



MONASH University
Medicine, Nursing and Health Sciences

Centre for Developmental Disability Health Victoria
- Better Health, Better Lives -

A new home, a new beginning:
*from family home to supported accommodation
~ a personal perspective ~*

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CDDH VICTORIA

Introductions

Dr Jane Tracy
General Practitioner,

Centre for Developmental Disability Health Victoria



Academic unit
Monash University Faculty of Medicine, Nursing & Health Sciences
University of Melbourne. Faculty of Medicine, Dentistry & Health Sciences

Mission: To improve health outcomes for adults with developmental disability by developing the capacity of generic health service systems to better meet their needs.

Funding: Disability Services, Dept of Human Services, Vic.

Activities: Educational, Research, Clinical, Advocacy.

For more information:
www.cddh.monash.org

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Last year - during the 2008 ASSID conference – my son Nick was offered a place in a DHS group home.




- We needed help with Nick
- & I had always believed that young people with disabilities should have the opportunity to move out of the family home at roughly the same age as peers - around 25-35 – for the sake both of the young person and his/her parents

BUT – like many parents - *I wasn't 'ready'*
(whatever that means
it's rarely the right time for parents!).

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Panic – wanted to run away from the decision	Shock	Fear	Uncertainty
Relief	When Nick was offered accommodation I felt		panic
Confusion and indecision – what should I do?	<i>It was – and is still at times - a painful struggle between my <u>head</u> and my <u>heart</u>.</i>		That I was abandoning or rejecting or relinquishing him
Who am I without Nick?	<i>What I <u>knew/know</u> to be right VS what I <u>felt/feel</u> to be right</i>		Guilt
panic			panic
			Loss (anticipatory)
			panic
			Grief

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I knew this was a precious opportunity for Nick - a new beginning – an opportunity for a young man to have some more independence than a mother can give.

And I know parents find this hard....

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So, how has it been?

1000 times more difficult than I thought it would be – for Nick ... and for me!



Some of the things that have made the transition more difficult:

- **House staff instability & training**
3 house sups, 3 team leaders, holidays, long service leave, casual staff, shift changes etc
→ took a long time to know Nick, for him to have the confidence to try to communicate, to engage him, to do things with him – and to build trust with me.
- **Communication problems**
within and between house, family and day program
- **Conflict** between expectations of family and some house staff – others have been great throughout.
- Difficulty building new **relationships** – with staff & residents.



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Behaviours of concern





- Nick
- Staff
- Me




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Things that have supported a successful transition





- **Staff** - some amazing & committed staff
- **Transition plan** – incl. visual aids to support understanding
- **All About Me** Book - so house staff got to know Nick (prepared by day service)
- **Person centred active support** – a framework & understanding we could share
- **Residential Services Practice Instruction Manual** – great document - philosophy, & ideas & resources
- **Family setting up Nicks room** – a way family could contribute to Nick having a familiar comfortable environment with optimal independence in entertainment (music, DVDs etc)
- **Staff getting to know and like Nick - and see past his behaviours to the fabulous person he is.**

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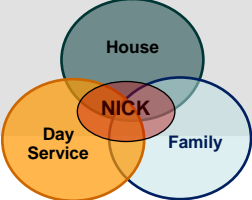

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Other important factors :

- **Sensitive transition case manager** – really understood how difficult I was finding it and was warmly supportive, encouraging – and firm! - when decisions had to be made.
- **Leadership and support** from senior DAS management, team leader, house supervisor, house staff, day service managers and key workers
- **Support workers** – positive attitude, enthusiasm and energy, willingness to work hard to understand Nick, flexible and open to trying new ways, willingness to learn new skills (e.g. making communication aids)
- Establishment of a **positive, respectful ongoing collaboration** between house, family and day service.

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What has helped?


- **Stability** in staffing
- **Skill**, knowledge & professionalism of staff
- **Good communication** and **teamwork** between **house**, **family** and **day service** – esp. communication between key worker (home), key worker (day service) and family
- Strong positive input from **day service** – stable, familiar base for Nick during the day + contribution/problem solving – daily + planning meetings
- Strong advocacy from **family** – (however irritating that may have been at times!)
- **Individual Support Plan** - with Specific Measurable Achievable Relevant Timely (**SMART**) goals.




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Importance of Day Services in transition



- The core of Nicks life – *he hates holidays!*
- his friends – including his girlfriend are all there
- Staff have **known and supported Nick** for 6 years – deep understanding and very positive attitudes towards him
- Staff who have **known and supported the family** for 6 years – strong positive relationships



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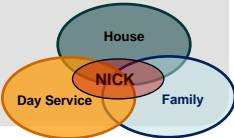
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So where are we now - 12 months down the track?

- Nick is happy and relaxed – *most of the time!*
- House, day service and family are **working together** to understand his behaviours – and when something goes wrong to **problem solve and intervene as a team**
- His **girlfriend came home** for dinner – and Nick was very excited and proud
- Nick has started forming relationships with the other residents
- As Nicks team** we regularly review his ISP & focus on the goals - making sure they are **still relevant** to Nick – and discuss how **implementation** is going and **problem solving** barriers to implementation together.



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My hopes for our future together as a team working to support Nick

- **Good communication: (daily diary, email, phone calls, meetings)**
 - Help Nick optimise his communication with his friends, family, house staff, day service staff & family
 - Good communication between house, day service & family
- **Working together to support Nick in his relationships**
 - Other residents
 - His girlfriend
 - Other friends
 - Family
- **Explore other interests and activities with Nick**
 - Movies and Concerts
 - Outings with friends
 - Holidays



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As his family – we will always be there for him

- Loving him
- Looking out for him
- Advocating for him when required

The move into his new home has

- Been a **new beginning** – a new chapter in his life
- **Enabled him to grow** and develop a sense of increased independence; himself as an adult (he is now more willing to engage in new experiences in an interested and mature way)



• Given me the chance to rest a little and to contribute to Nicks life and the lives of others in different ways.



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The keys to a successful transition are

- **learning from each other**
(house staff, person, family, day program staff, relevant others),
- **communicating effectively and respectfully,**
- **setting *S*pecific *M*easurable *A*chievable *R*elevant *T*imely goals**
- **and each person involved taking responsibility for ensuring they are achieved.**



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