

SUBMISSION TO: Environment and Public Affairs Committee

ISSUE: DSC's Privatisation of Accommodation Services

DATE: 7th August 2014

SUBMITTED BY: Lyrebird Parent Group

THIS SUBMISSION IS PRESENTED IN FIVE PARTS

PART 1: Main submission
PART 2: Rally Speech
PART 3: January letter
PART 4: Lyrebird (2008)
PART 5: Parent's personal comments

PART 1 MAIN SUBMISSION

INTRODUCTION

The 'hands on' staff at our home have been wonderful and we would like our thanks and appreciation to be noted. Our complaints are not with them, but those driving Transition / Privatisation.

Lyrebird Parent Group

Consists of five families representing

This is much more than parents just 'digging in their heels in the face of change'.

This is about a group of people whose experience, knowledge, wisdom, understanding and insight is being blatantly ignored by those forcing this policy.

None of us would be 'bucking the proposal' if we did not have real, serious concerns.

It is not fear of change per se, but the problems and negative impact that Transition will have on our group's children.

Before proceeding

As part of our introduction please now read Submission Part 2 - Rally Speech.

GENERAL POINTS

On the surface to an 'outsider', it may seem that things are satisfactory, but there are underlying issues not immediately obvious which need to be addressed, and serious questions that are yet to be answered.

We voice, in very strong terms:

1. opposition to the compulsory Transition policy, and call for it to be overturned
2. concerns regarding the policy itself
3. lack of input from residents, carers and families
4. concerns how policy is being implemented.
5. inadequate attention given to 'if something goes wrong'
6. a call for an inquiry

Our main complaints

1. Issues raised by family back in 2008 have continued to be ignored.
(ref Submission Part 4)
2. A blanket decision being made for all, regardless of individual concerns.
3. Families and hands-on staff knowledge, experience, wisdom continually ignored.
4. Appalling lack of ready information from DSC.
We often hear rumours from the community before we hear from DSC.
5. Lack of understanding for the stress on family, and the disregard of our need for moral support

Choice

We are not against Transition as such. If that's someone's choice, we wish them the best.

Our group has made it quite clear that our choice is 'same house - same staff'. We made it back in 2008, when DSC tried to get us to move house from Thornlie to Armadale; and we have made it known again in recent months.

Minister Morton has tried to convince parents that Transition is all about choice. This is nothing but political spin. Our choice is being denied us because, as she puts it, 'not an option you have been given'. The only logical conclusion from that comment is that it's not really about real choice at all. Which begs the question – what is the real agenda? It is appalling that nearly ten months later we still have not been given an adequate explanation.

True choice, surely, would include maintaining the status quo as a valid option.

We would like someone to explain to us why/how most of the concerns and questions raised in 2008 have been ignored whilst this Transition policy has gone ahead.

We will refer to that (Submission Part 4) later.

Individuality

Each House has a different dynamic, concerns and fears. Every home’s parent group should have been consulted. To make a blanket decision affecting the future of so many people based on limited knowledge, lacked sensitivity and respect, but much more importantly, it means that decisions are not based on resident’s real individual needs.

Parent Voice

It is not acceptable for Ms Morton to say ‘I have listened, I just don’t agree with them’

No one can disagree with someone else’s reality - in this case, our reality is years and years of personal:

- experience
 - knowledge
 - wisdom
 - understanding
 - insight
 - intuitive caring
- driven by the love of family and long-time carers.

Those driving this policy cannot claim this same reality. This should be of paramount importance, and outweigh the current proposal.

Comparative measure of experience

A comparative measure of personal/real experience (at Lyrebird) versus that of the policy drivers is instructive:
parents collectively hold 505 years of experience,
staff hold approximately a further 100 years and
policy drivers nil.

Lyrebird 600 + years
Policy drivers [

In all honesty, how can the policy-drivers be allowed to dictate without consultation?

