

Key points to be covered

- What is life like for people with a disability?
- The impact of models on structuring our thinking.
- Our experiences are not the same as our family member, client or associate so only they can say how their life is.
- We need to assist people with a disability to speak their voice, but to realise that this may result in them moving in directions that we do not like.
- Ultimately they need to speak on their own.

Some Common Life experiences of People with a Disability (From W. Wolfensberger)

- **TREATED AS DIFFERENT, even Deviant:** not belonging, different and devalued.
- **REJECTION:** Perhaps by family, neighbours, community, society, service workers.
- Cast into one or more **HISTORIC DEVIANCY ROLES**.
 - Object of Pity, burden of charity. • Eternal child
 - Menace. • 'Animal-like' or 'vegetable-like'
 - Sick or diseased
- **STEREOTYPED:** "marked", "branded", "deviancy imaged".
- **"DISTANCED"** Usually via **SEGREGATION** and **CONGREGATION**.

Some Common Life experiences of People with a Disability (From W. Wolfensberger)

- **LOSS OF CONTROL**, perhaps even autonomy and freedom.
- **PHYSICAL & SOCIAL DISCONTINUITY**.
- **LOSS OF FREELY GIVEN RELATIONSHIPS** and substitution of artificial/'bought' ones.
- **DE-INDIVIDUALISED**, treated as one of a class of people.
- **INVOLUNTARY MATERIAL POVERTY**.
- **HAVING ONE'S LIFE WASTED**.
- **IMAGED AS 'BETTER OFF DEAD'**, even being made dead.



"PAROLE APPROACH"
TO SCHOOL INCLUSION

Key points of the devaluation and wounding

- Almost all of the problem is related to how *people with disability are treated*, not the disability.
- The traditional approach to disability is based on a medical model of *impairment as the problem*, which needs intervention to assist. Hence a focus on therapy and separate specialist intervention.
- Even if we know the person with a disability intimately and share their life over many years, we DO NOT experience the wounding.
- This means that it is essential that the people learn to speak for themselves as they are the only ones to really know what their life is like.

