

AMPARO Advocacy

Submission on the

National Disability Advocacy Framework

July 2022

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Introduction

AMPARO Advocacy (AMPARO) welcomes the opportunity to make a submission on the draft National Disability Advocacy Framework (NDAF) 2022 -2025. Whilst not exhaustive, we highlight key arears for improvement in the Framework.

AMPARO Advocacy (AMPARO) is a non-profit community organisation funded by the Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships to provide independent, individual and systemic advocacy with and on behalf of vulnerable people from culturally and linguistically diverse (CALD) backgrounds with disability.

AMPARO is recognised as a Disabled Persons Organisation being governed by a voluntary management committee, the majority of whom are people from a CALD background with disability.

AMPARO is well respected across the multicultural and disability sectors as the only organisation in Queensland that specifically works to protect the human rights and wellbeing of vulnerable Queenslanders from CALD backgrounds with disability and has done so since 2004. The majority of individuals that AMPARO works with are from refugee backgrounds experiencing multiple and complex layers of disadvantage, often isolated from their own communities with limited English proficiency and not accessing mainstream services or specialist disability services, including the NDIS, to the levels they should be.

AMPARO would like to acknowledge the excellent work of the Disability Advocacy Network of Australia (DANA) and add our support to the submission by DANA on the draft Framework and what is needed to realise its intended Outcomes.

AMPARO's Vision of independent advocacy.

AMPARO's individual advocacy addresses serious issues of social and economic isolation, unfair treatment and discrimination, we represent those who are least able to defend their own rights and interests so their fundamental needs are met, and they can actively participate, engage and contribute to family and community life. AMPARO believes that independent advocacy is needed to ensure equitable access to government and community services and important information and to support the full inclusion of people with disability across all levels of society.

Our Mandate

AMPARO Advocacy takes our mandate from important United Nation declarations, Federal and State antidiscrimination laws, policies and principles which promote the rights of all people as well as expectations for the lives of people from a NDIS with disability.

The **Convention on the Rights of Persons with Disabilities** in particular provides advocates with a mandate to assert the rights of people with disability to education, health, work adequate living conditions, freedom of movement, freedom from exportation and equal recognitions before the law.

Principles of Social Advocacy

Independent social advocacy is provided in a way that respects and meets the language, cultural and religious needs of the person and group and is guided by a strong commitment to the following principles of:

- Human Rights
- Social Justice and
- Inclusive Living

Key Elements of AMPARO's Social Advocacy

- 1. Taking positive, ethical action
- 2. Being on the side of someone who is vulnerable
- 3. Understanding the position and life experiences of the person
- 4. Being independent with minimized conflicts of interest
- 5. Focusing on the fundamental needs,

AMPARO's Independent Social Advocacy:

- welfare and interests
- 6. Doing advocacy with vigour and a sense of urgency
- 7. Remaining loyal and accountable over time
- 8. Acknowledging the possible costly nature of advocacy.
- Represents the rights, interests and wellbeing of people with disability who do not have a voice, or close family or friends who can support their aspirations or speak on their behalf.
- Addresses serious issues of discrimination, violence, abuse and neglect of people with disability.
- Builds individuals capacity to understand their rights and voice their concerns where possible.
- Provides important information in an assessable and meaningful way so they can make informed decisions
- Provides intensive advocacy assistance for individuals to:
 - Resolve complex service provision or complaints issues
 - Deal with discrimination, criminal and child protection issues
 - Fully participate in mental health and guardianship tribunal hearings
 - Access government benefits, payments, pensions and support services
 - Access essential information and state funded mainstream services, including housing, health, education, and language services
- Prevents an escalation of the person's issues and vulnerability, and in the long term saves government and public resources.
- Seeks to build and repair close relationships around the person, an important safeguard.
- Identifies systemic failures and brings these to the attention of those in positions of power and influence to effect positive changes in practice, policy and legislation.
- Respectfully challenges poor approaches and responses from service systems.
- Encourages services to meet their obligation under Federal and State Policy Frameworks and to work in ways that are culturally safe, competent and responsive.

Why is Independent Social Advocacy Needed?