And this is just some of Lyrebird’s residents – what would the grand total imbalance look like? (we are not privy to personal information about residents whose families are not in the Lyrebird Parent Group)

Multiply this measure with every house for the truer imbalance.

We fear the affect on the security, stability, and safety of our children.

Perhaps best explained by this stool analogy

seat = security, safety stability

legs = the three vital elements.

1 staff

2 building

3 mates / routine of everyday life

If any one leg is broken, however temporarily, the whole stool is compromised. Whoever is sitting on it at the time, is in danger of injury. Our children are sitting on this stool – real live people with real live emotions and vulnerabilities. Moving house or pulling out our staff is compromising their wellbeing. Who knows what the personal and practical costs of repair would be?

Radical change without due forethought, planning, and back-up alternatives, is fraught with problems, if not dangers. Continuity is essential with our children – it provides them **security and safety**

With our children **stability is a major issue**. If compromised, it results in high levels of anxiety, stress, and sometimes fear. Some residents respond by lashing out physically, putting the safety of themselves and/or those around them under threat.

Their mental, emotional and physical welfare is in jeopardy until things get put back on an even keel again. This is the everyday reality even now, so to have a major change such as total staff loss and/or moving house, the threat of major behavioural problems and safety issues are a very real.

Policy makers must be made aware of how quickly a volatile situation can erupt, and how long it can sometimes take to get things back to normal, not to mention how demanding this can be on even experienced staff.

Surely there is a **duty of care** to consider the safety of both residents and staff – not just at ‘hands on’ level, but also the policy makers that put the staff in that situation in the first place.

Staffing – Change of team

It would be fraught with problems

Loss of residents’ sense of security and stability

Immeasurable grief for some

Would affect the efficiency in their routine as new staff ‘learn the ropes’

Increased risk rates without experienced staff on hand to handle the unexpected.

Potential OSH issues for both residents and staff.

Staffing **Training and qualifications**

Even passing our children over to staff with equal training and qualifications would be bad enough. But to pass them on to people with less training is totally unacceptable, especially when considering that it won't be long before they start facing aging and associated health issues

Routine and continuity

A sudden total change of team, or a breakdown / major shift in everyday routine will jeopardise the well-being and emotional security of residents and staff.

On-going continuity is essential.

Over the years, staff come and go, for whatever reasons – always have, always will. That's just an unavoidable reality. Responses vary depending on the individual relationship. It could be anything from minor adjustment to a very deep **grief**. But on-going continuity, and the rest of the team and house-mates, help to carry them through it.

- Mental and emotional health is at risk here. Grief without understanding, coupled with confusion and a lack of security that comes with having familiar staff will cause severe stress.
- This causes major negative behaviour in several of our residents

At the very least, there needs to be a substantial period of staff piggy-backing for a change-over period.

Who will determine how long is long enough?

What if:

- staff and parents disagree with this time-frame and want an extension?
- a resident doesn't cope?
- the new provider decides to accept the other residents, but not the one not coping?

INADEQUATE INFORMATION

From the beginning (Oct 2013) families have not been given adequate information.

Periodic updates could be noted more for their spin content and lack of detail. Over the last ten months we have had to ask more questions than there have been information points on offer. And we still don't know what really lies ahead.

Can someone please explain how is it that nearly ten months down the track, families are still needing to ask 'Are we part of the 60%?'

Even in January there was not a comprehensive list of alternative service providers readily available. This also poses the question: how has DSC been properly servicing recent community enquiries without it?

We can't ask the home staff, because they have been told not to discuss things with parents.

Despite asking 'where can we go / who can we talk to', we were not informed about the 'meet the board' sessions that have been held since the announcement.

We are finding information from 'outside' (not from staff) and having to approach DSC to confirm or deny.

- We were not even told that that we would lose our staff,
- In mid June, we heard of the impending departure of the Executive Officer for Accommodation, Wendy Cox. Despite a periodic update in the meanwhile, we did not receive mail until Mon 4th Aug to confirm she had left the previous Friday.

Why is important information being withheld from families?

And by whose authority?

