"Government or Non-Government Care in Australia?"

Supported accommodation group home care for those with an intellectual or multiple disability - government and non-government

Life for Luke Modra in DHS direct care was: *Would arrive home for day visit from a DHS care home naked, with torn clothes on his head. Continually anxious, agitated, destructive and self-harming. Shunned human contact and would cover himself with a blanket in fright. Had almost no interaction with people. Meals would be passed through the door and carers would walk through a specially designed cage.*

Life for Luke Modra outside DHS direct care is: *Dresses himself, shaves and brushes his teeth each day. Has started singing again and regained his love of exercising, riding and running. Can talk freely with most people, can look you in the face and talk about how he is feeling. He now has room to move on a grassy, rural property where there are no locks on the doors. Staff don't restrain or talk aggressively to him and Luke's carers have told his family they consider themselves his mate and they feel privileged to look after him.*

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BRIGID O'CONNELL
Health reporter
oconnellb@heraldsun.com.au

With a little bit of tender loving care, Luke Modra has gone from "the boy in a DHS cell" to a happy, functioning adult.

Luke's story, told in the *Sunday Herald Sun* in 2009, revealed how the human spirit could be crushed by a stark state care system with little human contact or stimulus.

As one of Victoria's most severely autistic people, Luke was the archetype of the case authorities left to wither in the too-hard basket. At 15, he was placed in state care where his violent outbursts and his complex way of processing the world left him languishing in prison-like conditions for 20 hours a day for six years.

But now after a year living free from the system, his parents, Mark and Ellen Modra, have a message for the Department of Human Services: by swapping restraint for care and punishment for understanding, the severely disabled can live happy and productive lives without families being destroyed and lives ruined.

"What DHS still hasn't learnt is that these people just can't get over their autism it's there forever," Mrs Modra said. "Either they put the money in for ongoing support for our children ... you might as well say that if Luke's not supported, his life isn't worth living because his life was horrific."

After the Sunday Herald Sun highlighted Luke's case in 2009, staff from a non-government-run disability support agency in the small NSW town of Deniliquin contacted the Modra family to say it could help.

With no other care options in Victoria and with the family still coping with the death of Luke's 17 year-old sister, Hannah, the offer seemed too good to be true.

But workers from Yallambee came and spent time with Luke and his family. They coped with his worst behaviours, understood that autism hadn't affected his intellect and told the family it would be a privilege for them to take Luke on.

Since February last year, the 22-year-old has swapped his sparse cell for his own three-bedroom unit on a 4ha farm, where the doors are never locked and he can run and cycle until he's exhausted.

Instead of having his meals passed through a door and his carers separated with specially designed cages, Luke is cared for by young men who do not blame him for his difficult behaviour and who call him their mate.

"Luke wasn't going to live if he stayed at DHS," Mrs Modra said. "He was so sick, so tortured and just so unwell that we didn't have a choice about getting him out." The magic recipe at Yallambee is simple stuff.

People with severe disabilities can live happy and productive lives if they're given a liberating environment, supported by caring and respectful people and given things to do and look forward to.

Luke does not have more support than he did under DHS care, but he has carers who are being his "moderators" to the world.

"When I see the young farmers who are looking after Luke, what I see is young men who have struggled in their lives," Mrs Modra said. "But when they see Luke and his behaviours, they're not afraid. They don't blame him for it. "They know that when they went off the rails, there was always a reason."

Last week, the *Sunday Herald Sun* revealed the plight of Colby Hickie, a 24-year-old with severe autism and Down syndrome who had lost the ability to communicate and complete daily tasks such as cooking and showering in the two years since DHS removed his specialist carers.

But as young people such as Colby are being left to deteriorate under state care, the Modra family is adamant that Luke's model with the financial backing from DHS can be life-changing for other Victorian families.

For Mr Modra, the moment that summed up his son's incredible progress over the past year came as they watched a movie and sucked on icy poles in Luke's home over summer.

"There wasn't a glimmer of anxiety of anything, it was just normal, relaxed," Mr Modra said. "We didn't know if he would recover, but now he's up there, we know what he needs for the rest of his life."

Two years ago, trying to create that same scene would have been a heartbreaking and stressful mission.

"If DHS brought Luke to visit us, he would arrive naked, his clothes completely shredded," Mrs Modra said. "It would be hell for our other children because he would be screaming, yelling and he'd attack you."

The Modra family are talking with a support organisation in Victoria which they hope can model the care Luke is receiving now, to bring him closer to home early next year.

LISA Comment": There are certainly many residents languishing in DHS group homes receiving little more than basic minder care at best.

"Can all residents now expect the DHS to ensure they receive quality of life care within the direction, intention and spirit of the department's care policies, standards and values, to live happy and productive lives (PCAS) without families being destroyed, lives ruined and elderly parents feeling unable to depart this world in peace?"

We suspect not! Our findings show DHS/DS/DAS regional management above house supervisor cannot properly manage the business of ensuring care level and quality is fully and consistently implemented at their group home service points within the direction, intention and spirit of departmental care policies, standards and values, and within residents' BSP and PCP.

Our findings also show the department's regional management above house supervisor cannot man-manage direct care staff "lore", "peer-pressure" and general disruptive behaviour not conducive to the provision of proper and consistent quality of life care for the residents of their group homes.

As the Modra family discovered with such trauma, real quality of life care is mostly outside of government direct care services - outside of DHS (Department of Human Services, Victoria) direct care services.

LIFESTYLE IN SUPPORTED ACCOMMODATION (LISA) INC.
Tel: 03-9434-3810: Email: vk3qq@optusnet.com.au
Web: www.lisainc.com.au : www.lisa-aus.blogspot.com
NOTE: We are always interested in feedback and information; general, specific, good or bad.
if you wish anonymously: Our mail address is 73 Nepean Street, Watsonia, 3087