AMPARO's experience is that Queenslanders from CALD backgrounds with disability and their families confront additional disadvantage and multiple barriers that prevent them having: equitable access to important services and information, understanding their rights, exercising choice and control, and resolving concerns.

As a result, they can experience discrimination across many areas of life, and experience poorer health, higher levels of unemployment, social isolation, financial disadvantage, and housing stress. Furthermore they are often not accessing important mainstream services or specialist disability services, including the NDIS, to the levels that they should be, including early intervention supports for children.

As the Disability Royal Commission has shown, many people because of their significant impairments and decision-making capacity, are NOT able to speak up or voice their concerns nor are they able to challenge services and systems that do not meet their needs or are in fact harmful.

AMPARO reported to the DRC that, people with disability from CALD backgrounds and their families often experience '*ongoing exclusion*' within their community, and that '*stigma and shame*' can contribute to their being: less likely to seek help outside of their immediate family, more isolated from other people in their communities and lacking understanding of the rights and options available to them.¹

The Disability Royal Commission's Interim and Progress reports highlight that '*culturally and linguistically diverse people with disability can experience multi-layered discrimination and disadvantage'* and widely acknowledge the intersectional disadvantage this cohort experience, including:

- Multiple forms of discrimination, including on the basis of disability, race, ethnicity, language, location and visa status.
- "The cumulative disadvantages experienced by particular groups of people with disability, especially First Nations people and members of culturally and linguistically diverse communities."²
- Encounter particular barriers based on attitudes towards disability and ethnicity, as well as being unable to access information.³
- Often becoming isolated by having little connection with other people with disability or people from their cultural community ⁴
- Lack understanding of the rights and options available to a person with disability.
- *"People with communication disability, culturally and linguistically diverse people with disability and people with intellectual disability are particularly likely to be excluded."*⁵
- No reliable data available on violence against, and abuse, neglect and

¹ Royal commission into Violence, Abuse, Neglect and Exploitation of People with Disability- Overview of responses to the Experiences of culturally and linguistically diverse people with disability Issues paper. (November 21), p

² Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p1.

³ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p17.

⁴ Royal commission into Violence, Abuse, Neglect and Exploitation of People with Disability- Overview of responses to the Experiences of culturally and linguistically diverse people with disability Issues paper. (November 21), p5

⁵ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p9.

Systemic Advocacy

AMPARO's direct work with individuals, families and diverse communities, informs our understanding of the additional barriers and systemic failures that impact on the lives of people from CALD background with disability. AMPARO has been funded since 2004 to undertake systemic advocacy to bring these issues to the attention of those in positions of power and influence in Government and community, to effect positive changes to policies, practices and approaches that contribute to issues of inequality. AMPARO frequently shares our knowledge of the lived experiences of people from CALD backgrounds with disability to increase understanding of the specific challenges and additional disadvantage this cohort experience.

AMPARO has a long and respected history of contributing to the understanding of systemic issues at the State and Federal level and continues to be invited to attend consultations, workshops and to provide feedback on reports etc. to share our learnings from the individual advocacy work and other targeted outreach projects. Our submissions and attendance at public hearings are often quoted in Reports by Standing Committees on various inquiries, the Disability Royal Commission etc. At the Federal level this year, AMPARO has been invited and has contributed to the Refresh on the NDIS CALD Strategy through several meetings this year with the NDIS and the NDIA Advisory Council.

Unfortunately, the Queensland State Government in 2021 introduced a new state advocacy program, without consultation with Queenslanders with disability and advocacy agencies. AMPARO and other organisations lost the systemic advocacy funding they were receiving under this program.

The loss of targeted systemic advocacy by a Disabled Persons Organisation, that witnesses daily the negative impacts of poor service provision and complex systems on individuals from CALD backgrounds with disability and their families, is of great concern. The Productively Commission Report into the NDIS identified that both individual and systemic advocacy play an important role in *"ensuring independent oversight of institutional settings and … to preventing and addressing violence against people with disability".* ⁶

Strong Support for Independent Advocacy

There is strong support for the Federal, State and Territory Governments to continue to fund independent individual and systemic advocacy for people with disability:

- The Convention on the Rights of Persons with Disability (CRPD). Article 4 of the Convention of the Rights of Persons with Disabilities states that 'advocacy organisations have an important role to play in the implementation of the CRPD'.
- National Disability Insurance Scheme Act 2013 recognises the need for independent advocacy for people with disability that is separate from the Agency, the Commission and NDIS providers and free from conflicts of interest. And the General Principles guiding the NDIS articulate a commitment to "support the role of advocacy in representing the interests of people with disability."
- **Disability Reform Council (DRC) on 13 December 2019 agreed** that funding of independent disability advocacy is a responsibility shared by all jurisdictions.