PLEASE NOW REFET TO SUBMISSION PART 3 – JANUARY LETTER

- How is it that such important questions still needed to be asked three months after initial policy announcement.
- Some of those questions have yet to be acknowledged, let alone answered satisfactorily.

Is this because they

- Know and don't want to answer. In which case, why not?
- Or, they didn't have details to hand at the time? In which case, how could they push to implement a policy in this cloud of ignorance?

CALL FOR AN ENQUIRY

As you can see, many of our questions and concerns are long-standing. To date no-one has even acknowledged some of our questions – we hope this fact concerns you as it does us.

Please can you inquire into

Issues at time of policy announcement

- A blanket decision made for all, regardless of individual needs
- Lack of consultation with family and 'hands-on' staff
- Serious issues not being given due consideration
- Poor planning
- Lack of choice to stay with DSC
- Insufficient placements to cater for both DSC transfers and community needs

Issues since policy announcement

- No clear-cut explanation as to why
- No clear-cut explanation as to how our children will benefit
- Family concerns and protests not given due attention
- Inadequate information re Policy and its implementation
- Several serious issues still not addressed
- Concerns regarding lowering of industry standards and qualifications

General questions

We hope your committee can get concrete specific answers to these questions

- Who exactly is the driving force behind this?
- What is really motivating them?
- Who is really going to benefit?
- And how?
- Why are they pushing privatisation when there are still issues to be addressed
- Who are 'they'? Even this question gets a vague response.

CLOSING COMMENTS

We want to see them be made to be more accountable and transparent.

Why are they hell-bent on continuing down this path of thinking - regardless of legitimate widespread concerns? Develop private sector, yes, but to destroy what took years to build in the process? To deny so many of a valid choice? It simply does not make sense.

They have a duty of care, and must be held to account.

It is not acceptable that bureaucrats and politicians be allowed to:

- risk the emotional and mental wellbeing of so many residents.
- lower qualifications and care standards throughout the disability sector
- abandon direct responsibility of care for our society's most vulnerable
- disrupt employment and career paths of DSC workers

Parent submissions

Parents have been kept apart, despite calls for inter-house contact. We think that many don't even know about the petition, or this opportunity to voice their objections. Please keep this in mind when weighing up parent input.

Surely it would be pertinent to wait

Do a properly assessed long-term trial of a volunteer home (a fully transparent assessment including families and /or advocates).

Assess the long-term outcome of total privatisation in NSW before proceeding.

We do not have to do this just because other states are doing so.

In closing

With every letter, every meeting, every enquiry, every unanswered question, our resolve becomes greater to ensure the right thing is done for our children and to ensure their on-going well being.

We thank you for your attention and look forward to your response.

The Lyrebird Parent Group

P& J Jones	for
A & J Johns	for
A & M Kowald	for
M & J Shalders	for
T & M Sullivan	For

PART 2 RALLY SPEECH

ATTACHMENT TO submission from Lyrebird Parent Group
Re DSC's privatization of accommodation services

There was a rally outside Parliament House the morning the petition was tabled on Thurs 26th June 2014.

We asked if a parent from our group could address the rally in hope that someone would listen and take notice that:

- families are screaming to be heard – we have genuine real concerns and fears
- staffing issues aren't just about pay and career paths
- losing our whole team would have negative ramifications including our children's emotional and mental wellbeing, resulting in behaviours which could in turn:
 - create safety issues for both staff and other residents
 - bring to question DSC's duty of care
- We care about our staff and their issues.

I speak as a parent

I cannot believe I'm having to stand here today fighting for my son's fundamental right to safety, security, and stability.

Don't get me wrong – I'm not saying that NGOs don't provide this – but I am saying that with the government's current Transition proposal they are in jeopardy.

DSCs letter last October was a 'Titanic' moment. One minute we were cruising, albeit in stormy seas that is life with a severely disabled child. But at least we're riding the waves in a seaworthy vessel – yes? Wrong. Suddenly we are thrown overboard without a lifeboat – no warning, no explanation, no landmarks or beacons to show us which way to swim.

