

Model for children with severe intellectual disability living in out-of-home care

The Model:

- **Kingsdene Special Residential School**, Telopea, NSW.
- Residential School for 25 children with moderate/severe/profound intellectual disability
- Jointly funded by Government (State Education, State Disability, Federal Education) Anglicare and parent contribution
- Managed by Anglicare
- Operates Monday to Friday during school term

The School:

- 4 classes grouped primarily on ability.
- Classes focus on independent living skills and appropriate behaviour – mobility, feeding, picture communication, toileting, food preparation, shopping, healthy living and personal hygiene etc. (dependent on student ability)
- Music and Physical Activity feature strongly in the curriculum.
- Community access is also a focus. Where appropriate, students participate in “work experience” in the local area

The Residence:

- Continues focus on promotion of independent living skills and appropriate behaviour.
- Families grouped according to social compatibility and manageability and are different to class groups.
- 4 apartment style residences on far side of school grounds and 2 houses located a small distance away.
- 4 children per “Kingsdene family” with one house “Mother” who cares for her children before school and after school until 7.30 or later (children not ready for bed go to a shared living room and “mothers” rotate a late shift.
- Many of the children have poor sleeping patterns. Two night staff rove the four apartments and each house has one on call night staff.
- Each child has their own bedroom with personal belongings from home.
- Children return to “Kingsdene home” after school for afternoon tea with family group, then appropriate activity – park visit, shopping, hang out at “home” and use shared facilities i.e. school pool, trampoline, play equipment, water garden, visit another Kingsdene “family” etc.
- “Home” for bath, dinner & quiet-time with “family” before bed (stories/video).
- Each “Mother” has an assistant for bath/dinner routine and one shared assistant roves the 4 apartment groups during the morning dressing /breakfast routine.
- Frequent community outings including local restaurants for dinner once a fortnight
- Home to Mum, Dad and family on Friday afternoon
- Back to School Monday morning
- Home with Mum, Dad etc. for school holidays
- Home with Mum, Dad etc. during illness or injury

Disadvantages:

- No medical facilities provided, therefore children must have good general health. This excludes children who require tube feeding etc.
- Most of the parents miss their kids during the week, but the advantages far outweigh this disadvantage. Getting ready for school in the morning is an important skill development for all the children (with greater or less dependency). Likewise, getting ready for bed is an important skill development. Many of the children have such disturbed sleep patterns; they are literally learning to sleep through the night. Our children are boarding from Monday to Friday for very good reason.

Personal Note:

My son Charley has Angelman Syndrome. He is healthy, very social, affectionate, good looking and mostly very happy. He's gorgeous and lots of fun. Charley is almost 12 years old and has been assessed to have the intellect of an 8 month old baby. He has a 15 year old brother and a 6 year old sister. Charley's been at Kingsdene for 2 years now. We spent last year successfully fighting to keep the school and residence from closure.

Charley's mobility has noticeably improved – everyone comments. He demands much more freedom of movement at home – we have had a system of gates in the house for Charley's safety and our sanity. Charley has got used to increased freedom at Kingsdene and now objects loudly to the gates at home, so we will have to devise a new system. Inconvenient but a very welcome development – Go Charley Go! His behaviour in general is more settled. He quite visibly loves his teachers, house Mum and certain of his school mates. Charley's main goals at school are using a spoon and a fork independently, toilet timing, and sleeping through the night in his own bed.

I haven't worked since Charley was born. This year I'm going back to University to do a Graduate Primary Teaching degree. This will give me school holidays while Charley is still at school and, hopefully, flexibility when Charley finishes school. I feel I've been in a time warp for the last 10 years, totally pre-occupied with caring for Charley. Now I've got 6 years to catch up and organise things a bit for when Charley finishes school and comes home full-time.

I'm aware that the boarding school model is **not** the best option for **all** children with severe/profound intellectual disability and their families, but I feel confident that it is the best option for Charley and my family.

N.B. All the above information is to my best understanding as the parent of a child at Kingsdene Special School, Telopea, NSW.

Bernadette Moloney