Competing models and their implications

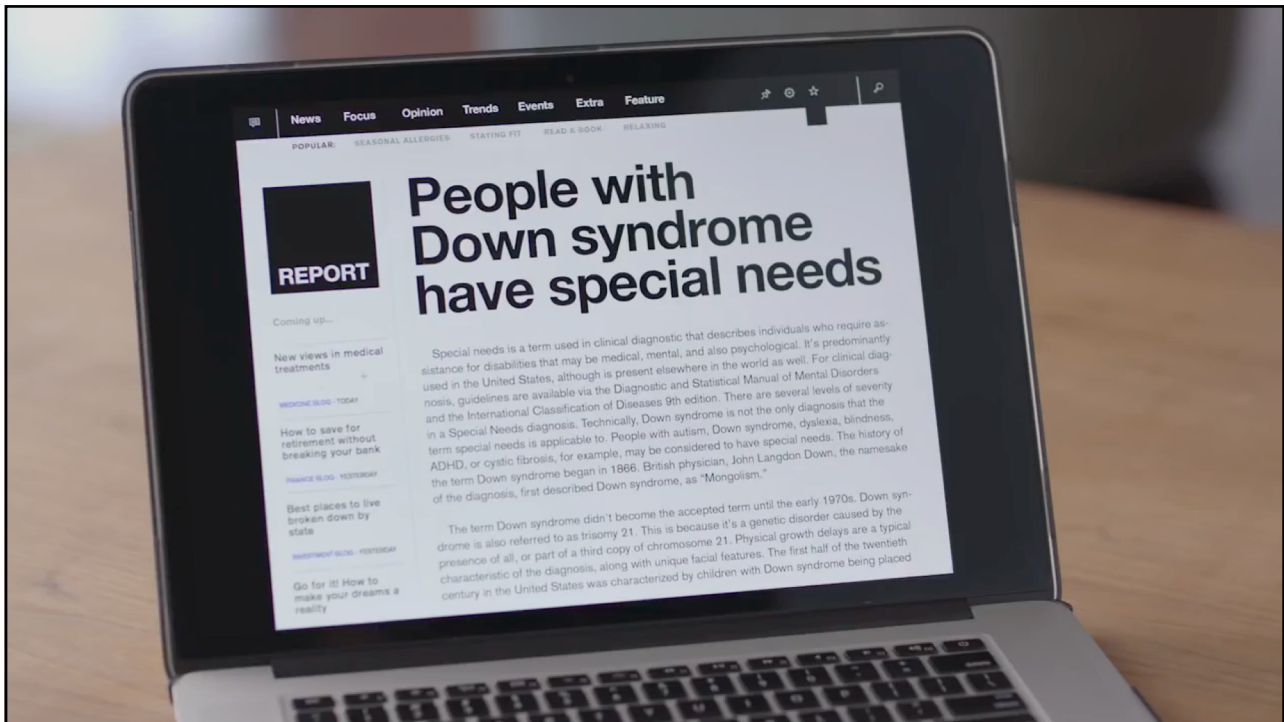
Medical Model

- The problem is in the people themselves.
- They need to be helped and treated so that they are able to meet the requirements of schools, workplaces and society generally.
- Specialists are required to meet these needs as they have '*special needs*'.
- Their needs can't be met in normal environments so special environments are needed.

Fact check! Do Special Needs Exist?

- "He needs a wheelchair". "That's special!"
 - The need is the *human need* of mobility. The wheelchair is just one way of addressing that need.
- "She need a speech therapist as she cannot talk." "That is a special need!"
 - The need is the *human need* of communication. Therapy is just one way of addressing that need.

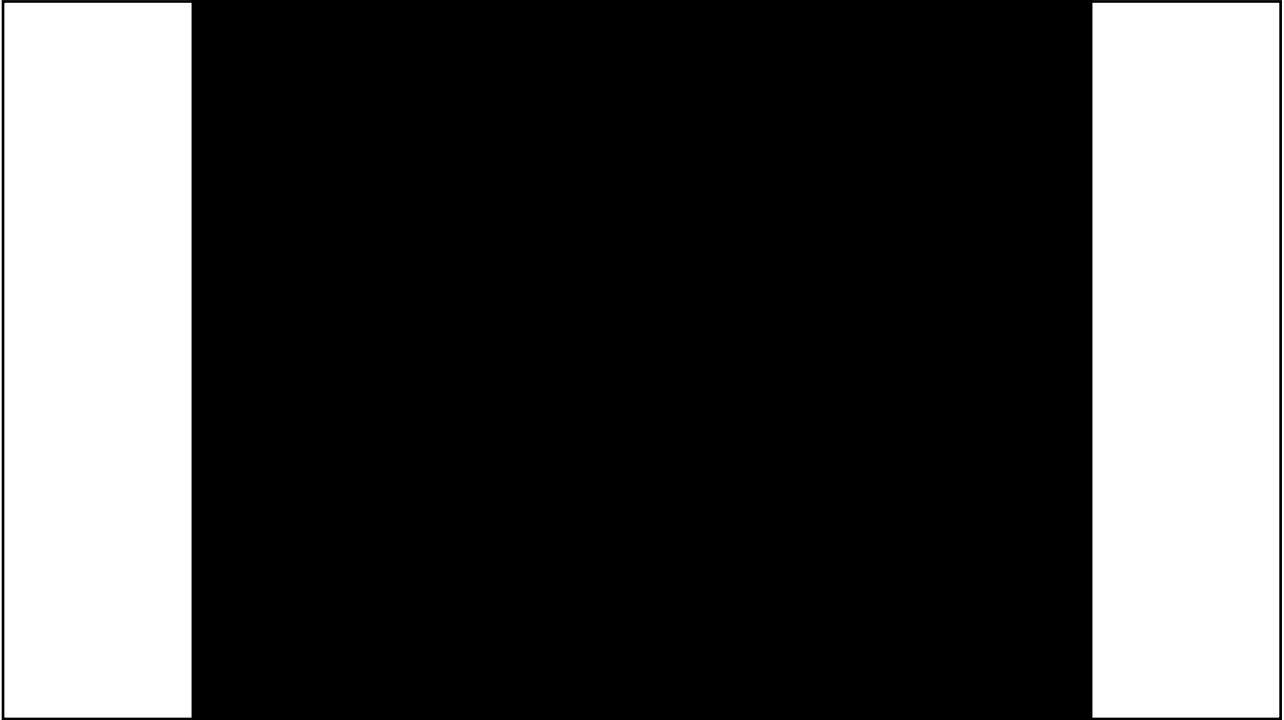
That is, *there is no such thing as a special need*. They are all just human needs that may require additional or sometimes adapted ways of being addressed. The danger is that once we define the need as 'special' it implies that we will need special people in special places doing special things. This is the path to a segregated life.



Competing models: Medical vs Social Model

The social model

- The 'problem' is in *the failure of the environment to adapt* to make allowance for the person's disability.
 - Ramps for access.
 - Curriculum modifications in the classroom.
 - Technological supports at work, school or in the home.
 - Personal assistance to manage the environment when needed.



