

People with Disabilities WA
individual & systemic advocacy



people with
disabilities
western
australia

Senate inquiry into the delivery of outcomes under the National Disability Strategy 2010 – 2020.

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Senate Community Affairs References Committee for the opportunity to provide comment on the delivery of outcomes under the National Disability Strategy 2010 - 2020.

PWdWA is the peak disability organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy.

PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

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Introduction

As denoted in the forward of the National Disability Strategy 2010 -2020 -

'The development of this National Disability Strategy is the first time in Australia's history that all governments have committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes. This commitment recognises the need for greater collaboration and coordination by all governments, industry and communities to address the challenges faced by people with disability. A new approach is needed to guide policies and program development by all levels of government and actions by the whole community, now and into the future. The National Disability Strategy will focus our efforts towards achieving a society that is inclusive and enabling, providing equality and the opportunity for each person to fulfil their potential.'

This submission presented by PWdWA considers how effective the National Disability Strategy has been in achieving better outcomes for people with disability since its inception seven years ago. The submission is based on direct feedback from people with disability, their families and carers and data from other relevant submissions PWDWA have provided that relate to the six key areas of the National Disability Strategy.

I'm glad the strategy is being given attention because I think it is extremely important vehicle for changing attitudes and actions

During March 2017, PWdWA conducted an online survey that sought feedback on a number of questions relating to the six areas. Eighty-five responses were received, 47% were from people with disability, 45% were a carer of a person with disability, and 23% were a family member of a person with a disability. For the purposes of this submission, we have categorised peoples' feedback under the terms of reference of the review namely,

- Planning, design, management and regulation of
 1. the built and natural environment, including commercial premises, housing, public spaces and amenities.
 2. transport services and infrastructure
 3. communication and information systems
- Potential barriers to progress or innovation
- Impact of restricted access for people with disability on inclusion and participation in economic, cultural, social, civil and political life

Recommendations

PWDWA have provided a set of recommendations that serve to address the shortcomings of strategy outcomes and ensure people with disability are equal and valued citizens.

Disability is diverse and complex by nature. PWDWA recommends that this is considered in all facets of the decision making process. It is recommended therefore that people with disability, their families and carers and those consumer organisations that represent them are included at all levels of engagement from board/policy decisions through to the design and implementation of projects.

Importantly, people with disability must be engaged as designers and co-designers in aspects of a strategy. People will only feel confident with a strategy that has been developed and continues to evolve by people who it is intended to support and whose lives will be severely affected if the strategy does not succeed.

- 1. The development of an operational plan with associated funding to enable the National Disability Strategy to be implemented.**
 - a. The plan to take a whole of Governments approach with each department and jurisdiction being accountable for the actions in the operational plan.**
 - b. The plan to be co-designed with people with disability.**
- 2. The development of targets and outcomes that are measurable over long periods of time and an evaluation methodology for the National Disability Strategy.**
- 3. All changes to Government policy at all levels is co-designed with people with disability.**
- 4. Increase the powers of the Disability Discrimination Commissioner and the Disability Discrimination Act to allow investigations of systemic issues and to mandate actions.**
- 5. The federal and state governments mandate that all local governments must have an inclusive footpath policy to ensure there is continuous and accessible paths of travel.**
- 6. The committee lobby for changes in legislation to mandate for universal access in building and residential design codes. This should relate to new housing builds and renovation projects.**
- 7. Review and investigate how transport costs are covered within NDIS packages to ensure that they are applied consistently and in a way that is meeting the needs of people with disabilities.**

- 8. Refuse all further requests for exemptions to meet the Access to Transport Standards.**
- 9. Mandate all public documents to have plain English versions, or summaries in the case of highly technical documents.**
- 10. All schools should be physically accessible and education ready for the inclusion of children with disability.**
- 11. Encourage business and the public sector to lead the way by demonstrating a commitment to increasing the number of people with disabilities employed, using quotas as a mechanism for measuring improvement.**
- 12. Develop workplace trainers with an experience of disability to offer inclusivity training for business, government, and employment services, with training delivered by people with disabilities or people with experience of disability.**
- 13. Provide further investment in research, particularly in the areas of assistive technology for people with disability, and inclusion in the community.**
- 14. Provide grants for key health sector services such as medical centres, dentists, podiatrists etc to gain access compliance and refuse endorsement/registration of practitioners who do not make an effort to be complaint.**
- 15. Government to implement and follow through with the recommendations on the Senate Inquiry into violence, abuse and neglect of people with disability.**
- 16. Individual and Systemic Advocacy to be funded appropriately.**
- 17. Funding for projects to meet the objectives of the National Disability Strategy and the ILC framework should be delivered by Disabled Peoples' Organisations and funded appropriately. A Disabled Person's Organisation is one that is run by people with disabilities for people with disabilities.**

