



DANA

Disability Advocacy
Network Australia

ADVOCACY AND THE NDIS SURVEY 2015

RESULTS

by

Joel Caskie

ACU Master of Social Work

MSocWk (Student)

Q1. Which NDIS trial site, or early transition site, does your organisation operate in? n=16

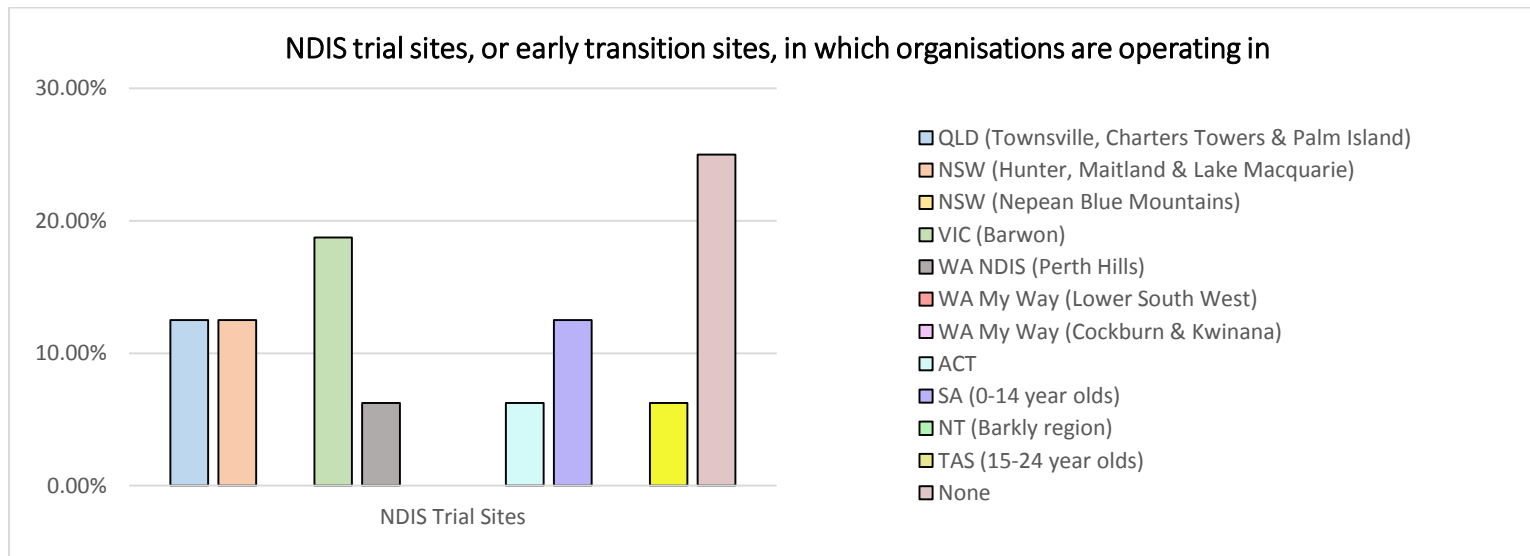


Figure 1.1 NDIS trial sites, or early transition sites, in which organisations are operating in (histogram shown as a percentage)

Q2. Has your organisation provided advocacy for any NDIS participants? n=18

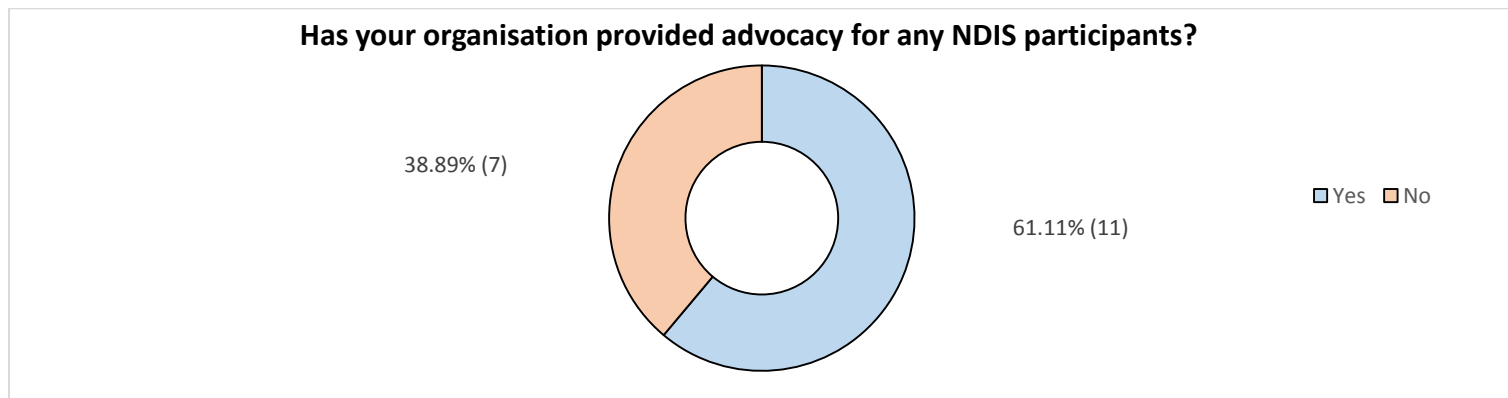


Figure 2.1 Has your organisation provided advocacy for any NDIS participants? (pie chart shown as a percentage)

Findings

25 per cent of respondents (n=4) from responding organisations identified that they were not currently operating in an NDIS or early transition site.

