both with long-term risk and single occasion risk, of all the States and Territories. This is true for men and women, although women have lower rates of risky consumption than men.

In addition, Aboriginal and Torres Strait Islander people, while more likely than others to abstain from alcohol, are more likely if they do drink to do so at risky levels (Australian Institute of Health and Welfare, 2011).

Overall, it is clear that more work is needed on accurate prevalence data in relation to FAS and FASD both nationally and in the NT. Without accurate prevalence data it is difficult to assess the level of resourcing needed to provide services for people with FASD and their families or to assess the size of the prevention task. More importantly, the lack of accurate prevalence estimates probably indicates under-diagnosis of FASD which has serious implications for the care provided to people with the condition and their long term outcomes.

Recommendation 1: Danila Dilba Health Service recommends that the Northern Territory Government support a review of existing diagnostic tools for FAS and FASD with a view to the uniform implementation of a valid diagnostic tool for FAS and FASD (validated for both Aboriginal and non-Aboriginal people) and the development of a standard data collection across the Northern Territory to allow both accurate prevalence data and effective diagnosis and treatment/interventions for people with FASD.

Recommendation 2: Danila Dilba Health Service recommends that the Northern Territory and Australian Governments develop a performance measure for ante-natal care, relating to alcohol screening at first ante natal visit for inclusion in child and maternal health data sets. The measure should enable separation of Aboriginal and non-Aboriginal data. This

would contribute to improving the knowledge base about alcohol consumption during pregnancy.

Recommendation 3: Danila Dilba Health Service recommends that the Northern Territory Government support targeted research by reputable research bodies to build on existing data in relation to risky alcohol use across the community and alcohol consumption by pregnant women.

2. The nature of the injuries and effects of FASD on its sufferers

The clinical effects of FAS and FASD are well described in the literature and this submission will not explore them in detail.

The terms of reference for the inquiry are focussed on the effects of FASD on those who have the condition. However, Danila Dilba Health Service (DDHS) suggests that this part of the terms of reference is too narrow. Given the estimates of prevalence of FAS and FASD in the Northern Territory (NT), and particularly among high-risk groups, there is a significant cohort of individuals already with FAS and FASD in the NT. These individuals, their families, communities and the services which they utilise need to be resourced and equipped with knowledge and skills to minimise the impact of the condition.

People with FASD will continue to be affected for their life time as will their families and communities. One example of the broader impacts of FAS/FASD, and ongoing parental alcohol misuse on the broader community and service sector, can be seen in the child protection sector of the NT. Research released at the Australasian Foetal Alcohol Spectrum Disorders Conference in 2013 revealed that 40% of children on Protection Orders had experienced prenatal alcohol exposure (in some locations this exposure was up to 88%) and 86% of children on Protection Orders had been affected in various ways by parental alcohol use (Walker, 2013).

The National Indigenous Drug and Alcohol Committee suggests that while there is no specific treatment for FASD, it is important to provide interventions for sufferers and their families to reduce the impacts on the individual, the family and society of the intellectual, academic and adaptive deficits experienced by those with FASD (National Indigenous Drug and Alcohol Committee. & Stokes, 2012). Of course, early diagnosis of the condition is important and the development and implementation of standard diagnostic tools as recommended above is critical.

The most immediate action that can be taken by the NT government is to formally recognise FAS/FASD as a disability in order to ensure that people with FAS/FASD and their families are able to access the full range of services that might support them.

Aboriginal Peak Organisations Northern Territory (APO NT) has addressed the role of primary health care, developmental child care, schools and the importance of identification of FASD and appropriate management of the condition in the justice system (Aboriginal Peak Organisations Northern Territory, 2011). DDHS supports the conclusions reached by APO NT.

3. Actions the Government can take to reduce FASD based on evidence and consultation

Danila Dilba Health Service (DDHS) fully supports the need to take action to reduce FASD, and for actions to do so to be based on evidence and consultation. We suggest that this needs to be undertaken in an holistic way and focus, not only on pregnant women, but on the alcohol culture of the entire community. The data included above show that the Northern Territory (NT) has high rates of risky alcohol consumption and that estimates of the prevalence of FAS and FASD for the NT are also higher than estimates nationally.

In view of statements by the NT Attorney General earlier this year, it is important to state that DDHS does not support the criminalisation of alcohol use during pregnancy. There is no evidence to support criminalisation as an effective intervention. The Australian and international literature support therapeutic approaches, interventions in the primary health care setting, parental education and parental support as effective methods to reduce alcohol use before and during pregnancy and DDHS encourages the Committee to consider the available evidence.

The National Indigenous Drug and Alcohol Committee (NIDAC), the foremost policy body in relation to Indigenous substance misuse issues, recommends a range of actions in relation to prevention – but does not recommend any actions to criminalise the behaviour of women during pregnancy. NIDAC's recommendations cover:

- social marketing,
- an integrated national policy,
- specific clinical guidance to ensure that the NHMRC guidelines on alcohol are incorporated into clinical practice,
- ensuring that all pregnant women are screened for alcohol use at the first antenatal visit
- training for all health professionals on FASD and ways to support healthy behaviour change.

