Neurodevelopmental Assessment Service (NDAS) Review Summary

Oct 2021

'When he got the diagnosis, I felt relieved as it's not my fault.' (parent)

'My daughter wants a diagnosis to understand herself better. People don't like labels, but she has them already, just unpleasant ones like rude, ignorant, aggressive. If she gets a diagnosis people might respond to her differently and understand her. I want her to have opportunities in the future not be stuck with the horrible labels she already feels.' (parent)

''Because we don't have a diagnosis for my daughter, we don't really know how we can help her or support her.' (parent/ carer)

Acknowledgement

Thank you to the many parents, carers, children, young people, professionals and organisations who gave their time to complete surveys and/ or be part of discussions about NDAS.
Thank you also to the whole NDAS team who continue to work in difficult circumstances to get the best service for the children, young people and families.
Particular thanks to the core NDAS team for their contributions and their ongoing dedication to this work, and to 'Thriving Families' and Highland Children and Young People Forum for their advice and help in involving children, young people and families in this review.

Background

The Neuro developmental assessment service (NDAS) for children and young people is a joint agency service between Highland Council and NHS Highland. The purpose of NDAS is to have a single process to enable differential assessment and diagnosis of a wide range of neurodevelopmental disorders in children and young people in the North Highland/ Highland Council area. Children and young people with suspected neurodevelopmental disorders frequently have complex emotional, social and health needs. A multi-professional approach ensures these needs are assessed in a way which gives confidence around any diagnosis given and aids the provision of suitable support. The specialist assessments usually build on previous assessments carried out within Health, Education, and Social Care and sits within the GIRFEC (Getting it right for every child) Childs Plan framework.

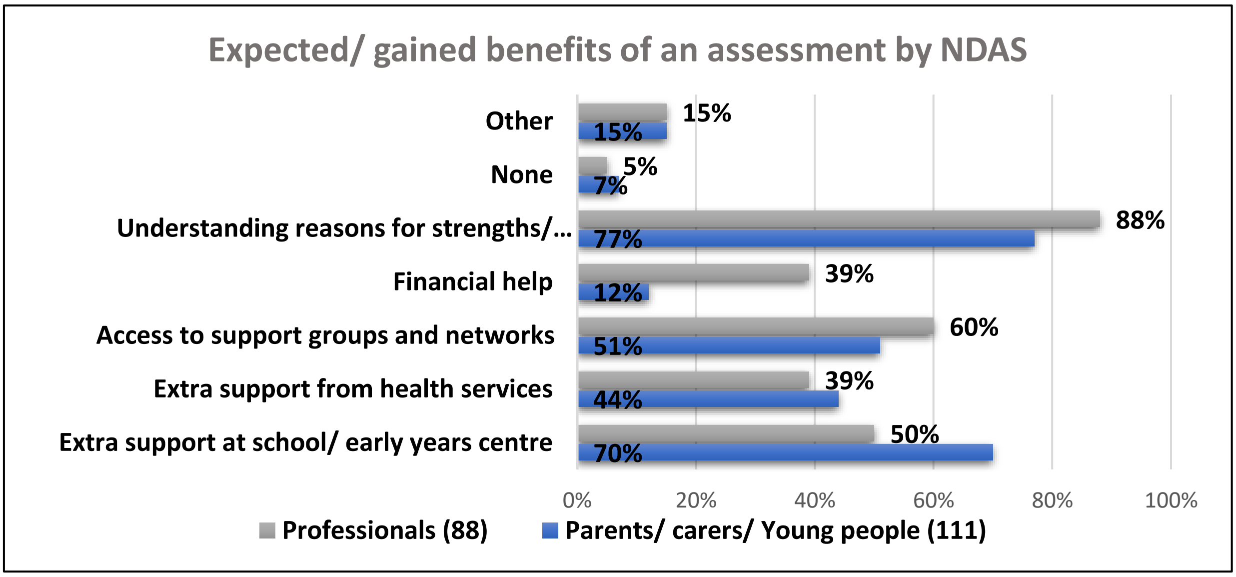
A review of NDAS was carried out in Summer 2021 which focused on: -

1. Getting the views of children, young people and families and professionals
   (Re. the United Nations Convention on the rights of the child (UNCRC) https://cypcs.org.uk/rights/uncrc/articles/ and 'The Promise' https://thepromise.scot/)
2. Understanding the Highland position – evaluating the current service provision, systems, processes and data
3. Planning for implementation of the Scottish Neurodevelopmental specification (8 Sept 2021) https://www.gov.scot/publications/national-neurodevelopmental-specification-children-young-people-principles-standards-care/

The review looked at the existing service provision, scrutinised systems, processes and data and most importantly got the views of the people who use the service to ensure improvements are shaped by the needs of children, young people and their families.