Then finally – weeks later (which seemed like eternity) a lifejacket was tossed into the water after us. Alas too late for some, already drowning with the guilt, anxiety, stress, anger, and fear.

This lifejacket was an assurance that if all parents agreed on an NGO option, we could remain in the same house. Then we discover the life jacket is has a major flaw. Any NGO taking over could not pick up the current DSC staff. Our trust and hope shattered yet again.

Years of knowledge and experience – vital for the intuitive care that comes with that – would all be lost. Vital because our children cannot speak. At best, a couple have very limited sign language. They rely totally on the staff for every basic need.

It's essential that we do not forget, that whilst these people are severely disabled, they are still real people with real emotions.

Our staff are not just basic carers – they are friends who have been alongside through thick and thin, some for many years. So add grief to the mix as well. Grief not just for one, but multiple losses of relationships - valuable relationships.

Over the years we have been blessed with some of the most beautiful caring people who have given so much of themselves. They have loved our children, and respected our position as parents; understanding without judgement, that it's not that we don't love our children enough to care for them at home, but that we cant.

We are struggling with many negative factors. These include :

Disbelief that such radical decisions are being made without adequate assessments, projections and process planning. And clearly no idea of the impact on the residents, or their families.

Betrayal that the people we should be able to turn to in a crisis – DSC – are the very people who are playing a central role in this process.

Anger toward ministers Morton and Barnett who put DSC in this position.

Disgust this is also a social justice issue, and our government should be held to account for running roughshod over the most vulnerable people in our society – those that cannot fend for themselves

Fear we are all frightened for our children's future. If such blatant disregard is shown for their needs now, whilst we are still here to advocate and fight for them, what will they do when we are gone.

I am angry that my time and energy is being taken away from my family to deal with this. Not for the sake of [redacted] himself, because we all love him dearly, but just because of his disability.

Morton's spin is that it's all about choice. Well, our home's parent group has made a clear choice – same house, same staff - and yet this choice is being denied us.

I am intent on putting up a damn good fight to have our parent voices heard.

PART 3 JANUARY LETTER

We have made notations on the attached letter to facilitate cross-referencing with our comments below.

Please read attached letter now

Date 6th Jan 2014
To Carl Strommen, Myra Parry, Wendy Cox, Ron Chalmers
From Lyrebird Parent Group

Comments

The Executor Director of Accommodation Services. Wendy Cox did respond 29th Jan. Why did it take three weeks? Surely these issues should already have been dealt with prior to policy announcement, with answers readily at hand.
Some questions have been answered, some not even acknowledged

- # 1 (reference Submission Part 4 'Lyrebird 2008')
- # 2a This situation was immensely distressing for every family in our group. It is appalling that families were left in this limbo for so long
- # 2b If an accommodation services compilation was not available, how has DSC been serving community enquiries lately?
- # 3a Most questions are simply from a family perspective,
However, some also have a broader public interest perspective
(Section Main General Questions 1 - 5 and Section Other Issues 2)
- # 3b This question has not even been acknowledged

4a Somewhere along the line this issue is not being given the concern it deserves. After the June rally Morton claimed she didn't know anything about this issue. If not, she should have because as you can see, we raised it with DSC. Where is the communication breaking down? Is DSC not passing on these concerns on to the minister? If it is getting to her office, why – or more importantly how – is it being ignored at this level? What has she (Morton) done to investigate and address this issue since (the rally)?

We would like a copy of her explanation, and a copy of the Policy and Procedure document.

What is going to happen to these people? It is not acceptable to simply say 'there is a complaints process available if something doesn't work out.' This is like a driver saying 'I'm heading for a T-junction with faulty brakes – can you fix them?' and the response being 'don't worry, if you survive the crash, there are panel beaters out there.'

4b This is a major, *Major* concern to all of us.

4c We currently don't have much faith in the system, and want some-one to audit policy and procedure around this issue.