Issues

The general view from people with disability is that the National Disability Strategy has defined many of the issues, barriers and stereotypes people with disability encounter on a daily basis. However, in terms of achieving outcomes, it is unclear whether it has been effective. Improvements have been made in individual areas but these have been in isolation and there appears to be no over-arching mechanism to know if the strategy has been effective.

The National Disability Insurance Scheme (NDIS) is widely regarded as a great feat of social engineering of modern times. However, it is important to recognise that this is still one element and the feedback suggests there is much work to be done to ensure the interface with mainstream services is happening. There is real concern that Governments have focused on the NDIS reform to the detriment of mainstream disability reform. Whilst it is acknowledged that the NDIS is providing greater choice, flexibility and control in disability services, these basic human rights should also be afforded in mainstream services.

PWdWA acknowledges the National Disability Strategy target areas for action; however, we are deeply concerned that no specific detail of measurable actions has been included. There needs to be a real commitment from the whole of Government to develop and implement an operational level plan that has measurable targets and achievable outcomes matched with the resources required to deliver the strategy. **(Recommendation one)**

In our consultation, many people talked about the 'closing the gap' identification of priority areas and measurement of outcomes that is used for Aboriginal and Torres Strait Islander peoples. The Information, Linkages and Capacity Building outcomes measurement work should also be used in finding ways to evaluate and measure the impact of the National Disability Strategy. In the original strategy plan the measurement of outcomes and evaluation of impact was always the weakest area. Without some sort of measurement framework there is a risk that the National Disability Strategy will continue to be implemented in an ad hoc way, with limited understanding of what works and what doesn't and any unintended consequences. **(Recommendation two)**

We should have a close the gap type of reporting system that the PM has to report in Parliament so we can see what difference the NDS is making or not

The Information, Linkages and Capacity Building (ILC) framework is an important element of the National Disability Strategy because it allows for the development, advocacy, engagement and active participation of all people with disability. It provides one of the mechanisms by which the National Disability Strategy can influence and shape mainstream services at a systemic level; to provide better outcomes for people with disability, their families and carers. There is a focus on increasing the independence and capacity of the person with disability as part of the necessary work

to increase participation of people with disability in the community. There is also the added benefit that this can potentially alleviate the pressure on families, carers, and systems that are already over stretched and under resourced. The ILC framework should therefore be a pivotal part of the National Disability Strategy. **(Recommendation three)**

The work of the National Disability Strategy is huge; this submission gives an overview of what issues/barriers/challenges people with disability still encounter on a daily basis based on what is important to them. Many of the recommendations provided are already grounded in legislation and or policy. What is lacking is the commitment to monitor, enforce, and implement this legislation, holding organisations accountable to ensure people with disability live as equal citizens. The main mechanism for holding government and organisations to account is the Disability Discrimination Act which is limited in its ability to enforce change to occur and is essentially based on individual complaints being dealt with one at a time. **(Recommendation four)**

Right now the onus is on the disabled person to make "individual" complaints over and over and over again. If I were to complain about every inaccessibility, I would have no time or energy to do anything else in my life. We are well past the 21st birthday of the DDA and there is just no excuse for any inaccessible public premises anymore. We should be able to lay a complaint to a third party body who will inspect and enforce standards.

Planning, design, management and regulation of the built and natural environment, including commercial premises, housing, public spaces and amenities. Transport services and infrastructure. Communication and information systems.

