

Generation Next 2019

## Resilience matters:

a developmental approach  
to nurturing resilience in young people with disability.

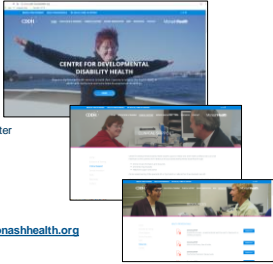


Dr Jane Tracy  
Centre for Developmental Disability Health

## Introductions

### Professional

**Dr Jane Tracy**  
Director, Centre for Developmental Disability Health,  
Monash Health



**Mission:** Improve health outcomes for adults with intellectual and associated developmental disabilities by developing the capacity of mainstream health services to better address their needs.

**Activities:** Educational, Research, Clinical and Advocacy.

[www.cddh.monashhealth.org](http://www.cddh.monashhealth.org)

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## Introductions

### Personal

Mother of two fabulous  
young adults:  
Nick and Emma.



## Nick

Nick has an intellectual disability, cerebral palsy and epilepsy.

He does not use speech communicate and requires a walking aid or wheelchair for mobility.



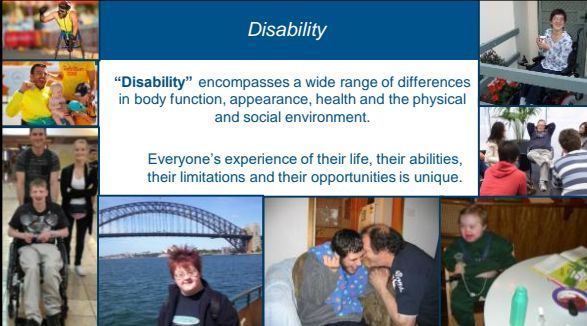
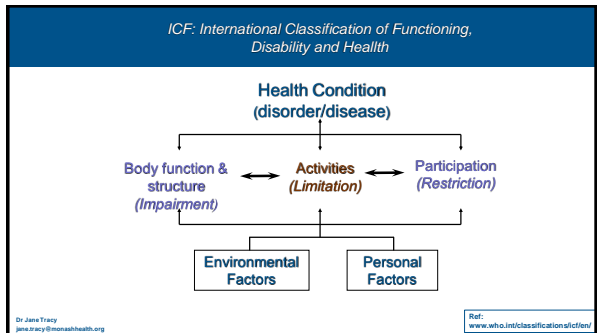
Being his mum has been tough at times and he has enriched my life enormously.

We have shared 33 years of fun and joy!

## Disability

“Disability” encompasses a wide range of differences in body function, appearance, health and the physical and social environment.

Everyone’s experience of their life, their abilities, their limitations and their opportunities is unique.

## Resilience

Life can be tough...

... resilience is about bouncing back and growing stronger through adversity.

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With thanks to Michael Leung

## Resilience in people with disability

People with disability often face more adversity than most.

How can we build their resilience to help them deal with, and bounce back from, that adversity?

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## First: Optimise Health

**Good health:**

- Physical health
- Mental health
- Dental / oral health
- Social & emotional health

**Optimal quality of life:**

- Comfort & wellbeing
- Function & independence
- Participation & contribution

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## Developing and nurturing resilience

- Many frameworks and models re building resilience.
- The **Wolvin model** from 'Project Resilience' appealed to me because of its **developmental approach**.
- It informs and facilitates building 7 components of resilience at each developmental stage.

Ref: Wolvin, S. & Wolvin, S.  
The Child, Adolescent & Adult Phases of the Resilience.  
www.projectresilience.com

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## 1. Independence

**Independence**  
As the young person develops....

**Straying:** Wandering away

→ **Disengaging:** detaching/separating

→ **Separating:** standing up for oneself.

Ref: Wolvin, S. & Wolvin, S.  
The Child, Adolescent & Adult Phases of the Resilience.

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## Independence ~ challenges ~

Having a sense of independence and control is an important component of resilience.

Physical, cognitive, social and/or sensory disability may make this more challenging.

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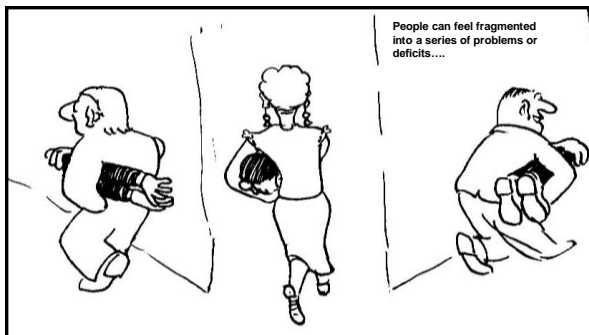
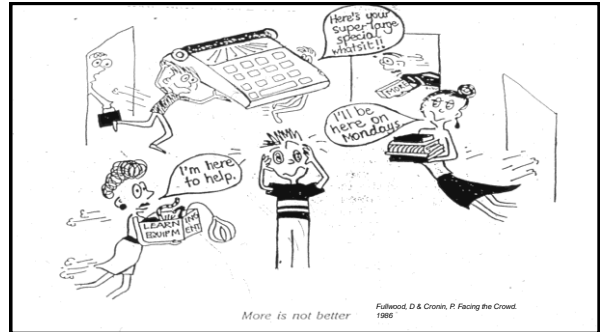
## Independence ~ challenges ~

- Family members, support staff, therapists may focus on:
  - deficits vs strengths,
  - helping vs coaching,
  - protecting vs stretching.