5 Despite asking where we could go to voice our concerns, we were not told about the 'meet the board' sessions, otherwise we would have prepared a submission and presented it last April. Only by chance did we find out about the session in mid July.

6 DSC has assured us that DoH will continue the lease, but can your committee get this guarantee from DoH themselves?

7 No-one seems to care that families are upset and hurting. Moral support has been sadly lacking. We have asked on several occasions for our contact details to be circulated to parents at other homes, so we can offer each other mutual moral support and information, to no avail.

We have not explained the full impact this is having on us, because this isn't about us – it's about our children. The stress cannot be put into words. At this point it's suffice to say it has been a living a nightmare for most, especially the first few months. But - it is only impacting us because we have a true understanding and insight into the reality of the consequences of this proposal.

Mr Carl Strommen
LAC 8, DSC

6TH January 2014

Dear Carl

RE: LYREBIRD WAY – DSC'S ACCOMMODATION POLICY

Could you please forward to Myra Parry, Wendy Cox, Ron Chalmers, thank you.

Below are comments / questions / concerns common to everyone in our Lyrebird parent group, which we feel are not adequately addressed by recent letters. *
Can you send a copy of your response to all Lyrebird parents please. We are hoping for an early a response as possible. Thank you.

* letters ref: 9th Oct. Director General Dr Ron Chalmers, and 14 Nov Wendy Cox

Areas of concern

Regardless of service provider, we have defined seven main areas of concern, many interlinked.

1. Building / physical facilities
2. Staffing
3. Finances
4. Parent voice / involvement
5. Day activities / transport
6. Duty of care / Advocacy / Watchdog.
7. Concerns of what happens after we pass on.

Our initial united response is that

We do not want our children moved. Whilst realizing the need to be open to opportunity, we've already assessed needs and concerns in 2008 when Lyrebird residents faced transfer to Armadale. We successfully stopped that transfer. There is nothing to warrant changing our stand now. If anything, our stand is stronger, as our kids have had even longer in Lyrebird, and so even more settled there.

We have no clear / concrete reference point

1. Without any clear-cut cornerstone there is no basis on which to build questions, and make the best decisions. We feel we are living in limbo, emotionally swimming against a tide of "what if"
2. At a glance DSC's second letter (Wendy Cox 14 Nov) though welcome, does not really give us the answers or assurances we are looking for.
3. We don't know:
 - 1 what options are available
 - 2 how to found out
 - 3 who best to turn to,(DSC website info and links have been less than satisfactory)

MAIN GENERAL QUESTIONS

1. DSC has assured us of continued accommodation BUT
Who determines what is suitable / acceptable?
What happens if there is a difference of opinion? Who adjudicates?
2. Who is assessing DSC's duty of care, and that this outcome is in the best interest of our children. Are they in a position to advocate for changes if they find there are short-comings.
Who is watchdog to ensure that DSC does not step away from its 'duty of care'?
3. What if transfer to another provider backfires? Who do we go to?
4. Adequate sufficient placements has always been an issue over the years, under both Labour or Liberal governments, so how is this situation going to miraculously improve now?
5. Who has done the assessments/ projections?
What have they based their working paper on?
How can we access this paper? Is it readily available to the public? If not, why? (If there is no such paper, how can such radical decisions be made?)
6. How are they going to go about things?
In bulk, or phases (Area by area? Disability by disability? Alphabetical?)

A HUGE CONCERN IS

How can DSC promise adequate appropriate accommodation with a private provider?

- On previous occasions some (Lyrebird) families have been told by other major service providers that they are not able to have our children for various reasons, including that our children are 'too high maintenance'.
- Private providers (in order to be financially viable and look good on record) will employ the best staff (both carers and admin) and handpick the easier clients. At best, this will leave needier clients with just average support (our concern is that it will be even less than satisfactory)
- What guidelines / regulations will be put in place to ensure this does not happen?