NB: Survey was conducted in the last quarter of 2015

Q3. Since the start of the NDIS trial in your region, for how many NDIS related issues has your organisation provided advocacy support?

The number of NDIS issues organisation dealt with ranged from 1 to more than 100.

Q4. What percentage of your clients who are NDIS participants are from CALD background, Aboriginal and/or Torres Strait Islander? n=14

- The mean average of clients who are NDIS participants from a CALD background, as reported by responding organisations is 12 per cent.
- The mean average of clients who are NDIS participants and identify as Aboriginal/Torres Strait Islander is 12 per cent.

Q5. What stages of the NDIS processes is your organisation involved in? (please tick all that apply) n=16

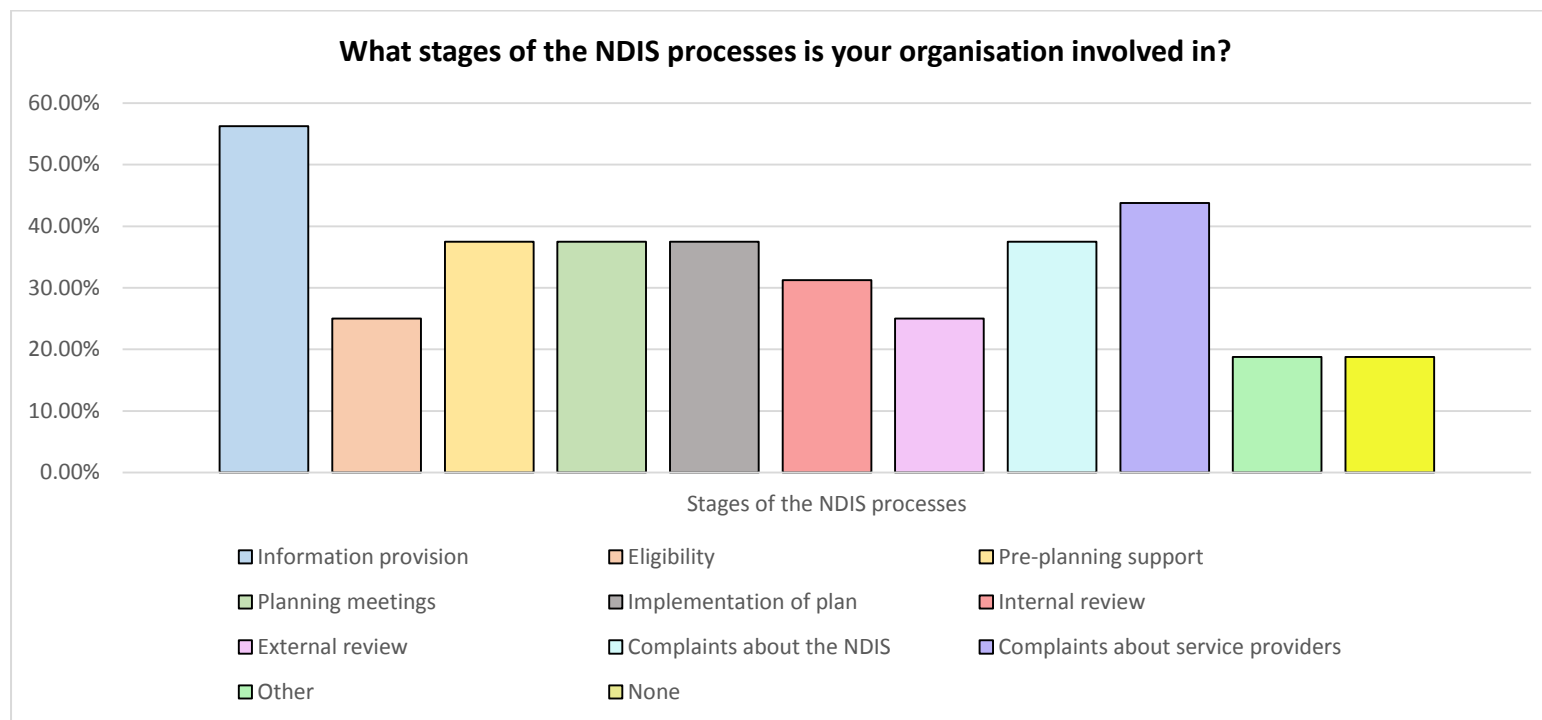


Figure 3.1 What stages of the NDIS processes is your organisation involved in? (histogram shown as a percentage)

Findings

Over 50 per cent of respondents from responding organisations (n=9) reported that they were involved in the information provision stages of the NDIS processes.