NIDAC further supports ensuring that high risk groups and communities receive additional support (National Indigenous Drug and Alcohol Committee. & Stokes, 2012).

3(a) Prevention encompassing the broader use of alcohol in the NT community and its consequences

NIDAC suggests that this kind of primary prevention to change the alcohol-related behaviour of the general population must be embedded into alcohol harm reduction strategies in order to reduce the incidence of FASD. NIDAC further suggests that an understanding of the social determinants of risky alcohol use should inform the targeting of any population-level interventions (National Indigenous Drug and Alcohol Committee. & Stokes, 2012). DDHS supports this view.

Any approach to minimising alcohol-related harm, including FASD, must address harm, supply and demand reduction. Detailed proposals have been put to previous inquiries and forums. The People's Alcohol Action Coalition for example, has dealt extensively with issues of supply reduction, the need for effective treatment programs based on evidence and the importance of early childhood interventions to break the cycle of disadvantage and alcohol abuse that affects many Aboriginal families (People's Alcohol Action Coalition, 2014).

Similarly, Aboriginal Peak Organisations Northern Territory has dealt extensively with issues related to the social determinants of alcohol abuse and the need to address supply (Aboriginal Peak Organisations Northern Territory, 2014). DDHS supports the recommendations of these two submissions and considers action on the broader issues of alcohol consumption and alcohol related harm critical to reducing the prevalence of FASD in the Northern Territory.

Recommendation 4: Danila Dilba Health Service recommends that the Northern Territory Government recognise that a reduction in FASD requires broad population based efforts to reduce risky and harmful use of alcohol and implement a response to alcohol related harm that encompasses supply, demand and harm reduction. The response must be evidence based and comprehensive and not focus exclusively on pregnant women.

Broad prevention strategies also require collaboration across sectors as the issues that need to be addressed do not fit neatly within a single sector. For example, DDHS will be undertaking a scoping study, in collaboration with North Australian Aboriginal Justice Agency and Aboriginal Medical Services Alliance of the Northern Territory, into the feasibility of running community-centred programs to divert defendants/clients, whose offending is intrinsically linked to their drug and alcohol issues, out of the criminal justice system. This would occur after a person pleads guilty and before they are sentenced (sentencing is adjourned for them to undertake treatment).

The study will look at what capacity exists in primary health care (and related community services) and justice services to participate in such a collaboration based on existing evidenced-based models in the USA and Canada. Such a model may include a primary health care provider such as DDHS facilitating a therapeutic treatment plan that could include Alcohol and other Drug counselling, GP mental health care planning, family support worker assistance to link up with social services such as back to work programs, housing assistance, financial counselling and community engagement programs.

Collaborative activities of the kind proposed are an important part of the prevention effort that is needed to reduce the overall level of risky alcohol use in the Northern Territory community.

Recommendation 5: Danila Dilba Health Service recommends that the Northern Territory Government support the collaborative efforts of front line service providers in addressing primary prevention in relation to alcohol misuse in the NT. Support should take the form of funding or in-kind support for program development, serious consideration of collaborative proposals and funding for implementation.

3(b) Prevention activities focussing on pregnant women

As an Aboriginal primary health care service, DDHS has extensive contact with pregnant women in a clinical setting. In addition to general clinics, DDHS operates a specific child and maternal health program at our Palmerston clinic . Additional programs, funding and resources from the Northern Territory or Australian

Governments would support further improvements in relation to FASD. In particular, DDHS raises the following points:

i General health clinic interventions and child and maternal health programs

Primary health care is a powerful source of health education and health promotion for Aboriginal women across their life cycle. While interventions to reduce alcohol use as part of ante-natal care are critical, as discussed below, it is also important for primary health care services to screen for alcohol use and offer sound health promotion advice for all women, not only those who are pregnant.

Primary health care is the entry point to ante-natal care for the majority of pregnant women. For many Aboriginal women, primary health care is accessed through an Aboriginal primary health care service, either community controlled or operated by Northern Territory Government. It is well documented that pregnancy can be an effective time to offer brief interventions in relation to health behaviours as parents are receptive to those health messages at this time. However, health professionals need to be well equipped with information and health promotion tools to support these interventions.

Many Aboriginal primary health care services, both community controlled and government clinics, provide specific child and maternal health programs in addition to general primary health care with the intention of delivering improved health outcomes for mothers and babies. While the programs are providing an excellent range of ante-natal, post-natal and child-health services, they, along with general primary health care, require additional resources and tools to further address alcohol consumption during pregnancy with a view to reducing the incidence of FASD.

