

*family*

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**Abstract**

These notes were taken by Judy Ellis, a parent leader who attended the Citizen Advocacy Annual General Meeting where Wendy Richardson spoke as a parent and how she sees the role of citizen advocacy in the context of family. **Keyword: Advocacy**

*Notes on a speech given by Wendy Richardson at the Citizen Advocacy AGM on 23/11/91 at Bondi Junction - including how some of it was interpreted by Judy Ellis. Wendy is the parent of 3 children - 2 of whom have intellectual disabilities. She is also a grandparent.*

Parents go on parenting. Her mother still asks if she is wearing a singlet; her grandson tells her that she's still a child because she's got parents! He believes that you're always the "child" of someone and that will only stop when your parents are dead.

Most children begin very early to defend their own decision-making roles, autonomy and control.

Parents are socialised to expect their children to defend their autonomy.

Remember that parents still carry on a monitoring/caring/assisting role with all their children. Some "children" make decisions that they won't allow that to happen at all, or the family separates, don't see each other at all; many accept it/understand it and try and live with it. Can't just take extremes and say because person is an adult then the parents/family have no part to play at all. This is going against what happens in every family.

Therefore we have to strengthen parents with children with disabilities to be able to "contrive" growing autonomy and decision making even though the person with the disability may not be able to actively defend their own roles. Have to show parents ways of getting appropriate supports in community to "defend" role as growing/interdependent adult - so this is where parents could really see that Citizen Advocacy has a place.

Citizen Advocacy needs to see itself as "sharing"/taking over/helping with the decision-making/autonomy. Doesn't have to be conflict although it may in some instances; it may be necessary for a citizen advocate to try and "repel" parents if what they are doing is totally against the interests of the person.

Citizen Advocacy has a very specific place too for "people who have become unparented".

Citizen Advocacy:

- has now entered our lives
- looks at what is worth pursuing
- is not the whole answer - just part
- may create conflicts

but we must try and work together as we are both a resource to each other.

Amniocentesis - a modern technology which could be used to assist families prepare for the challenges ahead.

Daughter was only offered amniocentesis on condition that she accepted an abortion if the child had the same genetic problem as her brothers. This is an

example of technology working against parents/families. Limiting the range of choices. Perhaps we could begin to believe that amniocentesis could become a tool to (1) prepare families (2) assist them (3) get information to them, instead of how it is solely presented.

Wonders about the present - the "good days". Are they really so good?

Years of bewilderment - years of negativity - ensure that parents are extremely wary of change, positivity, vision for the future. Why would/should they be trusting?

Dreams and hopes are often used to dull the fear and anxiety (e.g. perhaps it will all go away ... perhaps it's not so; perhaps there is a treatment?)

Conversely ... fear and anxiety dull the dreams and hopes.

Parents are first to know and last to admit.

Language used - the word most often heard is "Away" ... "Your son would be better 'away' at a school", etc. The word "away" is very powerful - it immediately negates "with the family", "sharing the care", "belonging", "part of the community".

Why is it that people offer support to the parent and don't relate to the person who has the disability? People seldom offer support, encouragement, strength, friendship to the person - always to the parent. That reinforces "burden".

Wendy ended the story about how her son Ian has "come home" (to the Illawarra) after 23 years. Expelled from Lorna Hodgkinson, expelled from Hall for Children, placed in Peat Island (from which he could never be expelled). She had written a poem about how she went to visit him there, and what it was like in 1967. (Seems very little has changed - JE)

Unfortunately I didn't write the poem down.