Benefits of an assessment by NDAS

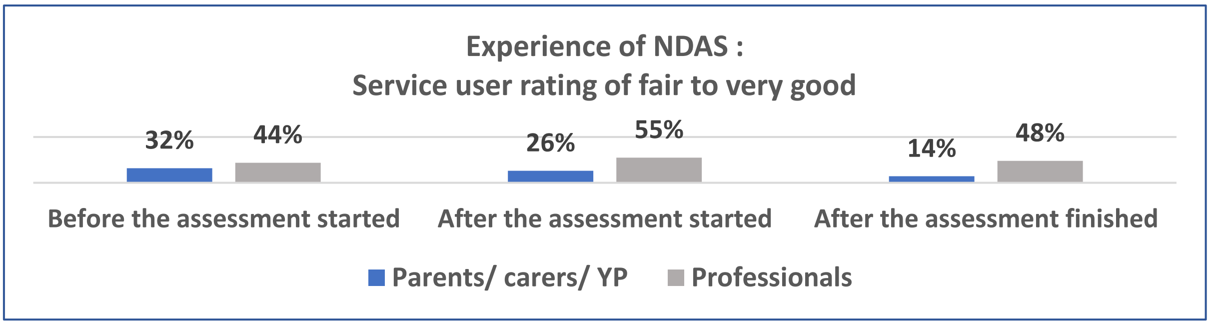
Most people who completed the NDAS survey have had, or expected there to be, several important benefits of an assessment from NDAS. *'It would help my son understand himself and also help society understand his needs.'*



Gaining an understanding of reasons for strengths and difficulties was the top response, with access to support, particularly from Education, also selected by most people. Further benefits mentioned included getting access to required medication (for ADHD- Attention Deficit /Hyperactivity Disorder) and reducing anxiety/ mental health issues.

Service users experience of NDAS

Children and young people, parent and carers generally rate their experience of NDAS poorly. Professionals' evaluations are better but still poor overall.