Recommendation 6: Danila Dilba Health Service recommends that the Northern Territory Government support further impact in primary health care and child and maternal health services through the provision of:

- **Funding for additional clinical positions (nurses and/or Aboriginal Health Practitioners) to develop and provide appropriate screening for alcohol use, brief interventions to support women (before, during and after pregnancy) in the cessation of alcohol use and referral pathways for women seeking support to cease alcohol use;**
- **Funding for additional support through family support workers to build relationships of trust and support with women both before and during pregnancy and their families;**
- **Increased outreach capacity across primary health care teams, and the child and maternal health services to take the services to the clients;**
- **Development and distribution of evidence-based tools and resources for brief interventions in the primary health care setting;**
- **Additional substance abuse treatment services suitable for pregnant women who identify as needing support for alcohol cessation, particularly those who already have children.**

ii Family Nurse Partnerships Program

The Australian Family Nurse Partnerships Program is currently operating in three sites in Australia. It is a program based on extensive evidence internationally and aims to:

- improve pregnancy outcomes by helping women engage in good preventative health practices
- improve child health and development by supporting parents
- improve parents' life course by helping parents to develop a vision for their own futures, including continuing education and finding work.

Evaluation in the Australian context is limited so far, with a formative evaluation published in 2011 and no further published evaluation since then. The 2011 evaluation noted that qualitative information and observations from mothers involved in the program suggest that the program was having a positive impact on the confidence of mothers and their mothering practices. It also acknowledged that the program is expensive and that with only three sites operating it might provide difficult to effectively evaluate it in the Australian setting. However, the international evidence suggests that the model will deliver a range of benefits to mothers and babies including reduced rates of alcohol and drug use among mothers and, over time, among children born to those mothers (Ernst and Young Australia, 2012).

Danila Dilba Health Service supports an expanded roll-out of the Australian Nurse Family Partnerships Program across areas with a large enough Aboriginal population to make the program feasible, noting that the 2011 formative evaluation suggested that governments consider hub and spoke models to achieve the critical mass required to operate the program.

With the recent announcement by the Australian Government of a significant expansion of the Australian Nurse Family Partnership Program, there is an opportunity to ensure that more Aboriginal people in the Northern Territory are able to benefit from this approach.

Recommendation 7: Danila Dilba Health Service recommends that the Northern Territory Government work with the Australian Government to ensure that the expanded Australian Family Nurse Partnerships Program includes an appropriate allocation to the Northern Territory and to ensure that the NT is included in the first stages of the expansion.

iii Accommodation support for at risk pregnant women and their families

Based on the experience of Danila Dilba Health Service (DDHS) there is a need for safe, health-promoting accommodation for pregnant women, and their partners and existing children, who wish to avoid the alcohol culture prevalent in the Northern Territory (NT) as well as the pressure to continue to consume alcohol during pregnancy. These women and their partners also frequently face other challenges to a healthy pregnancy including unstable housing or homelessness, poor access to nutrition and possible exposure to violence.

While there are some services and accommodation options available for women escaping domestic violence, and for women and families who wish to undertake an alcohol rehabilitation program, there are no suitable accommodation options for pregnant women and their partners who are seeking a safer, alcohol-free environment where they do not face pressure to drink or the ill effects of the drinking of others. In some cases of course, women may wish to enter such accommodation without their partners. DDHS considers that such a service is necessary and would support a number of health and social improvements for at-risk women and families.

While FASD and the wish to avoid alcohol might be a trigger to enter the accommodation, supported accommodation during pregnancy and in the early stages of parenthood can have a beneficial effect on ante-natal health, a healthy birth and a healthy start for the new baby.

For example, the Red Cross in New South Wales provides a comprehensive Young Parents Program that focusses on family restoration and preservation. It aims to develop the ability of young parents to live independently and parent successfully. The Young Parents Program is multilayered and provides a residential service, outreach program and aftercare. An evaluation of the program in 2010 concluded that it was successful in its aims and noted the following factors in its success:

- a dynamic program where staff skills are built to deal with the diverse and challenging behaviours of at risk behaviours
- a twelve month residential phase for the most at-risk clients
- collaboration with child protection services
- a community hub of support around the residential component (Spencer & Vogl, 2010).

As part of a long term approach to both reducing FASD and giving children a healthy start, a service like the Red Cross Young Parents Program is worth considering in the NT. It should be developed collaboratively among existing service providers involved in the care and support of families and particularly pregnant women.

Recommendation 8: Danial Dilba Health Service recommends that the Northern Territory Government immediately commence a scoping exercise to explore the feasibility of a service like the Red Cross Young Parents Program appropriately tailored to the NT environment and service delivery sector. The study should involve all relevant sectors including primary health care, legal services, corrections, child protection, family support services, homelessness organisations and accommodation providers like Aboriginal Hostels Limited. The implementation of our recommendation above regarding expansion of the Nurse Family Partnership Program would be an important input into such a service.

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