OTHER ISSUES

1 ACTIV

Is Activ an appropriate option? Some of our children are using their day placement, and some have /will have Hawkevale trust involved. Would this give rise to monies and services being too closely linked, and in turn, would this give rise to complacency and/or bias in Activ's decision-making, over what is really best for that individual?

2 DSC loyalties.

Does DSC serve us the consumer, or just the government?
What platform is available to voice our concerns, individually and as a consumer group?

3 Burden of 'the buck stops here'

We are all aging. What happens when we pass on? With private enterprise having to be 100% financially viable, we are aware that the dollar will determine choices over genuine care and concern. We do not want our 'normal' children to have to pick up this burden.

4 NDIS

How will NDIS define / acknowledge congenital disabilities. Will they be treated differently than 'normal' people whose lives have been affected by a dramatic accident?

What of Centrelink, special allowances, eg special equipment grants, concession for incontinence pads.

5. What guarantee that DoH won't have a policy change that will affect closure?

Thank you for your attention to these matters. We eagerly await your response.

I close in saying we all feel that we owe Lyrebird staff a huge debt of thanks and appreciation, and are concerned for their welfare, career paths etc.

Maree Kowald
Lyrebird Parent group
Maree Kowald

Please note that although I have an email address, I do not have readily available access to internet. If you send an email, can you please send text message so I know to get to a computer. 0415 692 188. or leave a message on 9457 5656.

PS

I would like to add a personal PS, as this has not yet arisen in our meetings. What counselling / guidance is available to DSC parents,

- in decision making
- financial advice
- and moral support?

PART 4 LYREBIRD 2008

ATTACHMENT TO submission from Lyrebird Parent Group

Attached is a letter written in response to DSC's announcement of their intention to move our children from Lyrebird in Thornlie to another house in Armadale six years ago. (DSC did not proceed with the transfer)

Most of the concerns and questions apply also to this Transition.

We hope your committee will address them, and also ask:

Today, nearly six years later, how is it that:

- families are having to repeat so many of protests and concerns?
- yet again, so many questions continue to be either insufficiently answered, or being ignored all together?
- privatisation is still on the agenda?

11 September 2008

Disability Services Commission
Lorraine Notley

Dear Lorraine

RE: Phone call Thurs 4 Sept '08 Re-housing Brian James Kowald from Lyrebird, Thornlie to Armadale.

I have not been able to respond to last Thursdays phone call before now. Your news of the department's irrevocable decision to close Lyrebird was just so unexpected it threw me totally off-balance. Dozens of questions, emotions and concerns swamped me all at once. I have now had time to clarify and process many issues. Below are questions and comments (not necessarily listed by priority) which I would appreciate you forwarding on to the appropriate personnel. I request a written response to every point. Some may take a few days, so multiple responses are OK.

Firstly, in response to your questions:

- Yes, I will attend the lunch meeting Sat 4 October. (The rest of my comments and questions can wait until then.)
- Yes, Brian's father Adrian and I do have contact. Even though it is cordial, I decided years ago that it was best not to play the role of 'go-between', and requested that the department contacted him directly.

Opening comments.

The more I consider this decision, the more dissatisfied I become with both the process and the outcome. I am seriously concerned about Brian's welfare - physical and emotional, and how he will be affected by the upheaval of having to leave his home of twenty years. I am appalled that such a major decision was made without any input whatsoever from family or day placement. If important issues such as these have been ignored, what else has been overlooked? This question raises doubt that the department's priority is really our children's welfare.