Complaints about service providers was the second most common stage of the NDIS processes organisations were involved in (n=7).

Pre-planning support, Planning meetings, Implementation of plan and Complaints about the NDIS were equally common stages of the NDIS processes organisations were involved in (n=6).

Q6. If your organisation has referred people for external review, have you... n=6

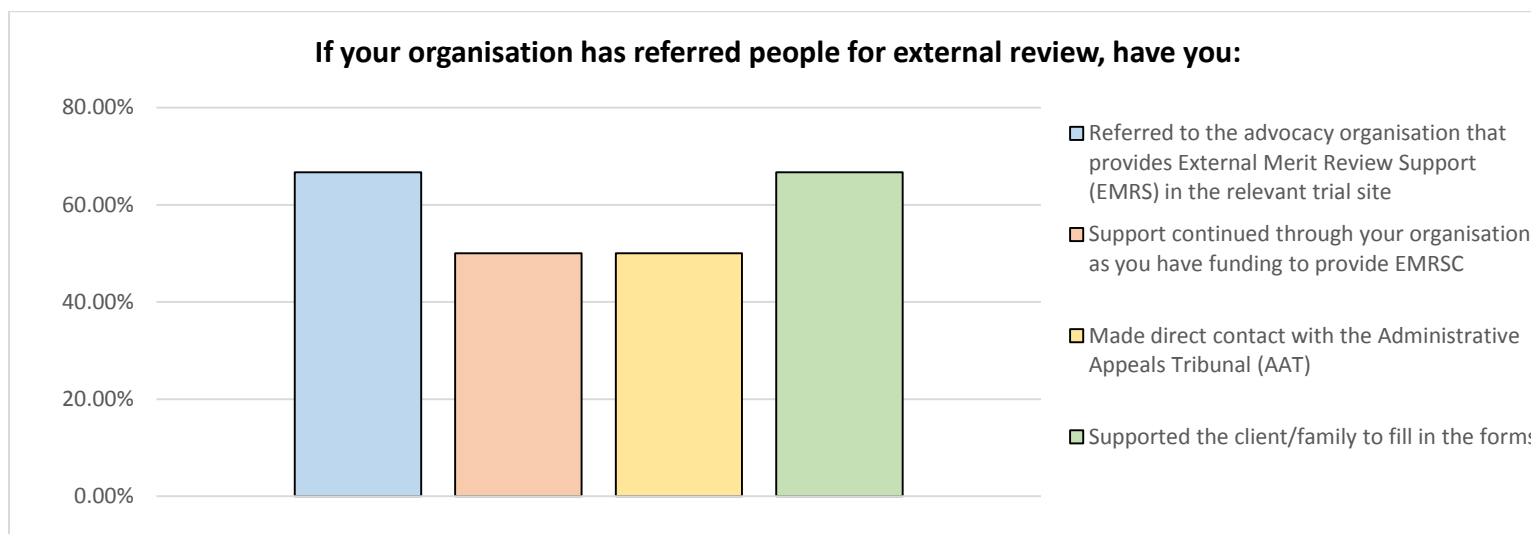


Figure 4.1 If your organisation has referred people for external review, have you: (histrogram shown as a percentage)

Q7. Do you have any clients who have been found to be not eligible for NDIS? n=18

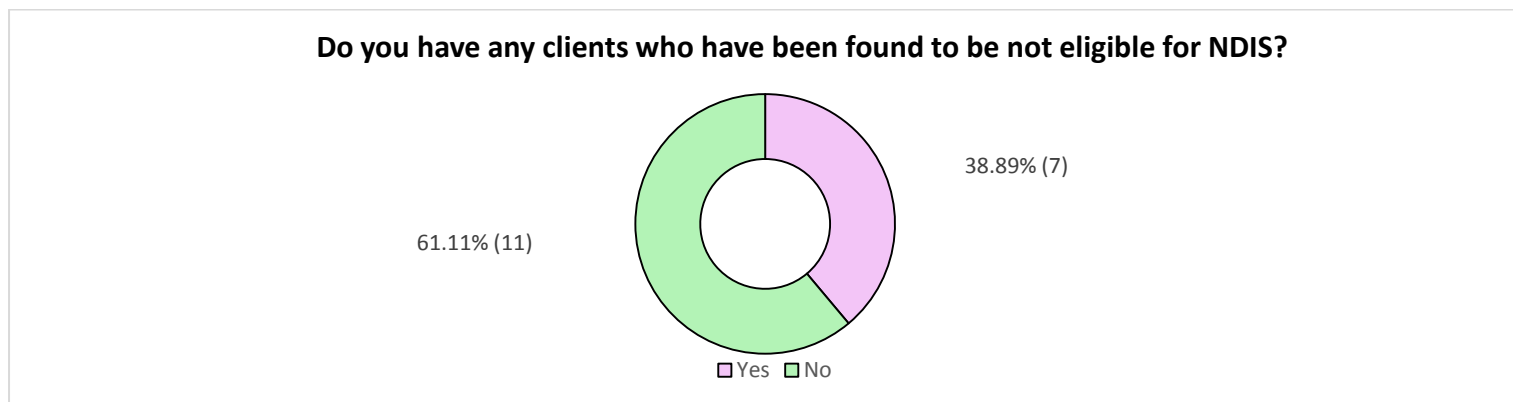


Figure 5.1 Do you have any clients who have been found to be not eligible for NDIS? (pie chart shown as a percentage)

