

15 January 2024

The Secretary
House of Assembly Select Committee
On reproductive, maternal, and paediatric health services in Tasmania
Parliament House
HOBART TAS 7000

Submitted via email: rmphs@parliament.tas.gov.au

Dear Secretary

SUBMISSION: LYSITHEA ASTRID ALLEN

Thank you for the opportunity to share my family's experience with the Tasmanian Health Service's current ability to provide adequate paediatric care for the state's children population.

My husband Shannon and I have two children, Elara (5 years old) and Lysithea (almost 3). Lysithea has recently been diagnosed with autism spectrum disorder (ASD). We are currently working with a team of medical professionals to ascertain what level of autism Lysithea has (1, 2 or 3).

Unfortunately for our family, to obtain this diagnosis has involved numerous phone calls, GP visits and emails since July 2023. This is because, to receive a diagnosis, either a paediatrician or a child psychologist must be engaged. The preferred option is a paediatrician and finally, after 7+ months of persistent efforts, we have secured a video consultation with this type of specialist on 22 January 2024. It is worth noting the paediatrician, Dr Britt Turner of the Royal Flying Doctor Service, is based in Melbourne. The idea that, in a developed country such as Australia, to get adequate healthcare for a child citizen one must source interstate assistance is absurd. The reason is simple, there are not enough paediatricians in Tasmania. I base this statement, not purely off our own experience, but off the many phone calls I have had with paediatric clinics in Tasmania who have advised they are unable to assist Lysithea and numerous discussions with other frustrated and desperate parents who find themselves in an unhelpful and unproductive health care system.

To provide evidence confirming the above statements, please see the below table for further information, noting that due to the high volume of follow-up Shannon and I have undertaken, this does not include every single phone call or discussion:

| Date | Person/Organisation | Information discussed |
|---------------|---|--|
| Mid-July 2023 | Lisa McFarlane Family Day Care Provider Adventure Patch | Lisa raised concerns with us regarding Lysithea's lack of speech, anti-social traits and behaviours including repetitive activities that could be a sign of ASD. Upon our consent, Lisa raised a request for Lady Gowrie Inclusion Agency Tasmania to visit Lysithea at her residence (which is where Lysithea is cared for) to observe Lysithea. Lisa advised that it could take some time for Lady Gowrie to visit Lysithea. |

| | | |
|----------------|---|--|
| 20 July 2023 | Dr. Nikki Randriamahefa, GP Cygnet Family Practice | This was an initial consultation to obtain referral letters to available paediatricians in Southern Tasmania. |
| Aug-Sep 2023 | Every paediatric office in Tasmania | We called every single paediatric practice in Tasmania seeking an appointment for Lysithea. These requests were declined due to lack of capacity from the doctors. We didn't record details at the time as we thought an opportunity would arise soon. It did not. |
| 21 August 2023 | Tasmanian Health Service | We received a letter advising that Lysithea had been put on the outpatient paediatric medical clinic wait list. |
| 6 Sep 2023 | Jo Nugteren CHaPS Nurse Kingston Health Centre | We booked in a follow up health visit to the childhood nurse. She flagged developmental delays. The purpose of this visit was to due to the fact we were advised that if we could get two healthcare/childcare workers to provide information that Lysithea was not developing normally, this would assist with an application to the NDIS. |
| 4 Oct 2023 | Donna Best Lady Gowrie | Donna visited Lysithea at Lisa's Family Day Care residence and advised further investigation would be advisable. |
| 27 Oct 2023 | Andrea Reece Early Years Coordinator St Aloysius Little Explorer's Program | Out of desperation due to the lack of doctors available to see Lysithea, we started taking Lysithea weekly to the school's 0-5year learning programs. Andrea assisted us by providing a referral to St Giles who would assist with Baptcare's application on our behalf to the NDIS. |
| 14 Nov 2023 | St Giles | I called St Giles to follow up and was advised that it could take 18 to 24 months for an appointment. Waiting lists do exist, but these are extremely long. |
| 16 Nov 2023 | Prue Hazelwood Family Support Professional St Giles | Prue emailed the referral off to Baptcare (Baptcare would send to the NDIS). This took some time to compile together as two independent health/childcare providers had to provide information for the application and with no paediatricians available to help, we had to find other professionals to help. |
| 16 Nov 2023 | Hobart Kids Clinic | I called to make further enquiries regarding available appointments and was advised they are not taking any new clients. Maree (Office Manager) advised me to call back in February 2024 to see if availability exists. She also advised two paediatricians are retiring later this year so wait times are likely to get worse. |
| 16 Nov 2023 | Hobart Paediatric Group | I called to make further enquiries regarding available appointments and was also advised they are not taking any new clients. Marianne (Practice Administrator) told me that one of their |

