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**Abstract**

Judy Ellis, a parent leader from NSW, believes it is vital to understand the contributions the past has made before deciding what the future will be. "For the movement of parent and /or consumer groups to work well, it is crucial to build on the past". She provides a historical perspective of parent groups, and discusses the changing nature of groups because of societal changes, attitudinal changes and the growing involvement of people who have disabilities. **Keywords: Families**

# PARENT GROUPS, THEIR PAST, PRESENT....AND FUTURE?

Judy Ellis

The question of the historical perspective of parent groups is an important one for us to address. In my opinion, it is vital that, before delving more deeply into what might be the future, we have to get to grips with the contributions of the past. For the movement of parent and/or consumer groups to work well, it is crucial to build on the past. The future - where we are going - is deeply intertwined with the following issues, to which I will return later. They are:

1. SOCIETAL CHANGES
2. ATTITUDINAL CHANGES  
both in the community and in parents and/or people with disabilities
3. THE INVOLVEMENT OF PEOPLE WITH DISABILITIES  
whether their disability results from an intellectual, physical, sensory or psychiatric impairment.

The last point is one which, risky or not, parents must take on board and deal with.

I would like to begin by briefly looking at the past. At the beginning of the century attitudes were so entrenched that to have a child with a disability born into a family was synonymous with stigma. The vast majority of parents placed their children in institutions which, regardless of the motives for which the well-meaning people had built them, were places of custodial care. The attitude of that society was that people with disabilities had no place in society - in fact they could even harm it. This attitude has prevailed well into the present century and we still face remnants of it today. As an example, in 1923, in a submission to set up a very well known organisation which is still operating today, the following rationale was used:

*"These feeble-minded girls are spreading through New South Wales, having illegitimate feeble-minded children....Something must be done to check this fearful social evil, and the public of New South Wales is only waiting for someone to make the start."*

So we see that the entrenched attitudes of the system set up in the 19th century were in fact being used later by those who were, in their time, regarded as the "new thinkers", the "progressives" in the field. As a result many of the private institutions too became places for the forgotten people. Into most State institutions were confined people of all types of disability; including a great many people with cerebral palsy who had obvious physical problems and great difficulty in communication. In fact, it was at this time that the great myths of "lunacy" and "abnormality" were perpetuated. They became the definitions of all who did not conform.

The lack of, for instance, medical knowledge too had a great effect on the development of services. Many children who had a physical disability died soon after birth. Attitudes too played an important part in ensuring that "different" babies did not survive; indeed, midwives and doctors of that era took definite steps to intervene. Those children who survived the medicos and the attitudes, were often later found in amusement arcades. If we, today, require one clear example of this heritage, then we should look no further than two words which we use today - "sinister" and "dextrous" and their meanings. One from "left" and one from "right".

So what was the PARENTAL input at that time? Well, to put it simply -

- 1) they were not wanted, and
- 2) they were not even sure that they could or should be involved.

Many probably felt that it would be best not to have anything to do with the "catastrophe" that had hit them. The vast majority were being informed that what had happened was "in their family". It is important to remember though that it was well-meaning people who theoretically built up the myth by initially suggesting that these people should be segregated for their own good. With the physical building of the institutions, it was easy for self-interest to creep in and for them to use the institutions for what they saw as the community's good. This applied, too, across the spectrum of disability and early reports and Public Enquiries contained such expressions as "permanently interned", "suitable for relegation", "potential for harmfulness", "grave national peril". As for parents, well, it is clearly documented that parents who produced such children should be "permanently checked". That kind of mumbo-jumbo still has grave implications and, through the decades, has influenced all the different types of parent groups, which have in turn influenced the development of services we see today.