⁶ Australian Government Productivity Commission – NDIS Cost, Productivity Commission Study Report (October 2017),p

• Australian Human Rights Commission's report, A Future Without Violence: Quality, safeguarding and oversight to prevent and address violence against people with disability in institutional settings (June 2018) asserts that:

A lack of individual advocacy services may result in people with disability being deprived of an advocate who is independent of service providers and the NDIA to promote and protect their rights, and may limit people's ability to identify and raise issues of violence abuse and neglect, as well as meaningfully participate in any quality, safeguarding and oversight processes.

- The 2011 Productivity Commission Inquiry Report into Disability Care and Support noted the importance of independent systemic advocacy in uncovering system failures, agitating for systemic change, disseminate best practice principles to service providers, and promote public awareness of the lived experience and needs of people with disability.
- The Productivity Commission Report into the NDIS (Oct. 2017) recommended that Australian State and Territory governments continue to fund disability advocacy organisations. The commission argued *that*:

"Both independent individual and systemic advocacy play a critical role in ensuring independent oversight of institutional settings, and contribute significantly to preventing and addressing violence against people with disability in these contexts. Commonwealth, state and territory systems must take steps to ensure that independent individual and systemic advocacy organisations have the necessary powers and are adequately funded to undertake their work within the Safeguarding Framework."⁷

• The Interim Report the DRC highlights the important role of disability advocacy:

"Advocacy and representation enable people with disability to have their voices heard at all levels of society and to influence issues of deep concern to them.... We have heard from many advocacy and representative organisations that increased advocacy is a key measure to address violence, abuse, neglect and exploitation and would lead to a more inclusive society. We have also heard that there is a lack of advocacy services, including for First Nations people with disability and people with complex needs, and that existing advocacy services are underfunded."⁸

1. Does the NDAF identify what is needed in the current and future disability environment? If no what changes need to be included?

Definitions of Advocacy are limited.

AMPARO would agree with comments made by the **Disability Advocacy Network of Australia's** (**DANA**) in their submission, that independent advocacy does far more than "…enable people with disability to participate in the decision-making processes that safeguard and advance their human rights".

⁷ Australian Government, Productivity Commission Report into the NDIS. (October 2017).

⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p18.

AMPARO believes that people with disability have the natural authority to influence the direction of their own lives, or where they have limited capacity, that their family where possible retains this authority. Advocates support informed decision making by providing meaningful, accessible information in relevant formats, about rights, choices and options.

However Representative Advocacy is often need to protect the rights, interests and wellbeing of people with disability who do not have a voice, or close family or friends who can support their aspirations or speak on their behalf. Some people are more vulnerable than others due to their disability or circumstances and may be unable to "participate in decision-making processes that safeguard and advance their human rights", or to challenge services and systems that are not working in their interests or are harmful.

The following statement on the National Disability Advocacy Program website captures some of what is important to independent advocacy.

Disability advocacy is acting, speaking or writing to promote, protect and defend the human rights of people with disability. The Australian Government, and some state and territory governments, fund independent advocacy to help people with disability who face complex challenges or are unable to advocate for themselves, and do not have family, friends or peers who can support them as informal advocates, to access advocacy support.⁹

AMPARO also considers that the advocacy definitions in the Framework have been over simplified and other important forms of advocacy are missing. We recommend including other important forms of advocacy, such as Citizen Advocacy, family advocacy and legal advocacy, as in the previous Framework and available on the Departments of Social Services, National Disability Advocacy Program website.

In undertaking the review of the disability advocacy framework, it is important not to lose valuable information that has long been recognised as critically important to protecting the rights of people with disability and this includes the value of different forms of advocacy.