1 Concerns re Department's appraisal and outcome

- A In the department's 'duty of care', where does a client's emotional stability and welfare rate?
- B Who was involved in the decision-making process?
- C What triggered the decision to close Lyrebird?
- D Can you outline factors/alternatives that were considered/investigated?
 - How were these factors listed in order of priority?
 - The letter (4 Sep 08) cited privacy problems as the main reason – if this continued being a issue after Main Roads erected the screens, why wasn't this discussed and additional steps considered (raising level of back yard and planting appropriate hedging trees)
- E Who made the final decision?
- F When was that decision made?
- G Who will explain why we weren't informed before now that this was even on the drawing board?
 - The decision to intentionally ignore the families needs explaining.
 - Were all the client advocates also kept in the dark?
 - The "we tell them all at once" approach suggests effort in keeping things under wraps: perhaps in hope of a 'fait accompli'?
 - Brian's Lifestyle review was only one week prior – and not a single thing was mentioned – which raises the question "who was holding back the truth from whom?" Was it DSC from Cheryl, or Cheryl from me?
- G What is the possibility / probability of keeping Lyrebird open?
 - With such a dire need for accommodation services, Lowana would readily fill with other clients.
- I What are plans for Lyrebird – sale? conversion to a respite facility? Other?
- J What are the alternatives to Armadale?

2 concerns re moving – general

- A Moving house is acknowledged as being one of the most highly-stressful experiences anyone can have, and without being able to understand why they are being wrenched from their home, will adversely affect our kids even more than most.
- B Can you promise to fulfil your duty of care in providing extra experienced staff to handle clients who respond to severe stress with aggressive outbursts. I have warranted concerns for Brian's wellbeing and safety and also for his belongings.
- C When / how does DSC intend to handle reimbursement for money we have spent on Lyrebird (eg his roller shutter and new window blinds).

3 concerns re Armadale

- A Armadale will negatively affect family contact.
Is the department not concerned about Brian's family life? Armadale is further away from nearly every one of my family and close family friends – three times the distance from myself (Parkwood) and even further from his sister (Kalamunda), uncles and cousins. This will affect the opportunities for casual 'drop-ins' and visits to family and friends, particularly his sister Melanie.
- B Favourite outing options will be limited due to extra travel time. (eg town, ferry, zoo, Tomato Lake, Riverton Bridge, Kent St weir, yacht clubs)
- C Staff – extra travelling time and cost will affect most current staff and will also affect interest in future job applications. I believe we will see a growing tendency to employ those willing to work 'out there', rather than who is best for the job.

Closing comments

That's all for now. I am looking forward to the responses in hope they will offer a clearer perspective and allay at least some of my concerns.

Sincerely

Maree Kowald

Adrian and Maree Kowald

TO: Environment and Public Affairs Committee

FROM: Adrian and Maree Kowald
parents of _____, resident at DSC's Lyrebird Home in Thornlie

Dear Committee

RE: DSC's proposed privatisation of our son's care

We endorse every comment in the submission from the Lyrebird Parent Group, and add the following personal comments.

We have always supported the concept that the Care Industry be dynamic, with new ideals and directions continuing to be assessed and developed. (After all, Lyrebird group home was a result of this very same process)

After L_____ was born, Maree became involved in several areas we thought would affect the quality of his future, including

- Attending conferences run by various disability interest and industry groups.
- Speaking at some of these, giving a parent perspective
- Sitting on the Policy Advisory Committee for the Slow Learning Children's Group (now Activ). This included assessing various accommodation establishments.
- Although _____ was already accommodated at the time, Maree supported the "Who Cares" campaign for more accommodation services, as placements were severely lacking.

We celebrated major milestones such as

- having a Disability portfolio established with a Minister for Disabilities.
- seeing DSC established
- fighting for group homes to replace places such as Purton and Devonleigh

After some years, with _____ settled and happy in his new group home, and with a growing sense of hope for his future, we stepped back from broader issues and just focused on his immediate personal interests.

Back then, the Parent Voice was given due attention, and carried weight. This is one of the reasons why we are so taken aback that Compulsory Transition had gathered such momentum without any proper family consultation. Another reason is the fact that the Parent Voice prevented the threatened closure of Lyrebird only six years ago.

Adrian and Maree Kowald

CONCERNS FOR BRIAN

For general concerns, please refer to the submission from Lyrebird Parent Group. We would also like to add the following comments.