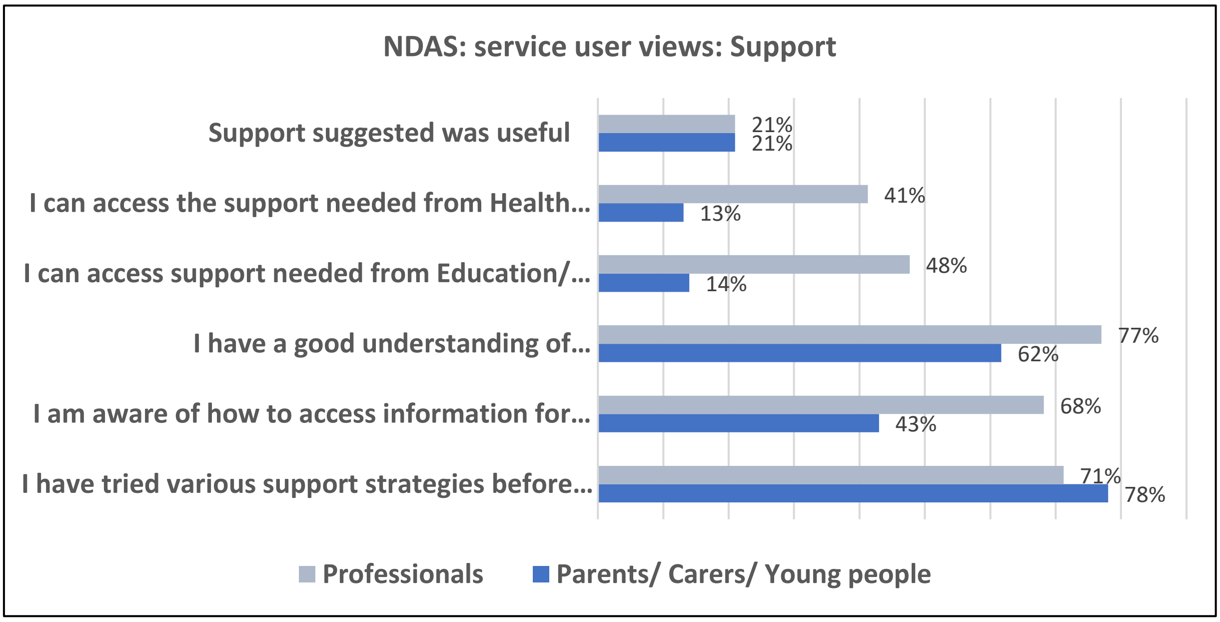


YP = Young people

The majority of respondents to the survey showed most concern around the lack of support available, poor communication, and waiting times.

Support

NDAS is an assessment service and other services provide ongoing support. However, there is currently little support available for children and young people and families during and about the assessment process and outcome. One parent said ''*There is no support offered through NDAS and that is what parents need most.'* Many people comment on the need for this type of support, along with ongoing support from Education, Health, Social Care and other services; and access to appropriate websites, training, etc.



50-60% of children and young people said the support they receive has been good.

Making support more easily available and personalised is needed. Less than half the young people and parents are aware of how to access information for advice and support. Comments included from one parent, ‘Without *the support from Thriving Families I wouldn't know who or how to contact for support’*.

The wider team do training, workshops and produce written and video information for children and young people, parents, carers and professionals. This links with the support which is available from a wide range of professions and third sector. NDAS is an assessment service, but most of the professionals involved provide support for children and young people, families and others within the rest of their working roles.

Communication

Parents, carers and professionals said there was a need for improved communication: “*There needs to be clear communication – what happens and when, what to expect, where to get support”.* Most parents felt there were huge discrepancies in the information and support they received, depending on which professional they spoke to or what school their child attended.

The parents felt it would be really helpful to have a key contact they could liaise with: “It’s *exhausting constantly repeating your story to different people”.*

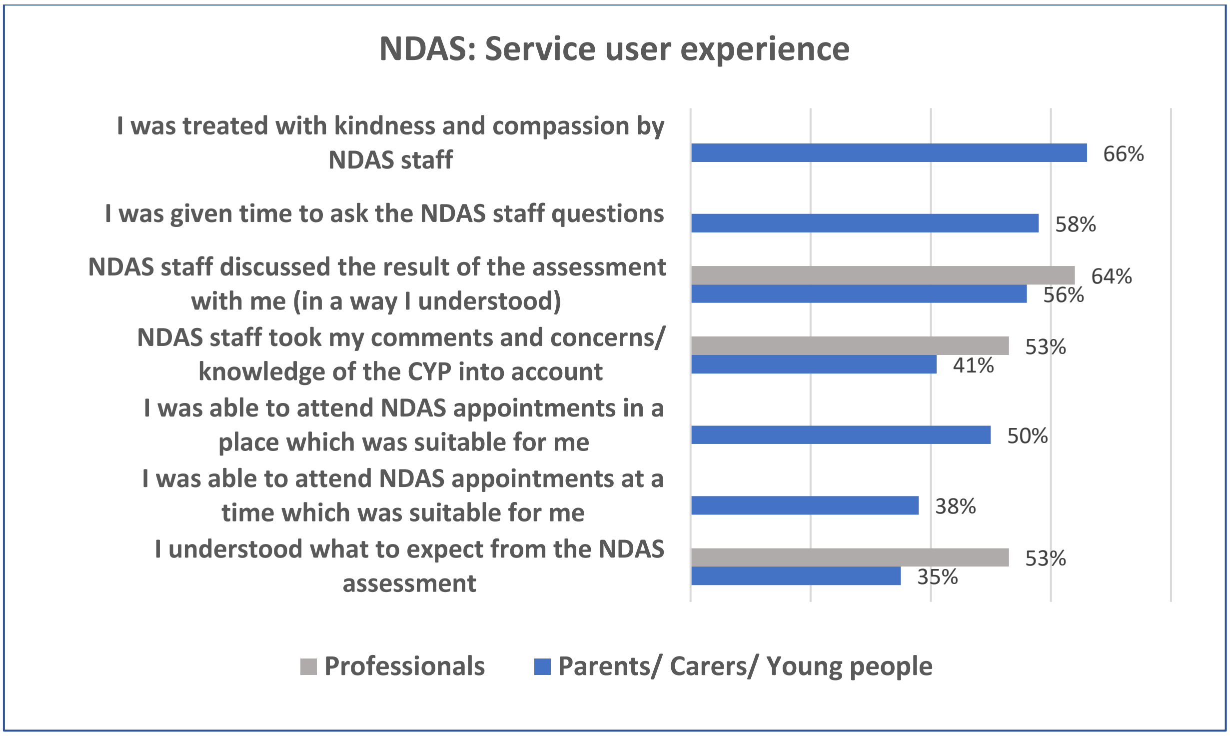
They said that emails and written information are really helpful, as well as digital resources such as online Pines sessions and Pines You Tube videos. Face-to-face sessions are helpful for some, especially where technology is a struggle, while recorded sessions would be useful for others.