 AMPARO also supports DANA's recommendation to include other international human rights treaties to inform and support the implementation of the Framework.

2. Are the principals of the NDAF Appropriate for guiding the delivery of advocacy for people with disability?

The broad principles informing the National Disability Advocacy Framework for 2022-2025 are supported by AMPARO, however we would strongly recommend the addition of the following:

 Independence: Being independent with minimised conflicts of interest must be included as a standalone principle.

⁹ Australian Government, Department of Social Services. Disability Advocacy, 6 July 2022. <u>National Disability</u> <u>Advocacy Program | Department of Social Services, Australian Government (dss.gov.au)</u>

Being independent with minimised conflicts of interest means that advocacy organisations and advocates make concerted efforts to minimise ways that their advocacy efforts can be compromised. To this end, advocacy needs to remain apolitical, as well as independent and distinct from service delivery. People (advocates) need to identify and deal not only with real, but also with perceived conflicts of interest caused by having other roles and allegiances. They also need to identify factors that might compromise their own efforts by examining their attitudes, values, needs and relationships, to minimise personal conflicts of interest.¹⁰

The Fact Sheet on Disability Advocacy, currently on the Federal Government's Department of Social Services Website, articulates well why advocacy needs to be independent:

Why Does independence matter?

A disability advocate must be independent and act solely in the interests of the person with disability who they are supporting. An advocate cannot be independent if they, or the organisation they work for, might benefit in some way from influencing the outcomes of the advocacy – this would be a conflict of interest. A conflict of interest can happen in many situations, for example, a support worker helping a person with disability to resolve a complaint about the disability service that employs the support worker. Government-funded independent advocates can act solely on the side of the person with disability and without a conflict of interest.

This differs from National Disability Insurance Scheme (NDIS) Local Area Coordinators, for example, whose role is to link people with the NDIS and to provide information and support in their community, but not to act as advocates. It also differs from NDIS Support Coordinators who have an interest in 1 National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Act 2017 (Cth) s9. maintaining services and/or funding relationships and have restrictions on how much they can support the direct wishes of the person with a disability.¹¹

In this **Fact Sheet** the Department of Social Services shows a strong commitment to the important principle of independence to ensure *"advocates are solely on the side of the person with disability and without conflict of interest"*. ¹²

AMPARO has often witnessed situations where because of competing demands, services providers put the needs of their organisations, staff or funding bodies before the needs of persons with disability they are meant to serve. This often results in the abuse and neglect of people with disability; there is ample evidence of this in the current findings of the

¹⁰ Mary Kenny and Jan Dyke. *Promote Protect Defend Advocacy in the lives of people with disability*. A learning resource to stand by, for and with people with disability. (Oct.2004),p 12

¹¹ Australian Government, Department of Social Services. Disability Advocacy Fact Sheet, 6 July 2022. (<u>https://www.dss.gov.au/sites/default/files/documents/12_2018/disability-advocacy-fact-sheet.pdf</u>).

¹² Australian Government, Department of Social Services. Disability Advocacy Fact Sheet, 6 July 2022. (<u>https://www.dss.gov.au/sites/default/files/documents/12_2018/disability-advocacy-fact-sheet.pdf</u>).

Disability Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability.

• AMPARO welcomes the inclusion of <u>Respect for Intersectionality and Diversity</u> as an important principle, however this need to be reworded and strengthened.

People from CALD backgrounds with disability continue to be significantly underrepresented in accessing, specialist disability services, including the National Disability Insurance Scheme (NDIA), and independent advocacy. The ongoing disparity of access continues largely because disability service systems, including advocacy agencies, have not been well funded or supported to develop cultural competence at all levels of their organisations and to embrace the principles of substantive equality and non-discrimination.

AMPARO believes that the principle of <u>Respect for Intersectionality and Diversity</u> must be strengthened, to ensure advocacy is delivered in ways that both recognise and address the additional barriers people with disability experience as a result of the intersectionality and diversity.

The Australian Multicultural Access and Equity Policy developed in 2018 should be included as a key principle in this Framework, to support the development of <u>culturally competent</u>, <u>safe and</u> <u>person-centered practices</u> across the advocacy sector.