Findings

Two thirds of respondents from responding organisations (n=4) who referred people for external review have referred people to the advocacy organisation that provides External Merit Review Support (EMRS) in the relevant trial site.

Two thirds of respondents from responding organisations (n=4) who referred people for external review supported the client/family to fill in the forms.

Almost 40 per cent of respondents from responding organisations (n=7) reported that their organisation has clients who have been found not eligible for NDIS.

Q8. Have the clients who have been found not eligible appealed the decision? n= 8

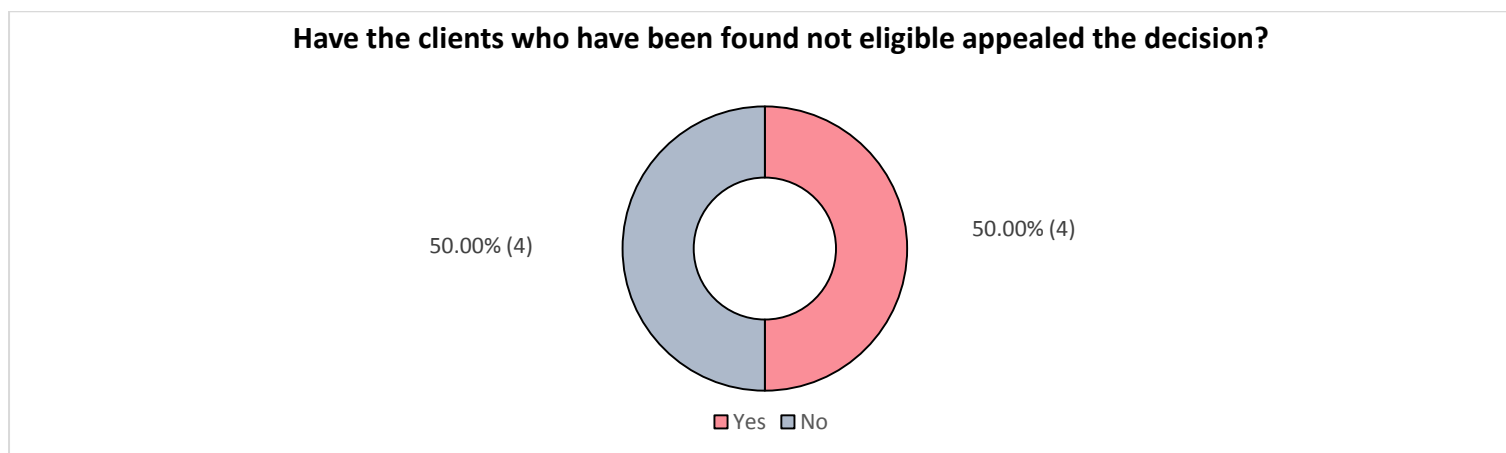


Figure 6.1 Have the clients who have been found not eligible appealed the decision? (pie chart shown as a percentage)