People with disability believe little progress has been made in challenging prevailing attitudes towards disability. There are still widespread misconceptions and stereotypes informing the attitudes and behaviour of service providers, businesses, community groups, governments and individuals. This is impacting on the rate of change and policy across areas in government. For example, in Western Australia the Department of Health working with Disability and Housing engaged with people with disability on options for closing a multi-bed institution for people with spinal injury to our investing in more contemporary options of housing and support. Meanwhile another arm of government has given land to a different service provider to build a multi-bed institution for people with degenerative disability next door to where the original institution would be closing.

In the built and natural environment, the lack of access to buildings and facilities is a barrier to full participation in the community, and there is considerable frustration at the slow pace of change at the practical and policy level to ensure universal design principles are included in the development of all new public and private buildings and

infrastructure. Many of the respondents to our survey said that they felt that complaining was useless 'Nobody Listens', that they either didn't know how to complain or who to complain to, or that they felt scared to complain.

30% of our survey respondents said that they could not access the community readily from their home without getting in a car or van first. When asked what the difficulties

The footpaths are shocking. Not level and not enough light at night. Cars parked on footpaths, road works where footpaths should be.

in accessing the community were, the issue of curbs and lack of curb ramps, as well as missing or badly maintained footpaths came up consistently. Our survey responses showed that people were still finding lack of access in many buildings, particularly buildings having accessible toilet

facilities, as well as signage being clear. Another consistent issue was being able to access transport and safe pedestrian crossing points. People found that they generally could go to large facilities such as major shopping centres or major recreational areas or parks but had a lot more difficulty accessing small local parks, local shops, and particularly those shops with street frontage. For example a small local park may have a playground but no footpath to get to the park or to the playground, and no seating next to the playground. **(Recommendation five)**

In terms of housing, 29% of housing tenants in public housing are on a Disability or Medical Support Pension while another 30% are on Age Pension in WA. Our survey showed that those in public housing were still not in accessible housing with comments like 'Our housing is 70% accessible for us'. It is important to build new homes which are more accessible and easier to adapt to an individual's specific needs. There also needs to be a focus on retrofitting existing houses to these same accessible standards. This will benefit people with disability across the age spectrum. There is a major issue here that is contributing to the problems with housing supply in the NDIS. Modifications to make houses accessible are expensive and in a private rental are often required to be able to be removed at a later point in time. This means that people with disabilities who require accessible housing turn to the public housing market first to get a house that has been purpose-built. It is extremely difficult to get private rental that is already modified and buying a house and paying for major modifications is often just out of the realms of their

We have asked HomesWest for a wheelchair house, a three bedroom, as my mum will end up in a wheelchair plus I need a carer to stay to help me when mum is in hospital. They told us none is available in our area and maybe years, so we might have to look elsewhere as it not fair on mum either. Plus the paramedic can't get into our unit as the stretcher don't fit so I have to be hoisted outside by the patio for all the neighbours to see. Been waiting since July 2015.

capacity and available funding for most people with disability. On top of this, the Department of Housing still encourages outdated models of housing with their website stating ‘... *The Housing Authority may build group homes or cluster unit developments to meet a person's disability and social needs. The Housing Authority manages a number of programs and a purpose built home can be constructed within any of these. For example group homes and cluster strata titled units are provided through the Community Disability Housing Program.*’ **(Recommendation six)**

Barriers due to transport options also came up frequently in our survey, and this is consistent with other consultations we have done on access to community services and facilities. Transport consistently comes up as the second or third barrier in every area, from access to health and education, and to issues with the NDIS. Firstly, we would like to point out that covering the cost of transport is still a major issue in NDIS plans. We have seen numerous complaints about how much transport a person can get covered in their plan and how service providers pay or do not pay for transport that they may provide for accessing the community. The lack of access to public transport often forces heavy reliance on the expensive and sometimes unresponsive taxi system. People with disability who are reliant on taxis as their main transport cannot afford to go out, with extra costs ranging from \$40 to \$100 a day depending on where you live (if you were going to work 4 or 5 days a week you could be paying \$200 to \$500 a week in taxis after taxi subsidy in WA). Both public transport and taxi's in regional and remote areas are extremely limited or non-existent. The diversity of disability means that although the ideal might be to have fully accessible public transport as the transport option for people with disability, in practice that is just not possible for everyone.

I have limited access to public transport and taxis are prohibitively expensive. I often have no choice but to walk up to 7-8 kilometres between public transport services.