This policy aims to to ensure its programmes and services, and those funded to deliver services on behalf of government, meet the needs of all Australians, whatever their cultural and linguistic backgrounds.

Trauma informed practice approach should also be included as a key principle to inform the Framework.

Adopting a trauma-informed approach to delivering advocacy is critical given advocates are often working with people with disability who have experienced significant trauma over many years, the impact of abuse and neglect. Even when the abuse has stopped, the ongoing effects of trauma are often not recognised by those around them, it may be that they only have services in their lives, as a result they are rarely supported to access appropriate counselling services.

The majority of individuals that AMPARO works with are also from refugee backgrounds and often experiencing the ongoing effects of Post-Traumatic Stress Disorder (PTSD). AMPARO's staff recognise the signs of trauma in individuals and families and seeks to respond effectively.

The National Disability Insurance Scheme and Demand for Advocacy

Historically people from CALD backgrounds with disability have largely missed out on State funded disability supports due to the systemic barriers that existed in those systems of supports. Through our advocacy work we assist individuals to understand, access and navigate mainstream and specialist disability supports including the NDIS. We see daily the enormous difference the NDIS can make to

people's lives. Since the early development of the scheme AMPARO has strongly advocated for the NDIS to be designed and delivered in a way that would meet the needs of CALD participants, that is culturally competent, responsive and person centred.

Unfortunately however the NDIS is a complex specialist disability service system that has been poorly designed with structural barriers and limitations that make it difficult and sometimes impossible to navigate. As a consequence people from CALD background cannot equitably access and participate in the Scheme. Because of this we continue to witness lower than expected participants from CALD backgrounds and too many failing to implement their plans, often because of a lack or total absence of Support Coordination funding, because the additional barriers they experience are not well understood or acknowledged by NDIS planners.

There has been a significant increase in the demand for individual advocacy since the roll out of the NDIS in Queensland. AMPARO receives requests for individual advocacy to assist with:

- Understanding their rights in relation to the NDIS, the potential benefits of accessing the scheme and what is necessary
- Access to the NDIS, including support to undergo medical assessments to secure a diagnosis of disability and evidence of impact of their impairment
- Assistance with Plan reviews because they have either not been able to implement their plans or have poor NDIS Plans that cannot meet their fundamental needs.
- Changing service providers as they are receiving poor NDIS support
- Ensuring service providers, including NDIS and Partners in the Community are providing interpreters and translated information

NDIS Quarterly Report for June 2022 shows that people from CALD backgrounds are still not accessing the NDIS to the levels that they should be, and not enough is being done to address issues of disparity and therefore the need for advocacy.

Across Australia:

- While 20% people with disability come from homes where a language other than English is spoken
- ONLY 9.3 % of NDIS participants are from a CALD background or speak a language other than English at home

In Queensland:

- While 13- 15 % of people with disability come from homes where a language other than English is spoken
- ONLY 5.6 % of NDIS Participants are from a CALD background or speak a language other than English at home

AMPARO has been fortunate to receive funding to undertake several projects in addition to the advocacy work, that have enabled targeted outreach with CALD communities to identify those who may not have heard about the NDIS or who need intensive support to access the Scheme. These projects have included the Multicultural Community Connector Program and the State Program, Assessment and Referral Team (ART).

However all of these projects are time limited and there is often inadequate planning and little accountability taken to ensure those identified during this work are not abandoned when programs cease. AMPARO has a policy that we do not abandon people we become aware of through this work, that may need advocacy and or other supports, and we continue to work with many people long after projects are 'completed', with our limited resources.

AMPARO believes that additional advocacy funding needs to be allocated to specialist independent advocacy agencies that understand the additional needs of people from CALD backgrounds, particularly those with limited English proficiency and a history of trauma. Specialist advocates understand the impact of systems on individuals and have the knowledge, skills and experience to respond with culturally competent, safe, person centred and trauma informed approaches to address their additional needs.

Most people that AMPARO advocates for are also experiencing many challenges accessing other Federal and State funded mainstream services, including education, health, income support, housing, family and child support, justice system and without independent advocacy many fall through the gaps and miss out on these essential services, benefits and supports.