Q9. Have any of your clients retested their eligibility for NDIS? n=8

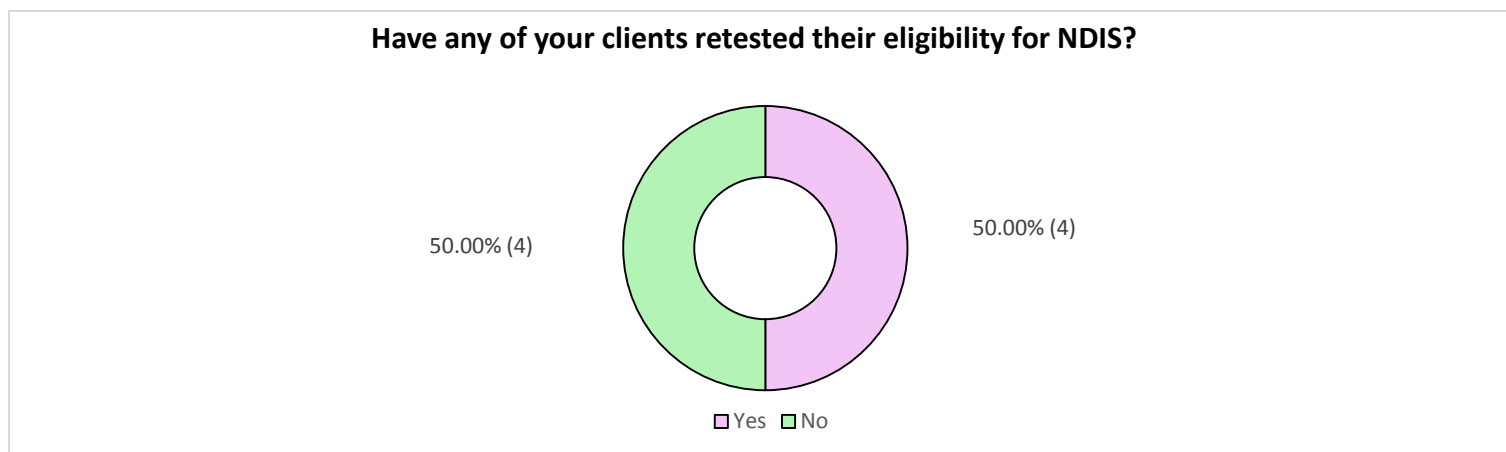


Figure 7.1 Have any of your client retested their eligibility for NDIS? (pie chart shown as a percentage)

Comments

"They were not eligible for the current cohort – e.g. outside the age range"

"Yes, and have been made eligible"

Comments

"[The client was] deemed as a health responsibility, not [meeting] permanent criteria [for] funding, [but] through further supportive evidence [the client was] then successful"

Q10. What are the main issues for NDIS participants for whom your organisation is providing advocacy? n=9

“Needing assistance to deal with NDIS applications including pre-planning and planning meetings; difficulties finding proof of disability for marginalised clients”

“Unresponsive service providers who exert decision-making power over clients”

“Having the necessary information and completing forms... there has been conflicting information about what information is required and who ought [to] provide it... the involvement of advocacy assisted in clarify these issues”

“Support with plan reviews and communicating with NDIS and service providers seem to be the most pressing issues”

Q11. What are the main triggers for a person needing an advocate in regards to NDIS participation? n=22

“Fear of the planning process and meeting with unknown people. Service providers not listening/not supporting choice and decision-making”

“Navigating and understanding the system, planning support and knowledge, supporting someone to have a voice and challenging decisions”

“Not understanding processes and what NDIA do; Not being provided with enough knowledge/info to make choices; Feeling overwhelmed by the guidelines/legislation; Feeling they are not listened to or respected [for] their lived experience”

Q12. What difference has it made to the outcome for the client to have an advocate involved? n=11

“Increased response from NDIA when an advocate becomes involved”

“Clients have remarked ‘nothing would have progressed without your support and I would not have got his outcome’; People feel extra set of ‘eyes/ears’ give them confidence to express their choice and control”

“The client’s confidence to make complaints improved as well as consideration of how the client might use the funding to achieve a better outcome (i.e. leave the unresponsive service provider and pursue different options)”

“Enormous! It’s the difference between getting what they want and what other people say they can have”

Key points

Service providers were identified as being a barrier for NDIS participants

NDIS pre-planning and completion of relevant forms were identified as a barrier for those wishing to participate in the NDIS

The following were identified as reasons for requiring advocacy:

- NDIS pre-planning and completion of relevant forms and documentation
- Not understanding the NDIS system
- Not being provided with enough information to make informed decisions

The differences for client outcomes with an advocate involved include:

- Increased NDIA responsiveness
- Faster progression in planning for NDIS
- Increased levels of client understanding and confidence
- Empowering clients to get what they want

Q13. Has your organisation experienced any barriers to providing advocacy to clients who are participants in the NDIS?
n=18