How can people build personal power and gain skills in speaking out?

Children

- Having a vision that you build with the child and continually revisit with him or her.
- Surround the child with high expectations.
- Build in maximum choice in the child's life so the child is continually expected to make decisions. This can be as simple as two choices for breakfast through to major life decisions such as type of schooling.
- Teach strategies for making decisions – reasons for and reasons against. Then balance the options before deciding.

How can people build personal power and gain skills in speaking out?

Children

- Teach *self-control* rather than 'manage' the child.
 - "Helen, you can choose to stay outside after the end of school recess, but if you do you will have to finish your work after all of the other children have gone home". "Instead, you could choose to come in now and we will start with a story and you will go home with all of the other children". What would be a good choice Helen?"
 - Then follow through: "Oh, that was a bad choice. Oh well, you will just have to do your work after school". I'm sure we will make a good choice next time". What would be a good choice?" "Yes, coming in after recess". OR "Great choice, I am so proud of you making such a great choice." "We will come in and read a story".
 - If a 'bad choice' is about to be made: "Helen, what would be a good choice to make here"?

How can people build personal power and gain skills in speaking out?

Children

- Give practice in speaking if they are capable of speech.
 - Small parts in a play.
 - Telling news at the beginning of a school day.
 - Coach child on what to say and give practice.
 - Role play a situation in a fun way.
 - Prepare them for a debate: Reasons for and reasons against. Then have them present one side.
 - If no speech, involve them in preparation and then have a classmate co-present what has been prepared.
 - Prepare a speech on an iPad or computer which the child presses to start.
 - Prepare a PowerPoint presentation with the child with points written, and they present.

How can people build personal power and gain skills in speaking out?

Young people

- Teach the social model framework.
 - They will have been heavily influenced by the medical deficit model.
 - Their self esteem is likely to be low.
 - They will have had many failure experiences and so may have low motivation.
 - The social model provides a framework to see issues as a shared issue that is not their fault. "Society disables".
- Make people aware of key human rights and legislation.
 - UN Declaration on the Rights of Persons with a disability (CPRD) which defines inclusion as a human right of the person.
 - National legislation outlawing discrimination on the basis of disability.

How can people build personal power and gain skills in speaking out?

Young people

- Self Advocacy Groups
 - Best if the individual decides to join.
 - Highly likely to need support in the initial stages.
 - Preparation of presentations in PowerPoint etc.
 - Role playing structured negotiating situations of increasing levels of difficulty.
 - Key role is to develop skills, not push a particular position of interest to supporter.
 - As they become more effective, there will be often fierce reactions from families, services and government groups.
 - It is highly likely that supporters will be accused of 'putting people up to it' and brainwashing. Hence the need to be careful that there is no pushing of supporter agendas.

How can people build personal power and gain skills in speaking out?

Young people: other research

- Involvement in self advocacy groups increased health and well-being through new roles and identities.
- People were able to develop an identity different to the one that society had given them (i.e. the stereotypes).
- Developing their own identity was often in conflict with people around them who wanted to protect them from dangers and disappointments.

How can people build personal power and gain skills in speaking out?

Young people: other research

- Possible steps for school students:
 1. *Build disability awareness and self – discovery.* Often people had hidden their disability from them to protect them. Knowing who they were was a first step to empowerment.
 2. Make them aware of what is available for them in the school situation for support.
 3. Work with students on setting goals and teach self-monitoring.
 4. Build experience in participation and presentation both at the school and in the wider community.
 5. For the more capable students, developing internet groups, blogs or Facebook groups can be very effective at educating others and empowering.

How can people build personal power and gain skills in speaking out?

Young people: other research

- Key point was that the process of development of a self advocacy group was an evolving process with people initially joining for social interaction but evolving to greater participation.
- This means that there is no perfect model for their development
- It is this evolution that builds resilience as the group develops naturally depending on its members. As they become empowered they are less likely to be put down by agencies or staff, but the danger of paternalism is great.
- The overall impact of building empowerment and resilience was increasing optimism of members.

Summary

- The life realities of people with disability are of continual wounding and high levels of vulnerability.
- They have been traditionally defined by a deficit model that has dramatically affected their level of autonomy and control.
- If they are given an alternate model and awareness of their rights and laws in their favour, they can gain more empowerment.
- Supporters can have a powerful impact in teaching advocacy skills and strategy, but they need to minimise influence.
- Self advocacy groups can be a powerful way to increase personal development, resilience and capacity to speak for themselves.