They said that a post assessment follow up “*would be really important regardless of the outcome and whether you got a diagnosis – it’s overwhelming at the time, so good to have some time to think and process things, then check in with someone maybe 4-6 weeks after with any questions you have and discuss next steps”*

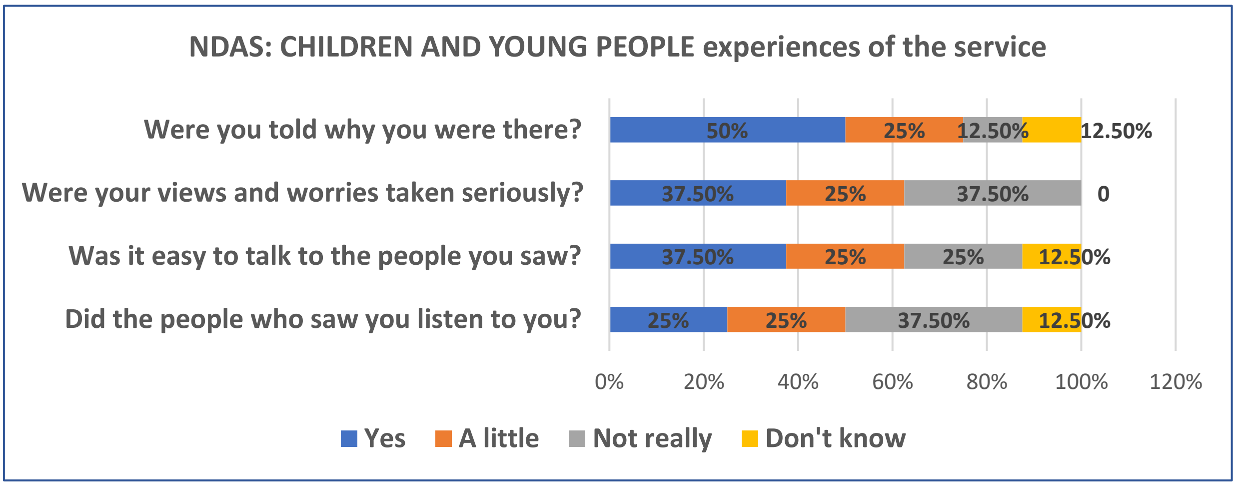
The assessment process

Survey results show that two thirds of parents felt they had been treated well by NDAS staff and just over half said that they had time to ask questions and staff had clearly discussed the results of the assessment with them. There is some work needed to improve the experience for all service users.

Only half the parents said the place the assessment was held in was suitable, so looking at whether children and young people could be seen in their local community should be considered. Patient focussed booking may also need to be considered as most said the time of appointments was unsuitable.



Children and young people mostly felt that they had been listened to and that they could talk easily with the professionals, but some had a different experience.



Most parents in the focus groups felt they were having to “*fight to get anywhere with anything”* and commented about the toll this takes on their mental health and their wider family’s well-being. Most agreed that “*It needs sorting now, not in the next 5 years. How many children and families are being failed?”*

Waiting times

The long waiting times have been the focus of all formal complaints and most informal complaints. Nearly all young people, parents, carers and professionals are very concerned about the length of time children and young people have to wait to start and then conclude an assessment. Comments from parents include- "*I accept there might be a wait of 6 months but not years and years; that's unacceptable."* and *'The time delay is wholly unacceptable. Two years plus in a child's life is far too long.'*

The current situation

Pre request discussions and Triage

Those who may want to make a request for assessment must first book a pre request discussion with an experienced NDAS professional from the core team. This was introduced to try to ensure more appropriate requests for assessment and to ensure that the children and young people are added to the right list for the right profession at the right time.