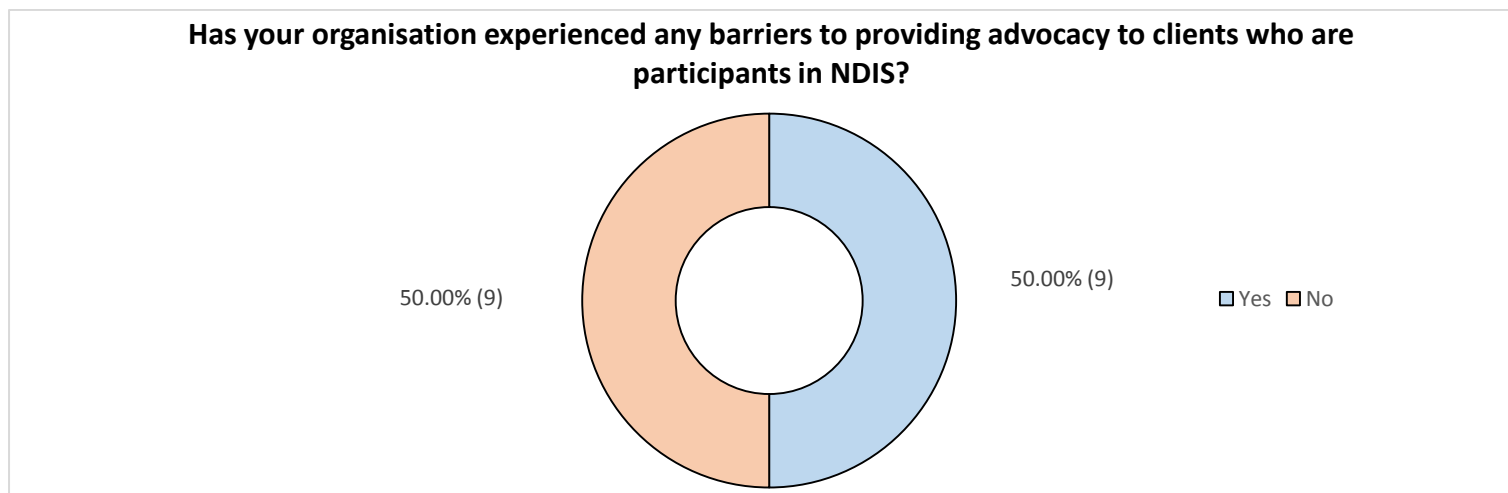


Figure 8.1 Has your organisation experienced any barriers to providing advocacy to clients who are participants in NDIS? (pie chart shown as a percentage)

Q14. Does your organisation need increased resources to adequately assist people with disabilities with NDIS issues?
n=18

- All respondents from responding organisations (n=18) reported that they **need increased resources** to adequately assist people with disabilities with NDIS issues.

“At present the NDIS is only available to children in SA but when it is fully rolled out all the vulnerable people we advocate for will be affected and we expect there to be a significant increase in the need for advocacy from other vulnerable people with intellectual disability who are likely to be disadvantaged without assistance”

Comments

“At times when the client requests we make contact with the NDIA (at client’s request), the agency will not get back to us but to the client, who then is not prepared/fearful”

“Not receiving information about how to get support and advocacy. The NDIS and other key websites do not mention how to go about appealing decisions in clear enough language and is not easily found”

Comments

“The need for advocacy is more in demand than ever. Community-based advocacy is a crucial link and provides an accountability component.”

“We feel this population may be disadvantaged if they are not independently supported and connected with each other when in transition to the system”

Q15. How does your organisation obtain relevant information regarding NDIS? (please tick all that apply) n=17

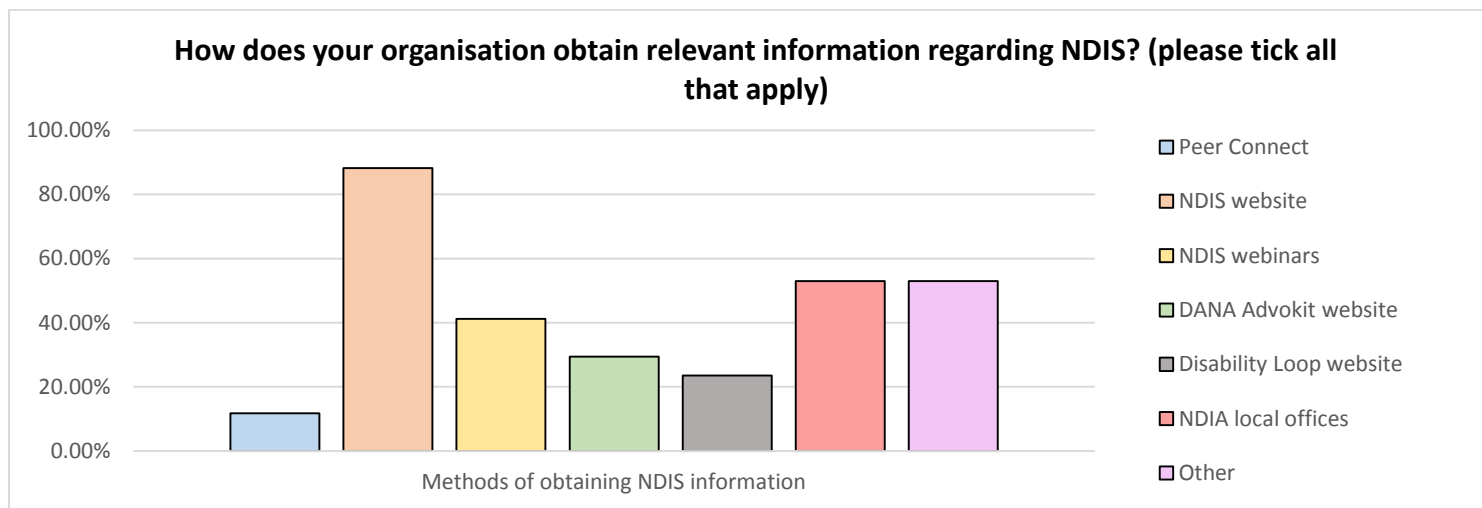


Figure 9.1 How does your organisation obtain relevant information regarding NDIS? (histogram shown as a percentage)

Q16. Do you feel that the NDIS website provides information that is relevant and helpful for your organisation? n=14



Figure 10.1 Do you feel that the NDIS website provides information that is relevant and helpful for your organisation? (pie chart shown as a percentage)

Findings

90 per cent of respondents from responding organisations (n=15) reported that they obtain information regarding the NDIS from the NDIS website.