| | | |
|-----------------------------|---|---|
| | | paediatricians is retiring so they are currently in a dilemma with what to do with the several hundred client-base this doctor currently serves. |
| 20 Nov 2023 | Speech Pathology Tasmania | We finally found a speech pathology clinic that was willing to take on a new patient, although booking in a series of appointments wouldn't be available until 2024. We emailed off all required information. |
| 23 Nov 2023 | Dr. Nikki Randriamahefa, GP Cygnet Family Practice | Due to the lack of paediatricians in Tasmania, we requested that she send referral letters to any child psychologists in Southern Tasmania who would see a child as young as 3 years old. |
| 23 Nov 2023 | Anita Dow MP Rebecca White MP Guy Barnett MP Jeremy Rockliff MP | Out of desperation I wrote letters to these MPs. |
| 30 Nov 2023 | Michelle Etherington Electorate Officer for Anita Dow MP Deputy Leader of the Tasmanian Labor Party | Michelle acknowledged receipt of our correspondence regarding Lysithea and made me aware of this committee's existence. No reply or acknowledgement from Mr. Barnett or Mr. Rockliff's offices has been received to date. |
| 19 Dec 2023 | Ashleigh Fife Speech Pathologist Speech Pathology Tasmania | 1 ¾ hour initial investigative consultation with Ashleigh pertaining to Lysithea's speech delay, which is a hallmark symptom of ASD. |
| 21 Dec 2023 | Dr Ali Morse Clinical Psychologist PSYCH2U | Dr Morse met with Lysithea and Shannon to investigate suspected ASD. This diagnosis is currently in progress, and we are awaiting a written report from Dr Morse to present to Dr Britt on the 22 January 2024 as a paediatrician needs to be involved when diagnosing ASD. |
| 28 Dec 2023 | Yingsel Dasam Nurse, Early Childhood Coordinator Baptcare | Yingsel called and emailed us to assist with processing through our referral for Lysithea to the NDIS. |
| UPCOMING APPOINTMENT | | |
| 22 Jan 2024 | Dr Britt Turner Paediatrician, Royal Flying Doctor Service | |

After reviewing the above information, noting that we are still only at the start of our health care journey with Lysithea, it is safe to say that the system to obtain help for young children who are not developing at normal rates in Tasmania is confusing and difficult. We have also paid for almost all appointments out of pocket, which we are able to do due to our stable financial position. Other families would not be able to afford this expense and would rely on the NDIS for funding, or simply be unable to proceed down the path we have taken.

It is worth noting that the Tasmanian Autism Diagnostic Service (TADS) states on their website that *"it is really important your child sees a paediatrician before meeting us"* and that even if a psychologist wants to refer a child, a paediatrician must still be seen. This is a State Government service, and it is nonsensical that the essential connection to TADS, being a

consultation with a paediatrician, is impossible to quickly obtain in Tasmania, with years of waiting to be expected.

Timewise, childhood is a small part of a person's life, yet it is the most formative portion as children experience notable development in major and minor motor functions, communication, and social abilities. This is because the brain's ability to reorder itself through neuroplasticity, essentially forming new neural pathways, is much easier when a person is very young. Therefore, the need to act quickly when ASD is suspected in a child is so important.

According to the Raising Children website "early interventions should happen as soon as possible after a child's needs are identified". It is safe to say that this is not happening consistently in Tasmania. Our experience with Lysithea's ASD and the Tasmanian Health system is just one example. How many other Tasmanian families are out there, floundering and essentially deprived of the health care that their children need?

In conclusion, as noted by the Australia Government's National Autism Strategy, there is a growing number of Australians on the autism spectrum and these individuals have a 20-year gap in life expectancy compared with the general population, are seven times more likely to be unemployed and have a higher risk of homelessness. We are committed to ensuring Lysithea has the best opportunities given to her to defy these odds and, for the future of Tasmania, the government should be treating the state's paediatric situation with the absolute seriousness and urgency it merits by addressing the lack of paediatric services in this state immediately.