Although we are strong advocates in ensuring that public transport is fully accessible to all people with disabilities we acknowledge that there are a small number of people with very high support needs, that may have large electric wheelchairs, and/or challenging behaviours, that find public transport extremely difficult to use. Within this there are also a group of people who have difficulties when using taxis. On top of this there is still the issue that the public transport system is not fully accessible for people with disabilities and there are ongoing cases of discrimination by taxi drivers, plus an inadequate supply of multipurpose taxis. For some the issue is due to location and footpaths missing as important access links, forcing people to use roads unsafely or not go out. Transport issues must be addressed to reach the realisation of the National Disability Strategy. **(Recommendations seven and eight)**

Access to information remains is another area that remains problematic for many people with disability. There is no consistency in providing information in alternative accessible formats, including easy English versions, and apart from those government departments that specifically provide disability -related information there seems to be little effort to make things even plain English. There is also a lack of alternative formats

for people who are deaf and hearing impaired when generally dealing with businesses and government departments. **(Recommendation nine)**

Potential barriers to progress or innovation

Education- People with disability report the education system is desperately under-funded and staffed by teachers who received little or no training with regard to disability. There is widespread ignorance and fear of disability and little or no promotion of the benefits of inclusion. Parents consistently tell of their the lack of choice of educational setting and the measures they were forced to go to in order to ensure their child had basic needs addressed. People with disability support the notion requiring all teaching degrees to have a compulsory disability component and insure this element is achieved before a new teacher can be registered. Ensuring that all teachers are trained in how to teach students with disability and that all schools prioritise professional development in disability for existing teachers is important. Providing in-class support, trained professionals like occupational therapists and speech therapists, as well as equipment and facilities will assist people who require additional support. We believe that States need to increase the funding for Education Assistants and match this resource to individuals student's needs, which will assist in achieving better outcomes for the person with disability. There is also a need to require all new schools (and those that are substantially upgraded) to have facilities that cater for students with a disability. This includes full accessibility of all infrastructure, teacher training to ensure teachers teach for all children and creating a school environment that welcomes children with disability, including participation in extra-curricular activities and school community social events. **(Recommendation ten)**

Zero support, We tried. Lack of safety at mainstream school, lack of individual curriculum, assumption that he should be in a special education setting.

Employment- There still needs to be a cultural shift in the perception of employing people with disability. One of the fundamental concerns for people with disability is that a whole raft of changes can be made to make it more effective for people to access employment but unless there is a similar investment encouraging employers to employ people with disability their prospects will remain poor. People with disability believe better links need to be forged with employers to promote the value of employing people with disability couples with funding investment to support community education, and media campaigns. There needs to be a greater emphasis from the public sector including government to employ people with disability, leading by example to promote the benefits to other professions and industry. People who sit on recruitment panels should have a greater understanding of disability, training on disability awareness should be part of process to become a panel member. There needs to be better connection from school to employment so that all school leavers with disability are eligible for the Eligible School leavers programme and ensure that

they are referred to Disability Employment Services. Our experience is that Business will not make change only on good will so there must be incentives for business to participate in disability awareness and inclusivity training, reducing barriers for the inclusion of people with disabilities in the workforce at an organisational level.

(Recommendations eleven and twelve)

I want education to decrease general community ignorance. An agency that can liaise with businesses to help pwd integrate into that business. Better attitudes from employers, better access to education and training, more flexibility eg working from home and adapting workplaces

Perception- People with disability are often seen as 'other' to the normal range of expectations the community has, and so it is then easier for people with disability to be treated differently. What we see as neglect or abuse in the general population, (such as being in a locked cupboard at school) is seen as being necessary management of disability. To counteract this tendency to see people with disabilities as 'other' there needs to be a more natural inclusion of people with disability across all media and all aspects of the community.

Education, awareness raising, peer support,
Think outside the box, see our difference as
a strength not a disadvantage!