**Balance needs to be found – and constantly reviewed:**

**protection, safety, assistance  
VS  
risk, challenge, learning.**

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## Independence

~ opportunities ~



Encourage and support as many direct, unmediated experiences as possible...  
to build independence, competence, agency, mastery, confidence.



## Independence

...in communication & in entertainment.



Photo albums, laminated photos, other visual aids and his communication book.



Notice board – instant access to laminated photos for conversation.



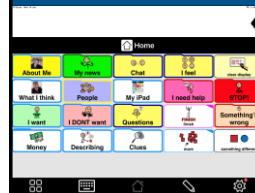
Technology for independent entertainment

**Build on what the person CAN do**  
– e.g. recognise pictures

**– and what they WANT to do –**  
e.g. look at photos, talk about their interests listen to music and watch movies..

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## Technology has transformed!



The iPad has given Nick an independence in communication (communication App Proloquo2Go) and entertainment he has never had before.



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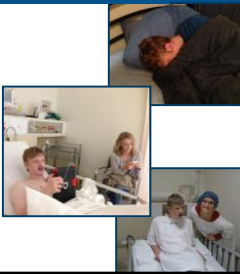
## Behaviour is communication

**Behaviour is a communication**  
 – About physical, emotional, sensory or social state....

And there are so many changes in journey through adolescence into adulthood!


**Behaviour will change** according to:

- **Environment:** social, physical, sensory, emotional
- **People:** understanding, support, inclusion ...or reverse!
- **Size:** Growth (size, strength) → greater physical impact.
- **Development:** changing physical, cognitive, social needs.



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## Power



Supporting the experience of choice, power and independence – even if not quite the reality!

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## Understanding someone's behaviour

- **Consider from their perspective:**
  - Perception, understanding, experiences
  - Interests, passions
  - likes, dislikes
- **Has something changed?**
  - Physical: pain or discomfort
  - Mental: anxiety, depression, psychosis
  - Environment: changes: people, places, activities.
  - Sensory: hypersensitivity or sensory loss
- **Appreciate developmental stage**
  - supporting the person to develop trust, autonomy, agency, control, value, meaning and contribution....
  - Testing limits – taking risks!



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## 2. Relationships


### Relationships

*As the young person develops....*

**Connecting:** Trust & fleeting ties with others

→ **Recruiting:** Deliberate attempt to engage with helpful/supportive peers & adults

→ **Attaching:** Mutually gratifying – characterised by give & take.

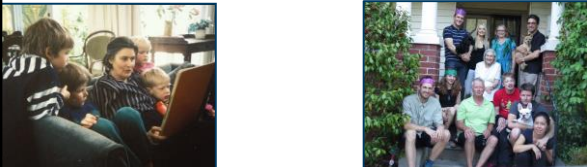


Ref: Wolin, S. & Wolin, S.  
The Child, Adolescent & Adult Phases of the Resiliencies.  
www.ecolipso.com

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## Relationships

- **Having a sense of belonging, of being valued by others, of having trusted people to turn to are all contributors to resilience.**
- Physical, cognitive, social and/or sensory disability may make this more challenging to make and maintain relationships.



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## Relationships ~ challenges ~

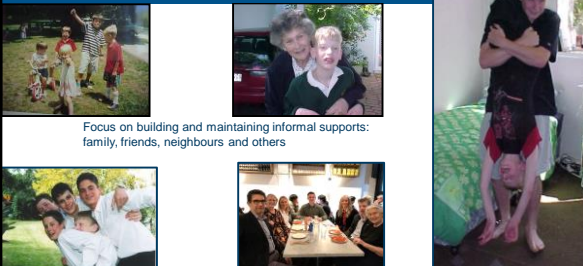
- Identifying, building and maintaining friendships and other relationships may not be prioritized.
- People may have family & paid support people in their life – but few friends & other informal relationships.

**Balance needs to be found – and constantly reviewed:**

**Protection, safety, assistance  
VS  
risk, challenge, learning.**

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### Relationships ~ opportunities ~



Focus on building and maintaining informal supports: family, friends, neighbours and others

### Relationships

Building and maintaining friendships may need active support and assistance from others to:

- Provide **opportunities** to meet peers.
- **Notice** who they like spending time with
- **Facilitate** opportunities to build the relationship, after hours contact, activities, building shared interests – eg movies etc.
- Provide **practical help:** transport, personal care, time, social skills **coaching** & other specific assistance as required.