Requesters are then invited to submit information for those children and young people who are appropriate for NDAS. Once this information is received NDAS professionals triage each case and decide whether the child or young person's needs are best met by an NDAS assessment. Professions involved with NDAS can also present cases for consultation.

These discussions are prioritised above other NDAS work in order to provide signposting to other services or support if this is more appropriate at that time than a request being made to NDAS. Waiting times are usually a few weeks.

Waits for assessment to start

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The wait times for assessment to start have increased each year as there has not been staff capacity to cope with the backlog and demand and because of Covid restrictions.

The NDAS waiting times for most children and young people increased greatly during the Covid period. The NDAS professionals did some face to face and video appointments when possible following Government guidelines. However, most assessments couldn't happen as close contact and/ or observations in the child or young person's normal environment are usually needed to get an accurate picture of their strengths and difficulties. It can be difficult to assess social and nonverbal communication on video or when masks are worn.

There is still an issue with assessing some children and young people when social distancing is not possible and having to wear a mask changes the ability to evaluate strengths and difficulties. Using masks means the results from some formal assessments are not standardised.

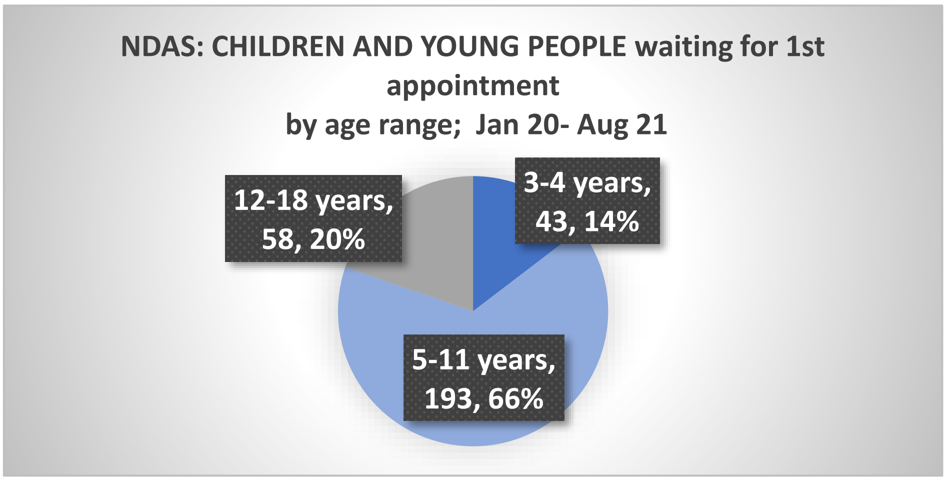
At present the average wait for assessment to start is almost 1.5 years, with some children and young people waiting well over 2 years depending on the professions required. Waits are longest where CAMHS (Child and Adolescent Mental Health Service) Clinical Psychology is involved.

Waits for completion of assessment

The numbers of children and young people and families waiting for assessments which have started to be concluded has stayed at around 250 for the last few months. Once started some assessments are completed within a few months but others can take significantly longer. The longest wait is now at just under 4 years from when the request was accepted. The main reason for most of the longest waits is the limited capacity in Clinical Psychology.