Assistive Technology- For people with disability, assistive technology has potentially life-changing effects, providing independence and peace of mind for those who need it most. Assistive technology comprises products and services used to provide assistive solutions enable individuals' functioning and participation. Assistive products include devices, equipment, instruments and software especially produced or generally available, for people with disability for better participation, to keep safe, to support and train and alleviate activity limitations or participation restrictions. The survey indicated that only 40% of respondents could access the support they needed, 38% could not. 20% were unsure which suggests that many people are unaware of what assistive technology is and what support they can get. For the people that are unsupported the main contributing factors are:

- Lack of funding to buy or upgrade assistive technology particularly relevant with App based products
- Practitioners not having the knowledge or understanding to implement technology
- Lack of specialists to install products or make repairs
- The bureaucratic process in order to receive the technology

- Lack of training available
 - Not knowing what is available or where to go to get it.
- (Recommendation thirteen)**

Students need access to learning to use assistive technology and TAFE and university courses should offer this as good practice

Access to Health Services - People with disability indicate that more training and education of health and allied professionals is required. This will ensure people with disability are treated and with dignity and respect when they present at healthcare facilities. The diversity of disability means that for some people there is a strong need for family and carers to be engaged, while others often find they are overlooked and health professionals only speak to the family member and not them. Health-promotion material needs to be accessible to people with disability including plain and easy English, and that better data collection is needed to monitor the overall health outcomes of people with disability. People with disability sited poor physical access to GP surgeries, allied professionals and hospitals. Some people disclosed that the

Many GP surgeries are still inaccessible, particularly examination tables. Many GPs have a very poor attitude toward this. Allied health is another major area where the physical premises are often not accessible. We were referred to a speech therapist who was up a huge flight of stairs; even my local physio has a step at the door!

facilities provided for in-patients at hospitals were very inadequate for their needs. There is a fundamental flaw for oral health and people with disability, many dentists' premises are inaccessible, it is extremely expensive for

treatment and there are very few dentists who are equipped to cater for the diverse range of people with disability. This relates back to a strong need to push for Access to Premises compliance for key services. **(Recommendation twelve and fourteen)**

Impact of restricted access for people with disability on inclusion and participation in economic, cultural, social, civil and political life

Our survey indicated that over 50% of respondents felt they WERE NOT included in social, sporting or cultural activities compared to 26% who were. Sadly, many of the comments to support this include:

- Social Stigma
- Inadequate access
- Exhaustion
- Not enough support

- Poor facilities/lack of facilities
- Barriers to social acceptance

“I’m not offered enough social support to get out amongst my community... Or there are not enough accessible activities within my community there is definitely not enough mental health support”

“..you are forever having to justify 'your' existence in 'their' world. It becomes tiring. Very quickly.”

“We have had families pull out of events we were participating in as they were uncomfortable being around my child with ID”

“..many inaccessible environments. This includes inaccessible performance spaces (I am in a choir), where it is assumed that there might be disabled people in the audience but never on stage”

The real impact of this restricted access is that people with disability are more likely to stay at home inside, with less variety of people around them, remaining in poverty. This leads to being at higher risk of mental health issues, and risk of abuse and neglect. It is also just exhausting.

There are very few people with disability who are in positions of influence and power that can make real change. When people work hard and get into positions of influence they are seen as ‘inspirational’ and the focus is on ‘overcoming adversity’. This feeds into the narrative of those that are not successful being objects of pity or just needing to try harder. Access to civic and political life becomes more difficult with this narrative.

There are also different issues for people with visible disabilities and those with invisible disabilities, particularly cognitive disability. The impact of restricted access can lead to abuse, neglect, and possibly interaction with the Justice and child protection systems.

Access to justice -A key factor contributing to the higher than average arrest rates for people with disability is insufficient police training. Currently, police training primarily deals with discrete disability issues instead of taking into account the ongoing social supports and needs of people with disability. Experience and statistics also indicate that Australia has failed to train prison system personnel and police to facilitate access to justice. Training in

The lack of accessible information when an incident occurs. Police reports that you have to sign without knowing what you are signing and proper representation cannot be afforded.

providing accommodations and supports to people with disability is neither compulsory nor consistent across different jurisdictions for judicial officers, legal practitioners and court staff. A lack of awareness about disability issues leads to discrimination and negative attitudes which create barriers to accessing justice.

People with disability can face barriers to establishing credibility when interacting with the justice system. Assumptions about the credibility of people with disability, in particular people with cognitive disability are constantly made by police and court officers, such as prosecutors, judges and magistrates.