Only half of organisations (n=7) feel that the NDIS website is relevant and helpful for their organisations.

Other sources of information identified by respondents included:

- forums and events;
- workshops;
- conferences; and
- regular meetings with the NDIA local office.

Comments

“Not enough resources for people with [intellectual disability] and it’s hard to navigate”

“Very [little] material is in local community languages”

“No clear and definitive answer to the question of how advocacy fits within the NDIS”

Q17. What kind of working relationship does your organisation have with NDIA staff? (please tick all that apply) n=16

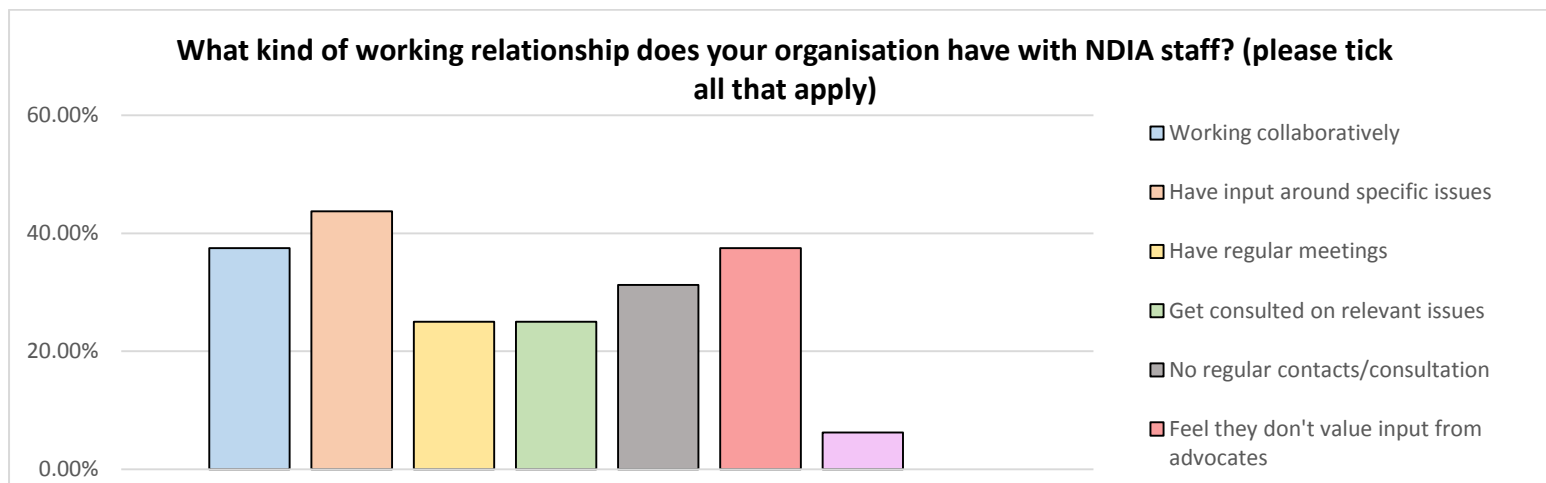


Figure 11.1 How does your organisation obtain relevant information regarding NDIS? (histogram shown as a percentage)

Q18. What is the NDIA responsiveness to advocates and clients regarding NDIS issues? n=13