3. Are the outcomes of the NDAF clear and achievable? Should there be others?

- AMPARO recommends that the following proposals by <u>Respondents to the DRC</u> <u>Fifth Progress Report</u>, be included in Outcomes that are expected of the National Disability Advocacy Framework, including:
- Involving people with disability from culturally and linguistically diverse backgrounds in policy development
- Strengthening data collection and use, including by standardising the definition of 'culturally and linguistically diverse' across all data collection mechanisms.
- Improving service access, navigation and quality, particularly for people whose first language is not English
- Improving the quality of disability support (advocacy support), including by providing more culturally appropriate supports and services.¹³

Furthermore, AMPARO would recommend improving data collection by including as a minimum: Country of birth, Ethnicity, Language Spoken at Home, need for an interpreter, Visa Status and Date of Arrival. This data would provide a much clearer picture of the needs of those accessing advocacy support and inform strategies and policy responses by advocacy agencies and funding bodies.

4. Are the responsibilities, reform and policy directions of the NDAF relevant?

• AMPARO would agree with DANS's comments that the advocacy sector needs <u>'strengthening, developing and expanding'</u>.

What we have seen in Queensland is an expectation that advocacy agencies meet the needs of people with disability across vastly expanded areas, with sometimes less funding or inadequate funding to

¹³ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – The Fifth Progress Report (February 2022), p45

effectively respond to the increase in demands for advocacy. This approach does not acknowledge the real need for people with disability to have access to face to face advocacy and why advocacy over the phone is often inappropriate and ineffective on so many levels.

Advocacy funding over the past 20 years has decreased in real terms with State and Federal Governments failing to pass on adequate indexation to funding to meet increasing operational costs of providing services or increases in Award wages.

The latest example of this is in the Queensland State Budget 2022-2023, where funded community services such as AMPARO, will receive indexation on funding of 2.88% when in Brisbane the CPI increased 6.0% over 2022, and Award wages will increase by 4.6%.

The Queensland Council of Social Services (QCOSS) has similarly raised concerns that the indexation being provided by the Queensland Government will not address the increased costs of delivering community services.

The cost of delivering community services has increased significantly. Unfortunately, the 2.88% indexation, which is reflected in this budget and should be applied to all community sector funding, **goes no way to funding these costs**. This month's welcome decision of the Fair Work Commission decision to increase minimum and award wages, together with the superannuation guarantee increase, result in a minimum of a 5.1% increase in labour costs for community organisations. To prevent cuts to services and job losses it is imperative that this year's rate of indexation be re-visit14.

 AMPARO agrees that the Framework should specify a commitment to fully funding disability advocacy organisation to meet the demand and need. This commitment should include ensuring sustainability and stability of the disability advocacy sector.¹⁵

The Disability Royal Commission has uncovered levels of abuse that any society would be ashamed of and made public what advocates have been saying for many years. Governments at all levels have failed people with disability, often aligning with large service providers and outdated models of support, such as group homes, that we know make people with disability more vulnerable, as is evidenced by the findings of the Disability Royal Commission. The advocacy sector across Australia is experiencing a crisis in terms of the lack of funding and increased demand for independent advocacy by vulnerable people with disability.

"Commonwealth, state and territory systems must take steps to ensure that independent individual and systemic advocacy organisations have the necessary powers and are adequately funded to undertake their work within the Safeguarding Framework."¹⁶

¹⁴ Queensland Council of Social Service (QCOSS) <u>QCOSS 2022-23 Budget Priorities -</u> State Budget Analysis (2022-2023). Viewed 8 July 2022.

¹⁵ Disability Advocacy Network Australia (DANA) Submission on the National Disability Advocacy Framework. July 2022.

¹⁶ Australian Government, Productivity Commission Report into the NDIS. (October 2017).

Finally AMPARO Advocacy would like to thank the Department of Social Services for undertaking this important review of the National Disability Advocacy Framework, and would recommend that further face to face consultation with people with disability who have benefited from advocacy and agencies funded to deliver advocacy across Australia is undertaken.

Yours sincerely

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