The movement which began in the late '40's and through the '50's was, therefore, a phenomenon which will be difficult to repeat ever again in the area of disability. Against all that prejudice, against a web of silence from the so-called "helping professions", parents banded together to defy the attitudes and provide services for their children. One of the strongest movements was by parents of children who had cerebral palsy and those with children with physical or sensory disabilities who became determined, quite rightly, to ensure that their children were not looked upon ever again as "mentally handicapped". While this had extremely positive implications for those groups, it also had some very adverse effects. It meant that those parents who did in fact have children with intellectual disabilities had to fight against views which were doubly antagonistic, which were perhaps grudgingly accepting of some disabilities but which still retained severe doubts about where people with intellectual disabilities fitted into the scene, if at all. It also began the power struggle - mainly to get a slice of the vital available money. I do not say this in any critical sense - simply a realistic one. This in turn has led to the fragmentation within the disability field and has ensured that it is not as powerful as it could have been.

As an example of what the movement meant for those with children with intellectual disabilities, think of the interviews you have seen where people talk of someone being incorrectly in an institution because they are not intellectually disabled - a view which, when presented in such a way, merely reinforces the view that institutions are OK for people who do have intellectual disabilities. However, over time parent groups which were set up in the intellectual disability area too became providers of "new" services. Using their own resources, and later gaining greater public awareness and financial support, parent groups of the '50's and '60's, in differing degrees of success, established

day centres, residences, workshops and other centres for different groups of children. Most groups set up services for children and then considered adult needs as their own children got older. They did this because the State, i.e. Governments, refused to recognise their needs. After all, it is only a recent phenomenon that the State has accepted responsibility for schooling for children described "ineducable".

Parent groups then literally forced the community, and subsequently, the Governments into acknowledging that "custodial care" was not good enough. Today we, therefore, see in Australia huge involvement by the voluntary non-government sector, which was commenced by parents. With the exception of the rehabilitation programs and some Regional State Corrective Services initiatives, the vast majority of adult services are controlled by the voluntary sector. Many schools, workshops, residential services are on the same "campus". I believe this is due to two factors:

1. Because of the exploitation and dreadful conditions which existed before the parent movement began, the groups themselves felt bound to protect their children from what society had done to them, as well as to provide them with positive services
2. The sheer enormity of levels of energy put in by parent groups to maintain these services has meant that most have had to capitalise on their assets and simply built-on more on the same block of land.

So while this effort was enormous, we now see that the services which parents built have become places which now serve to continue the segregation of individuals from the community.

And now, let us try and look at the '80's and lead into the '90's. New groups of parents and/or people with disabilities have formed. Most comprise those parents, who like the parents of the '40's and '50's want change. We cannot really examine these groups in much detail as they are still forming, still working out their priorities, but one certain commonality is that they too are part of the whole evolutionary process. Before we can even examine the ways in which they are trying to work, let us re-examine the 3 points mentioned before, and let us try and define some major issues under each heading. This may give us an inkling of the changing nature of the groups, as well as their role.

1. SOCIETAL CHANGES include
  - Demand for rights - Higher profile of minority groups;  
Higher level of awareness of disadvantaged and devalued people.
  - Economic Changes - Changing role of women in society;  
2 parents working
  - Awareness of discrimination
  - Greater commitment by Governments to provide equitable services
  - Technological change, research into new ideas
  - Move from segregation to inclusion.
2. ATTITUDINAL CHANGES include
  - Growing demands by parents to be involved in their children's programs, not just in providing services
  - Growing demand for education as of right in local schools
  - Growing recognition that all children should receive appropriate services regardless of parents' ability to be involved
  - Expectation of greater degree of community involvement even for

- people with very high support needs
- Growing demand for small, community-based services to meet individual needs
- Realisation that "specialist" services do not have to be in segregated environments.

### 3. INVOLVEMENT OF PEOPLE WHO HAVE A DISABILITY

- People are demanding self-determination
- Recognition that this relates equally to those who have intellectual disabilities but need different strategies
- Parents seeing their children as individuals - parents accepting that their children will grow to be adults; demand that services for adults should reflect adulthood
- Parents and people with disabilities fed up with being told what is best for them, either by Government or voluntary agencies
- Demand for meaningful and high-quality integrated education to give children skills for their adult life
- Legislation now exists on participation.

