



## **Summary of events in the support of B accessing NDIS entitlements 11/11/20**

CAYLUS outlined this case example in our presentation to the Committee on 14/10/20 and agreed to provide progress updates to the committee

### **Background:**

Client B was formally diagnosed as FASD as part of his family applying for Guardianship. This was granted to his aunt CK in November 2019. At the same time, he was awarded a Disability Support Pension (DSP) and approved for an NDIS Plan. The subsequent interviews required to finalise and action a plan failed to happen in part because of the client and his carers living in a remote community, compounded by language problems and COVID19.

It should be noted that CK is a thoughtful, motivated individual who is dedicated to looking after B. She works full time in the Papunya Aged Care program, has good English and is more adept at dealing with bureaucracy than many people in the region. However, English is not her first language and she has never been supported to fully understand the processes needed to navigate the NDIS.

From June 2020 CAYLUS undertook casework to facilitate the family having the required meeting for the NDIS to develop a Plan which would mobilise funding to support client B and his family.

B's behaviour has included a lot of sniffing petrol and other substances over his lifetime – as recently as 2019 - so he is well known to CAYLUS, hence our involvement in this specific case. It should be noted that we came into the NDIS story after B had been assessed as eligible, so we did not have to organise the assessment. We are sure there are many similar undiagnosed FASD cases in our region.

### **Carers entitlements**

B's guardian CK has been applying for a Centrelink Carers Payment. This could not be done from her remote community, so has required two trips to Alice Springs so far. The first trip was complex in many ways, as she had to bring client B with her as no care could be arranged in her absence. She had to provide a substantial amount of information - ID, 4 payslips, a bank statement, client B's birth certificate, a Medicare card. This was provided with CAYLUS assistance, but when she returned to her remote community, a nurse filling out a section of the application ticked the wrong box, meaning CK was not approved for a Carers payment and had to return to Alice Springs and start again. At the time of writing we think she has recently been approved but haven't seen confirmation of this yet.

## **CAYLUS actions to support NDIS access**

This is a summary of the actions taken by CAYLUS. It demonstrates the complexity of the NDIS process, and the substantial assistance required to get it working (we hope) for one Indigenous person from a remote community.

5/2/20 email from Disability Advocate Service (DAS) advocate to CAYLUS stating they would follow up remote NDIS teams plan to meet with B and CK re Preplan meeting. She found there had been no progress on remote team visits due to COVID19.

12/6/20 CAYLUS emailed to follow up DAS re NDIS status as CK reported no NDIS progress.

16/6/20 CK and CAYLUS spoke to NDIS about progress of claim. NDIS had tried to phone CK previous week but failed to get through.

18/6/20 DAS sent info to CAYLUS about the sort of support B could receive from NDIS. CK and BM discussed what support could happen in Papunya. One of the goals that CK identified was NDIS support for social activities for B to get him out of the house, promote physical activity and regularise his sleep patterns. Papunya Tjupi Aboriginal Corporation (PTAC) – an arts centre in Papunya that also runs a Men's Shed - were identified by CK as a potential support to B. Although he did not go there, she felt enough of his friends and relations used the Centre for him to feel comfortable there with support.

19/6/20 CAYLUS contacted PTAC who were interested in providing support to B. They have been partners on this journey and have shown willingness and flexibility but also careful consideration of the implications of involving B in their program.

23/6/20 Alice Springs NDIS arranged teleconference for Preplan Meeting on 25/6/20. They suggested CK draft a Plan for B, which BM assisted her to do. However, NDIS cancelled the teleconference, rescheduled for 30/7/20.

30/7/20 A CAYLUS worker drove to Papunya to help pull together stakeholders and facilitate the teleconference. CK the guardian, was found to be in Alice, but NDIS spoke to B and other family members, and to BM who by this point had been formally accepted by the NDIS with CK's consent as a stakeholder. This phone meeting, taking place on the veranda of a community house in Papunya, moved the PrePlan Meeting process one step closer to completion. The next step required CK to meet with the NDIS.

31/7/20 CAYLUS worker travelled back to Alice Springs and located CK and took her to NDIS office in company of DAS advocate for interview. NDIS showed flexibility in the face of these chaotic events, and the last part of the PrePlan interview took place on a Friday afternoon. During this interview, the draft Plan which CK and BM had drafted was submitted. CK was told the NDIS Plan would take a couple of weeks to "build".

8/9/20 – 6 weeks later - DAS advocate checked on progress of the Plan. Still being "built".

6/10/20 – 10 weeks after the last PrePlan meeting - CAYLUS emailed the local NDIS Manager asking about progress and was told the Plan would be finalised in two days.

8/10/20 Plan finalised. The Plan was for a total of \$118,795.76 for 7/10/20 to 7/10/21.