Regards



Angela Allen
0457 810 848

Sources:

Tasmanian Autism Diagnostic Service

<https://www.decyp.tas.gov.au/learning/supporting-student-need/tasmanian-autism-diagnostic-service-tads/>

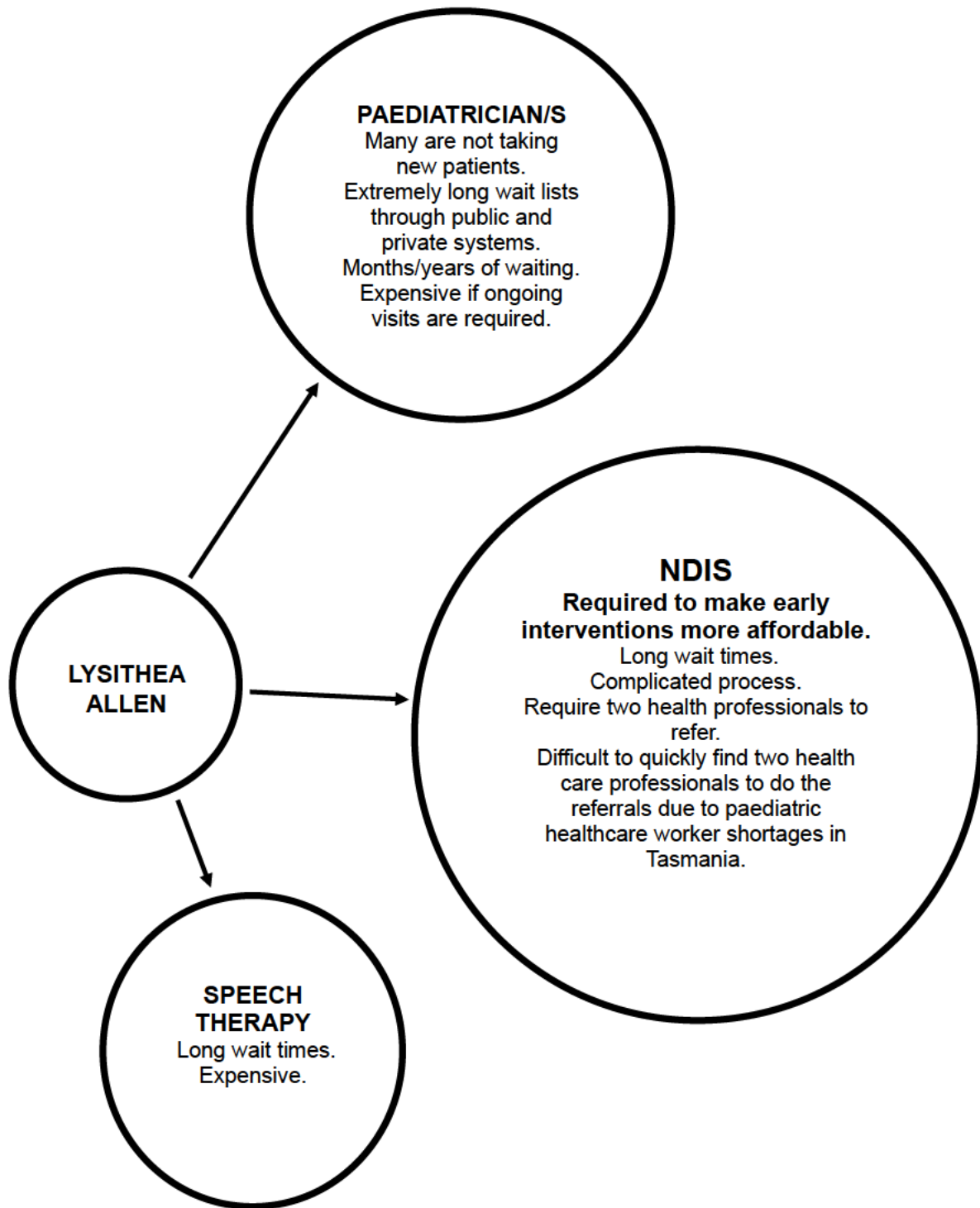
Raising Children

<https://raisingchildren.net.au/autism/therapies-services/therapies-interventions/early-intervention>

Australian Government Department of Social Services

<https://www.dss.gov.au/disability-and-carers/national-autism-strategy>

Paediatric health in Tasmania (Lysithea Allen experience – July 2023 to the present)



Many health care workers/agencies need to be involved including (but not limited to):

- GP
- Child Psychologist
- Speech Pathologist
- Paediatrician
- St. Giles and Lady Gowrie
- Bapcare
- Childhood nurse/s

Many of these charge for their services with little or no government rebate through Medicare.
All are needed to get the best intervention required for children with ASD.

Addition to submission, 30 January 2024

The only other item I would please like included is that following our paediatric appointment on 22 Jan Lysithea's status was updated to "Global Developmental Delay" as Dr Britt would like to see how structured speech pathology, child psychologist consultations and other items (including blood tests, etc) affect Lysithea's developmental delays. If they are still present, Dr Britt will confirm an autism diagnosis.