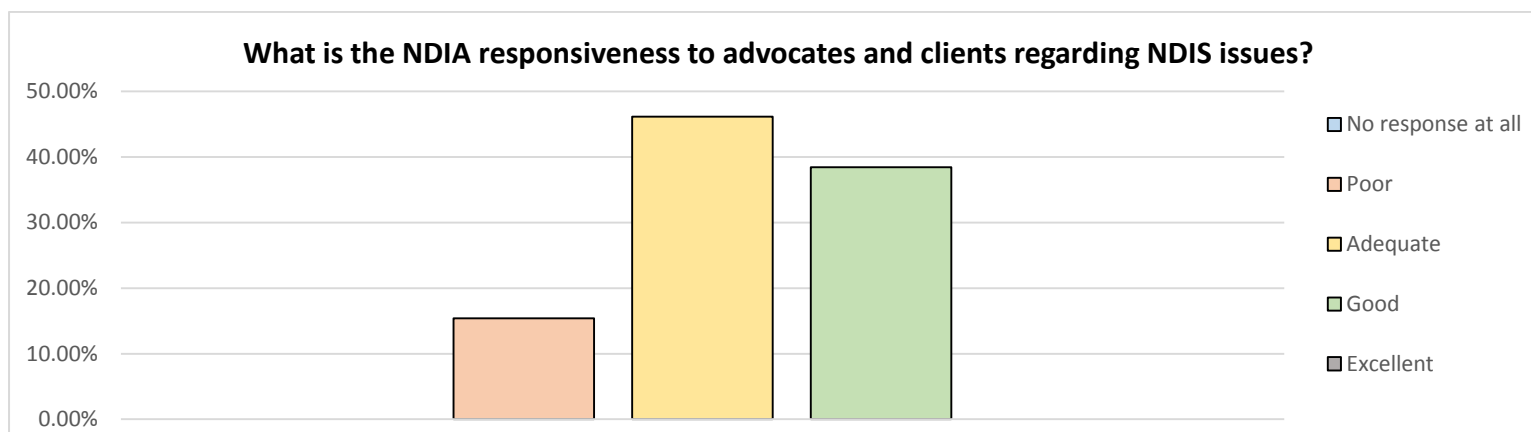


Figure 12.1 What is the NDIA responsiveness to advocates and clients regarding NDIS issues? (histogram shown as a percentage)

Findings

Over a third of respondents from responding organisations (n=6) reported that they felt that the NDIA staff don't value input from advocates.

44 per cent of respondent from responding organisations (n=7) reported that they have regular input with the NDIA around specific issues.

Almost a third of respondents from responding organisations (n=5) have no regular contact or consultation with the NDIA.

Less than 40 per cent of respondents from responding organisations reported that they have a collaborative working relationship.

Almost half of respondents from responding organisations (n=6) reported that they consider NDIA responsiveness to advocates and clients as *adequate*.

"They are not able to deal well with clients from CaLD/NESB [Culturally and Linguistically Diverse/Non-English Speaking Backgrounds]"

Q19. Are there any aspects of the NDIS legislation or rules that you think need to be amended? n=8

“An increased acknowledgment and positive positioning of the importance of providing advocacy in all of its approaches”

“Need for a birth certificate for many rural Aboriginal people may present a barrier to their eligibility. More flexible ways of establishing eligibility may need to be implemented.”

“Confusion around the difference between plan review and internal review, and the language used in the legislation and then by NDIS staff. Rules around the timelines for internal review can be confusing if people don't know if they have a new plan.”

NB: There was a review of the NDIS legislation being held at this time:

https://www.dss.gov.au/sites/default/files/documents/04_2016/independent_review_of_the_ndis_act.pdf

Q20. Has your organisation registered as a provider under the NDIA? n=17

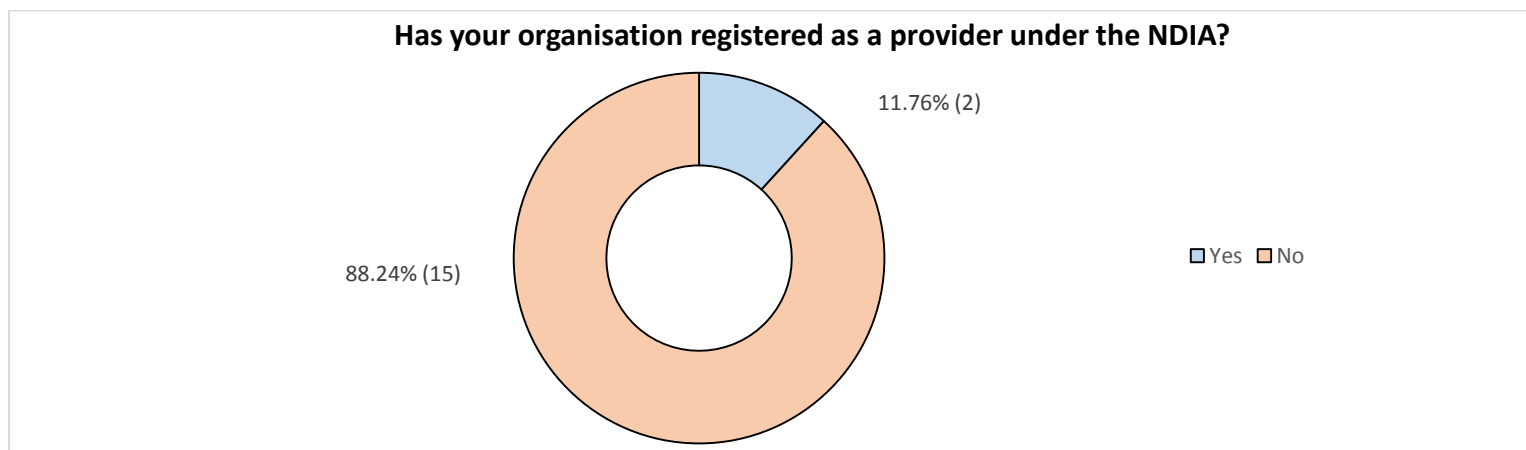


Figure 13.1 Has your organisation registered as a provider under the NDIA? (pie chart shown as a percentage)

Findings

“...It has been hard to keep up with NDIS news while actively working in the old system and not having time to invest in learning more about the NDIS.”

Key Points

Almost 90 per cent of respondents from responding organisations (n=15) reported that their organisation is not registered as a provider under the NDIA.

Two organisations have registered under NDIA in order to provide coordination of supports.