Emotional Health

... may be 'slow and limited' and lacks formal communication skills, but he still has normal emotions and sensitivities. He is very sensitive to moods and voice tones. He picks up doubt and stress in others. A major staff turnover in a short period of time will have a huge negative impact on him.

He reacts to the loss of familiar staff, especially his favourites. We know loss is a normal part of life, but to have multiple griefs would be particularly painful and difficult for him, especially without the security that comes from having his other familiar carers there to support him.

We challenge the heart of anyone who would purposely inflict this sort of anxiety and grief on anybody, let alone such a beautiful and sensitive soul.

Safety

At least two of ... housemates, when stressed by major change or upset in routine, can get very agitated and have been known to lash out. (I have personally been on the receiving end on a few occasions)

... would be very vulnerable if one of his house mates decided to lash out at him. He is much smaller than them, and weaker, and unsteady on his feet, and therefore totally unable to defend himself at the best of times. Add to this, a further vulnerability after every meal, when he must stay sitting upright for 20-30 minutes, with his harness on. He would be a 'sitting duck' without experienced staff on hand.

Surely there is a duty of care – not just at 'hands on' level, but more so the policy makers that put the staff in that situation in the first place.

Growing needs with aging

Both the continuity of staffing, and qualification levels, have direct impact on quality of care. We do not want to see a drop in staff qualifications as his needs grow with age.

Privatisation may result in staff with lesser qualifications looking after our boy. Our concern is growing as he gets older and getting closer to developing age problems on top of his disability.

He has very severe scoliosis, and cannot eat normal food or have normal drinks. He also has epilepsy and there is a family history of diabetes. Due to restricted movement, he has extremely limited fitness potential. All this does not bode well for his old age.

WIDER SOCIAL RAMIFICATIONS

From our experience, when it comes to seeking a placement, it's not so much that families *want* it, but rather, are in *dire need*.

What about the 'ripple affect' of this policy? Each transition into a private organisation, means one less placement available for families out in the community. Warranted there is a lot more on offer than years ago, but as always, it is still difficult to find suitable placement. We would also like to register a protest on behalf of all those families who will be negatively affected.

PRIVATISATION OF CARE

We support the private sector's growth in the Care industry. However, we disagree with them taking over long-term care that is already in place. No section of Care (whether it be disability, hospitals etc) should ever be put solely into the hands of a profit – driven sector.

There should always be choice.

We are concerned that West Australia is losing its heart. What is happening is simply unAustralian. There is a huge difference between having a 'welfare mentality' state, and caring about - and providing for - our most vulnerable. It is time to cry out loud and clear – WA is losing perspective on our Values.

NDIS

We are getting two messages regarding NDIS.

DSC has suggested a connection between NDIS and the move toward privatisation. But we have also heard that NDIS does not a determining factor.

The local federal MP has said that 'I'm sorry, but being realistic, the NDIS would probably not be rolled out in any real way until 2020'.

If the NDIS is an associated factor, as we are being told, surely it makes sense that privatisation plans should be put on hold at least until then.

If it is not, why are we being misled?

Adrian and Maree Kowald

CLOSING COMMENTS

Maree shall continue to advocate for _____ in everyday matters, and we shall both fight against what we believe is a flawed and (thus far) badly implemented policy.

If anything happens to our son as a direct or indirect result of this policy, we are going to hold the following people personally responsible for ignoring our concerns and warnings - Ron Chalmers, Bruce Langoulant, Helen Morton and any other person we discover in the meantime who has ignored our concerns. Also Colin Barnett, who as premiere is ultimately responsible for his ministers and government departments. This includes medical (especially epilepsy), negative behavioural changes, everyday care (particularly feeding and weight change)

His name is _____ – a beautiful young man who brings great delight to a lot of people. HE IS NOT A COMMODITY to be handed around at the beck and call of some people's idealism, or sold off to private enterprise to fulfil someone's political agenda.

We shall not waver in fighting for real choice, and for our son's right to maintain his standard of care.

We look forward to your response

Thankyou

Adrian Kowald

Maree Kowald