Note : although behaviour issues were identified in the PrePlan meeting, and written into the draft Plan which was provided to the NDIS, no allocation of funding was made to support behaviour training for B's family. In the draft plan under the Short Term section goals it read "He would like to learn how to better manage his behaviour. He would be able to do this by his provider connecting him to experts at behaviour management who could visit Papunya and train Ernest and his family in appropriate management techniques. He sometimes gets frustrated and violent with his family. " This oversight has meant that this training is not able to be funded currently. Consequently, CAYLUS is looking at funding this itself in the interim as B's current positive engagement may also put him in the path of potentially frustrating events in the new space, so support for people dealing with his behaviour would be better sooner than later.

15/10/20 CAYLUS attended the Alice Springs NDIS for an Implementation Meeting to discuss how the Plan can be utilised. This meeting went into the mechanics of accessing the Plan funds and was most useful. The operation of the NDIS is complex, and CAYLUS has yet to locate any flow chart or diagram that explains it. We have generated one as we go, with a whiteboard covered with acronyms and lines joining them up – it looks like something from a crime investigation TV show.

16/10/20 CAYLUS drafted a service agreement using a template from the NDIS website between CK and PTAC based on discussions with CK, who saw PTAC as the appropriate local agency to provide support to B. Also after discussion of options with CK, BM contacted Waltja Tjutanka Palyapayi Aboriginal Corporation (Waltja) a local Indigenous organisation, and after discussions about the CoS activities they undertook in the Papunya region, CK nominated that agency as CoS. Waltja and the DAS proposed another local organisation – the Central Australian Housing Association (CASA) as the Plan Manager, as they paid invoices quickly as opposed to some Plan Managers who Waltja reported took weeks to process payments. I discussed this option with CK, who elected to take Waltja's advice. I contacted CASA who accepted the role and notified the NDIS. CASA and CAYLUS have exchanged 10 emails clarifying aspects of the roles and services, and they have been very helpful.

28/10/20 CAYLUS staff ran a draft service agreement between CK and PTAC past CASA who made some suggestions which BM incorporated into the document. CK agreed and signed the doc.

4/11/20 PTAC ratified the above service agreement

Since ratifying the service agreement B has PTAC attended on four occasions, two during the week and two days on the weekend. On the weekend he was taken by PTAC staff in a PTAC vehicle hunting on the Saturday and on a trip to a nearby community on the Sunday to see a Ngangkari (traditional healer). These were stated ambitions for B which were in the draft plan CK gave to NDIS, so their achievement goes a long way to justifying the lengthy engagement that CK has undertaken to mobilise these resources.

Prior to these recent examples of actual service delivery to E, nothing but paperwork, meetings, phone calls and confusing systems had been CK's experience with the NDIS. In the longer term we hope CK's positive experience will contribute to our anticipated attempts

to mobilise NDIS support for other Papunya community members, who will see concrete results from the NDIS engagement.

The PTAC co-ordinator stated that B was comfortable in the space but needed one on one support from the PTAC staff while he was there. He did a painting on paper which showed some talent according to the Art Co-ordinator, and he will be working on canvas on his next project. A photo of his first artwork is included in this update.

11/11/20 PTAC submitted its first invoice and we received confirmation that this invoice would be paid.

A further missing piece of the puzzle is that we overlooked a document authorising CASA to be the Plan Manager, which was sent to CAYLUS 9/11/20. We will get this signed next Monday (CK in Darwin at Bible College currently) and hopefully that will be the last piece of the puzzle. The CASA document makes sense, but CAYLUS missing it, despite its crucial operation, is an example of the complexity of the paperwork and the issues involved in the supporting NDIS access.

### **Community Connectors:**

NOTE : Macdonnell Regional Council (MRC) are funded to provide Community Connectors to assist in remote communities but our experience in working with B is that these people have little training or capacity to be of use in helping navigate the complex NDIS systems despite CAYLUS efforts to include them. This is in part due to COVID19 preventing training. However, the MRC Youth Program have been very supportive MRC Youth have indicated they think there are a lot of youth in the region who have undiagnosed FASD issues and will be working with CAYLUS in the future to try to address this issue. This was touched on when CAYLUS presented to the committee a few weeks ago.

### **Conclusion :**

All up CAYLUS estimates it has taken approximately 65 hours of senior staff time to finalise the plan and get the first service delivery happening, and another 20 in relation to assisting CK to access a Carers Payment. This included 70 emails to and from the DAS, 72 to the NDIS, Waltja and other CoS providers, PTAC, MRC. There were also numerous meetings with stakeholders from the NDIS to B's family, as well as a CAYUS worker driving to and from Papunya to ensure the Preplan Meeting took place. We are sure that without this support, CK would not have been able to navigate the process and realise the support that the Plan provides.

We would also like to point out that as a community development organisation, CAYLUS was positioned to know the local agencies and mobilise and support them to provide this service. Generally, people in our region seeking to access the NDIS are unlikely to have anything remotely close to this level of support and expertise. This experience has shown that there are number of people in our region with disabilities that link to sniffing/substance misuse who are likely to qualify for NDIS support. CAYLUS will continue to try and support these people's access though this will be constrained due to federal funding cuts in recent years.



**B's first artwork**