Parties with friends & family



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### Challenging relationships



Support the building of trusted relationships – even challenging ones!

### Reciprocity: Giving to and doing things for others

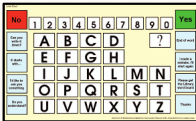
Encourage and support opportunities to give and contribute to the lives of others.



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### Communication

- **Children** may have communication strategies that work within the family and close circle.
- **Adolescents and adults** need to have independence in communication to engage directly with their wider community.

### 3. Initiative

**Initiative**  
As the young person develops....

Exploring: Trial and error  
→ Working: Problem solving, goal directed behaviour

→ Generating: Zest for projects and tackling challenging situations




Ref: Wolin, S & Wolin, S. The Child, Adolescent & Adult Phases of the Resiliencies. www.zprojectalliance.com



*Initiative:  
~ challenges ~*


- Being able to initiate action, to work towards a solution to feel a sense of agency and competence are components to resilience.
- Disability may make it more difficult to:
  - explore their world,
  - express their ideas,
  - engage in problem solving,
  - set goals and work towards them
  - experience the stretch of a challenge.



**Balance: protection, safety, assistance Vs risk, challenge, learning**

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*Initiative:  
~ opportunities ~*




The young person needs opportunities to explore, to try and experience the results, to work towards finding a solution to a problem they encounter – with encouragement and support.



*Explore, experience and test one's limits  
..... ideas and decisions – good and bad!*




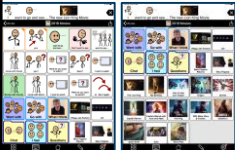
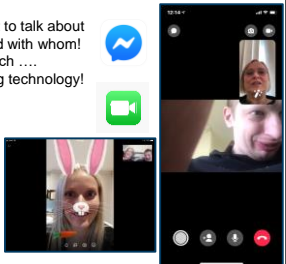
That looks fun. I think I'll go on that.



Maybe that wasn't a good decision!!

*Initiative  
...in communication and relationships.*

Deciding what to talk about and when and with whom!  
Low tech ....  
And now using technology!

**4 & 5. Creativity & Humour**

**As the young person develops....**

**Playing:** Imagination – rearranging experiences and ideas

→ **Shaping:** Using art and comedy to give aesthetic form to innermost thoughts and feelings

→ **Composing, laughing**  
Humour also relates to rearranging ideas, & capacity to see the absurdity in troubled times, to minimise pain with a joke



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Ref: Wolin, S. & Wolin, S.  
The Child, Adolescent & Adult Phases of the Resiliencies.  
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**4 & 5. Creativity and humour  
~ challenges ~**

Disability is regarded as serious .... joking around can seem less important than other priorities.



**But laughter is such an important part of coping with adversity**

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### 4 & 5. Creativity and humour ~ opportunities ~

- **Play, creativity and humour contribute to resilience.**
- Disability may lead to challenges in engaging in play.
- **Creativity = opportunities** to generate, explore and test ideas ..... Concepts can be manipulated and reframed in creativity and humour → problem solving and in finding ways to cope with adversity.
- The fun, learning and joy of **play, creativity & humour** should be valued just as highly as other developmental tasks.



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### 4 & 5. Creativity and humour ~ opportunities ~

Life is fun!



### 6 & 7. Insight & Morality


As the young person develops....

**Insight**  
Sensing something's wrong

- **Knowing**  
systematic awareness of the problem
- **Understanding**  
understanding of self & others, tolerance for complexity & ambiguity

**Morality**  
Judging  
Capacity to make good or bad decision

- **Valuing**  
Principled behaviour and decision making
- **Serving**  
Sense of obligation to contribute to the well-being of others.



Raf, Wain, S. & Wain, S.  
The Child, Adolescent & Adult Phases of the Resiliencies.  
[www.projectinsight.com](http://www.projectinsight.com)

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### 6 & 7. Insight and morality

**Developing the ability to sense right and wrong** – one's own moral compass - is important in

- deciding on our own actions and
- judging those of others.
- Important in **safeguarding against abuse** and exploitation.

• **Knowing not everyone shares your views** is important to resilience in coping with complexity & adversity.


**Developing a sense of one's place in the world** of relationships – how we all fit together in community - involves reciprocity, mutual obligation and responsibility .



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### Caring for others

Caring for and giving to others is part of belonging, of participating, of contributing.



### 6 & 7. Insight and morality

Involving people in discussions around differences in likes and dislikes, preferences and choices, discussing news, politics, voting etc – learning people see things differently -

..... will support them participate as citizens – including voting – and cope with the inconsistencies, complexity and unpredictability we all experience in our lives.



In summary, nurture resilience in young people with disability through:

Optimising physical and mental health

AND providing opportunities for people to experience:

1. Independence:
2. Relationships
3. Initiative
4. Humour &
5. Creativity
6. Insight &
7. Morality

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