And so, what we are looking to in the future is parents still leading in, and reflecting, all those changes - but for the first time, they face being called to account by people with disabilities, and by a larger and more informed body of parents who carry with them aspirations about their child as a valued and contributing member of the whole community, sharing ordinary places with the rest of the community with the support they require.

The parent groups of the future will be working as hard as those of the past but in a different way. The results will be less tangible in that they will not be in specially constructed places. The result of the growing parent movement will be seen in more and more children and adults taking their rightful place beside their non-disabled peers. Building on the successes of the past, parent groups will demand more and more commitment from Governments, they will also demand accountability to them and to their children or adults in the quality of service they receive.

They will begin to see services being offered to them as of right and they will (i) try and make them better (ii) try to work towards filling the gaps for their own children and for those on waiting lists in new and inclusive ways (iii) act as advocates for whole classes of children and adults with disabilities and families. As in the past, there is no way that the parent movement will not keep moving on.

They are seeking services as of right.

They are seeking services which support and empower them as a family rather than "replacing" them.

They are speaking out about not wanting to have to run their own services.

They are recognising that services run by parents have segregated people with disabilities from the community, just as traditional State-run institutions have.

They are recognising that their future role is in speaking out for more and better supports, which retain the person who has the disability as a valued member of the community and of the family.

# LANGUAGE DEVELOPMENT

|   | <u>Descriptive</u>  | <u>Definition</u>   |
|---|---|---|
| <b>First Period</b><br>Beginning of Century<br>through the 1920's | CUSTODY; REPRESSION;<br>STIGMA; HARMFULNESS;<br>COLONIES; SEGREGATION;<br>INSTITUTION   | Fool; Imbecile; Idiot;<br>Incapable; Utter Degenerate;<br>Lunatic; Vegetable  |
| <b>Second Period</b><br>1940's through to<br>1960's               | CARE; ACCEPTANCE;<br>TOLERANCE; CHARITY;<br>SPECIALIST;<br>FUND-RAISING;<br>SHELTERED WORKSHOPS;<br>RESIDENTIALS;<br>CENTRES; PITY;<br>TRAINABLE; TRAINEES  | Mental Defective;<br>Mongol;<br>Holy Innocent;<br>Ill/Sick;<br>Eternal Child;<br>Spastic; Crippled;<br>Subnormal  |
| <b>Third Period</b><br>1970's                                     | EDUCABLE;<br>ACTIVITY CENTRES;<br>THERAPY; SCHOOLS;<br>COMMUNITY<br>INVOLVEMENT;<br>PROGRAMS; EDUCATION;<br>AWARENESS; WORK;<br>DISCRIMINATION  | Patients;<br>Cerebral Palsied;<br>Mentally Handicapped;<br>Downs Syndrome;<br>Physically Handicapped;<br>Deaf; Blind;<br>Ill  |
| <b>1980's</b>   | RIGHTS; INCOME SECURITY;<br>RESIDENTIAL SERVICES;<br>EMPLOYMENT SERVICES;<br>ADVOCACY;<br>NORMALISATION;<br>INDEPENDENT LIVING;<br>OPEN EMPLOYMENT;<br>EDUCATION; INTEGRATION;<br>SKILL DEVELOPMENT;<br>INDIVIDUALISATION | Persons;<br>People with Disabilities;<br>People who are..etc;<br>Sensory Impairment;<br>Developmental Disabilities;<br>Developmental Disabilities;<br>Citizens;<br>Trainees |
| <b>1980's-1990's</b>  | SUPPORTED EMPLOYMENT;<br>INCLUSION; WORK;<br>PARTICIPATION;<br>COMMUNITY SHARING;<br>LIFE SHARING   | Individuals;<br>Valued members of the<br>community;<br>Contributing members of society  |