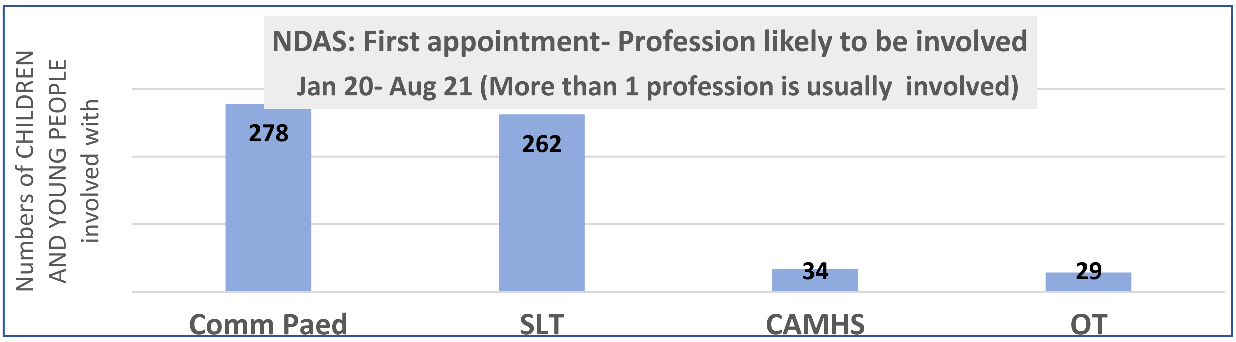
Less complex assessments are sometimes done virtually by one or more professionals using information from parents, children and young people, Education, etc. When a focus group of parents/ carers were asked about online assessment they agreed that "*anything is better than nothing*" and they would "*do anything to move things along*".

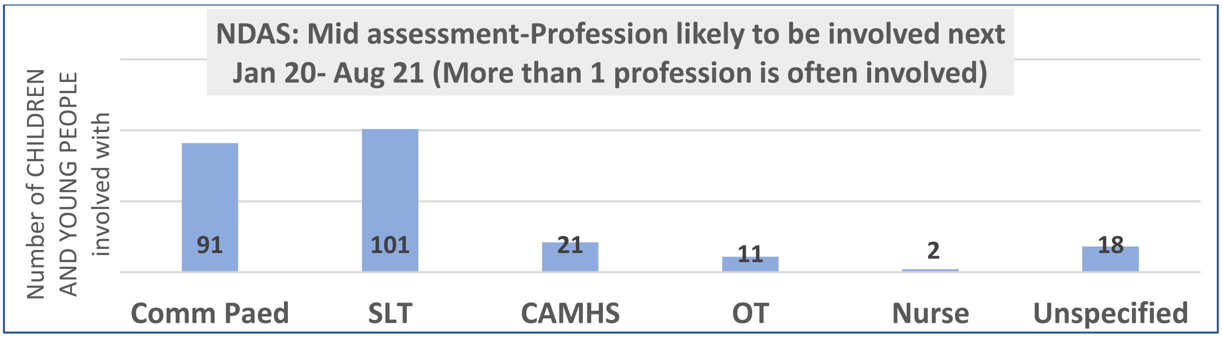
Around 20 percent of the children and young people on the list as waiting for a first appointment currently are 12-18 years old, and two thirds are 5-11 years old. Some of these could be assessed virtually if appropriate.



Staffing

The professions mostly involved in assessment following triage are Community Paediatricians and Speech and Language Therapy. Around 70- 85% of children and young people accepted to NDAS will initially be seen by these professions





There is no dedicated staffing for NDAS, and capacity is taken from existing community services for Speech and Language Therapy, Occupational Therapy and Community Paediatrics, and CAMHS Clinical Psychology. These services are themselves under considerable pressure. Current staffing capacity is insufficient to reduce waiting times greatly, and recruitment of staff is problematic.

Moving Forward in Highland

NHS Highland and The Highland Council are committed to ensuring children with neurodevelopmental needs get the right help when they need it. The review has enabled services to reconsider the approach to NDAS.

We need to-

1. Establish service and clinical leadership to the joint agency NDAS Service in Highland. This leadership needs to drive forward the necessary changes across the partnership to address the current waiting times and ensure the NDAS approach meets the needs of children, young people, families and professionals into the future.
2. Better support children, young people and families throughout the assessment process through developing an approach such as ‘key workers’ families can communicate with.
3. Ensure the NDAS specialist assessments continues to build on the existing child’s plan and other assessments.
4. Restructure the pathways into and through the NDAS process where necessary.
5. Ensure children and young people get the help needed in a timely way by improving our systems and ensuring we monitor the child or young person’s journey through their episode of assessment.
6. Be clearer about the scope of the neurodevelopmental service.
7. Identify appropriate and available skill mix and continue to develop the expert workforce, ensuring staff are skilled and confident in assessing the most complex of needs.

Options for a future model for neurodevelopmental assessment in Highland are currently being considered by NHS Highland and The Highland Council

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