Safeguarding - A quality and safeguards framework should enable people with disability to express freedom of choice with service providers who are transparent, flexible, and over all accountable. However, a significant amount of support and work is needed to ensure that this translates to practice as traditionally, people with disabilities have had little control over who provides services, information and support and how their service is delivered. The Senate Inquiry into violence abuse and neglect of people with disability had a number of recommendations that we are still waiting to see enacted properly. We think it is important to create an independent statutory complaints body and a mandatory reporting system for the elimination of restrictive practices. The body should work with mainstream safeguards including consumer affairs, police and court systems to ensure people with disabilities can use and access them, information is shared, and that mainstream safeguards will respond appropriately. Another important national safeguard is an independent 'Community Visitor Scheme' is established to monitor institutions where people with disability may be such as mental health facilities, group homes, education support units and special schools, justice centres and prisons accommodation facilities, in order to ensure that people with disability are not being subjected to abuse and neglect.

The role of advocacy is a necessity and needs an enhanced role in the NDIS Quality and Safeguarding framework, and in the need for the rights of people with disability to met in mainstream services and the community. Advocacy should be recognised accordingly and funded appropriately. Advocacy will support individuals to prevent and resolve issues; it will provide feedback for continuous improvement and ultimately reduce the need for corrective measures through a better resourced and more effective development domain which building natural safeguards includes. **(Recommendation fifteen and sixteen)**

I want to use advocacy. I feel I am not being heard as I am seen as a 'minority'. I want to be heard as a human being in need of PRODUCTIVE assistance and direction.

Economic Security –National data from the Australian Council of Social Service that reports 620,600 people with disability in Australia are living below the conservative, internationally accepted poverty line used to measure financial hardship in wealthy

countries. This accounts for over a quarter of people with disability in Australia. We asked respondents to our survey if they struggled to pay bills. Over 70% of people indicated they did struggle to pay bills. The main areas for concern include: electricity, gas and water, housing maintenance, health costs and medications and food. Many respondents are sacrificing therapy support and equipment so that they can pay for basic human needs such as shelter, and food. Many people rely on in-kind support and the generosity of others to maintain a quality of life. It is important that any welfare reform does not increase the hardship for people living in poverty. There is huge concern from people with disability, their families and carers and those that advocate for people that recent changes to benefits have had a detrimental effect for many of the people it is meant to support.

Conclusion

In conclusion, it is important that the National Disability Strategy challenges systems to fulfil their legal and best practice obligations by ensuring the enablers of the disability support system are adhered to fully. It is imperative that the key decision makers in mainstream areas such as health, housing and local government have an understanding of the need to include people with disabilities and an understanding of their obligations under the UNCRPD.

The person with disability must be the priority and mainstream services must integrate to provide services that are person centric and provide equal access regardless of the type of disability or location of the individual. Many government departments now employ disability inclusion or community development officers. It is essential that these officers are working within the parameters of the National Disability Strategy to develop strong networks which broaden the range and increase the reach of people with disability to ultimately enhance best practice in mainstream delivery. It is critical that effective training is provided to ensure best practice in mainstream services; PWdWA recommends that a network of trainers be created to ensure training is delivered by people with disability or people with experience of disability. Developing mechanisms, including peer support and self-advocacy, that empower individuals to be meaningfully involved will create policy and strategy that is meaningful for the people it is intended to support.

PWdWA strongly support the role of independent advocacy in the National Disability Strategy through the interface with National Disability Advocacy Programme and State funded advocacy. It is important to ensure both the individual and collective voice of people with disability is elevated and that service providers and mainstream services are continually challenged to improve through constructive and independent feedback. PWdWA is ideally placed to continue its role as independent advocate at an individual level, evidence provided from this is able to inform and direct systemic change.

There is a hope that the outcomes framework of the Information, Linkages and Capacity Building program of the NDIS and a more robust action oriented National

Disability Strategy will address some of these areas with the emphasis on building the capacity of community to include people with disability. The fear is that there will not be enough funding and that there will not be enough involvement and co-design by people with disability. People with disability understand the barriers to their inclusion and need to be at the forefront of ensuring access and inclusion initiatives meet their needs. **(Recommendation fifteen)**

Appendices

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