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Abstract

This article provides an overview of events leading up to the development of parent advocacy in Victoria in the form of VPAC - the Victorian Parent Advocacy Collective. It provides information on parent advocacy, difficulties parents may face in gaining opportunities for their son or daughter, and the qualities necessary in an advocate. **Keyword: Advocacy**

OVERVIEW OF THE DEVELOPMENT OF PARENT ADVOCACY - THE VICTORIAN SCENE

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1982 The Minister of Education (Mr. Fordham) set up a committee to undertake a MINISTERIAL REVIEW OF SERVICES FOR DISABLED CHILDREN throughout Victoria.

1984 The Committees recommendations were released in the report entitled "Integration in Victorian Education." Integration of children with impairments and disabilities became government policy.

The five Guiding Principles of the Review were:-

1. EVERY CHILD HAS THE RIGHT TO BE EDUCATED IN A REGULAR SCHOOL.
2. NON CATEGORISATION (children should not be labelled).
3. RESOURCES and SERVICES should to the greatest extent possible, be SCHOOL-BASED.
4. COLLABORATIVE DECISION MAKING PROCESSES.
5. ALL CHILDREN CAN LEARN AND BE TAUGHT.

A study of the submissions received from PARENTS by the committee revealed that parents of children with hearing impairments frequently felt overwhelmed by the number of experts that they encountered during the ascertainment process. Parents indicated that they felt very aware of the IMBALANCE in NUMBERS OF SPECIALISTS present, and the UNEQUAL relationship between the ASSESSMENT panel of EXPERTS and themselves.

The conceptual framework of the Review emphasised "the need to Equalise the relationship between the parents and the service providers, including professionals."

The Review also stated that "the ENROLMENT of children with impairments and disabilities in regular schools depends upon the acceptance of a BALANCE of responsibilities in the four stages of the COLLABORATIVE process.

SHARED INFORMATION

- " DECISION MAKING
- " ACTION
- " RESPONSIBILITY

"Parents have the right to procedural safeguards, ADVOCATES of their choice."

Finally, the Review stated that "the empowering of parents in the decision making process entails the provision of PARENT ADVOCATES"... at SCHOOL, regional and central level."

EQUALISING the relationship and preserving the BALANCE of persons on the decision-making group is important to the DEMOCRATIC decision making process.

In order to EQUALISE the relationship you have to provide a BALANCE MEMBERSHIP on the decision making group at the school level.

The INTEGRATION SUPPORT GROUP membership of

parents
parent advocate
teacher
principal
student (where appropriate)

reflects that BALANCE between SCHOOL-BASED and NON-SCHOOL-BASED persons.

Following the release of the Report of the Ministerial Review, the Victorian Federation of State Schools Parents Clubs and the Victorian Council of School organisations began negotiations with disability groups to determine the level of interest in forming a COLLECTIVE GROUP to establish a parent advocacy training program.

1985 On the 20th May, 1985 the then Minister of Education Mr. Cathie introduced a DELAYED ADMISSION process which made integration of children with impairments and disabilities conditional on provision of resources (which he and his Government had the responsibility to provide).

This was considered by parents to be an outrage and a denial of the right of the child's access to regular school, and was regarded as a major retreat in implementation of the Governments policy of integration.

Therefore, the 20th May 1985, became "D" day for disabled children in Victoria. It also facilitated the birth of V.P.A.C. The Victorian Parent Advocacy Collective was formed as a direct result of the introduction of the delayed admission process; it also served notice on the Government that we would not retreat any further, that we would hold them to account and insist that if "integration is a significant human right: (Ministerial Review 1986) and the declared policy of the Government then parents intended to make it a reality.

OCTOBER 1985 Heralded the first deputation to the minister of Education, and subsequent deputations have been held about once per term since that time.

WHAT IS V.P.A.C.? V.P.A.C. is a collective of organisations representing a variety of disability groups, together with the Government school parent and school council organisations.

ROLE OF V.P.A.C.

1. To train FORMAL Parent Advocates.
2. To lobby the Minister of Education about integration and advocacy.

WHICH GROUPS ARE REPRESENTED?

- . VICTORIAN FEDERATION OF STATE SCHOOL PARENTS CLUBS
- . VICTORIAN COUNCIL OF SCHOOL ORGANISATIONS
- . STAR VICTORIAN ACTION ON INTELLECTUAL DISABILITY
- . DOWN SYNDROME ASSOCIATION
- . ACTION GROUP FOR DISABLED CHILDREN
- . CHANDLER CO-OPERATIVE

- . PARENT ACTION IN DEAFNESS
- . ACTION ON DISABILITY IN ETHNIC COMMUNITIES
- . VISUALLY IMPAIRED CHILDREN' PARENTS ASSOCIATION
- . SPINA BIFIDA ASSOCIATION

These groups are parent organisations and are listed on the back of the INTEGRATION SUPPORT GROUP PROCEDURES (Ministry of Education document No. 144) and are the recognised organisations who provide trained formal advocates to support parents of children with impairments and disabilities in the integration process into regular schools.

MARCH 1986 Saw the introduction of the enrolment and support group guidelines, where the parent and parent advocate, together with principal, and teacher were officially acknowledged as formal and equal members of the I.S.G.

APRIL 1986 V.P.A.C. ran its first integration/parent advocacy training program.

We ran a total of four programs in 1986 (one of which had input from Douglas Biklen) and five programs were run in 1987 and eleven programs in 1988, have been run across the state of Victoria.

AUGUST 1987 The Review of the I.S.G. guidelines, which became the Integration Support Group Procedures, which are mandatory procedures for all Government schools in the state.

The PARENT ADVOCATE is clearly identified as a formal member of the I.S.G. Their role and function is spelled out in general terms on page 2 of memo No. 144.

It is the responsibility of the advocate to ensure that the I.S.G. procedures are followed and the rights of parents are protected.

Parent advocacy is not about "SAVING" parents, it's about "EMPOWERING" parents with NEGOTIATION SKILLS, INFORMATION and SUPPORT in order to PARTICIPATE on an EQUAL basis in the Integration Support Group process in their local neighbourhood school.

PARENT ADVOCACY IS:

- : supporting parents and encouraging them to be independent rather than dependent on an Advocate.
- : a partnership - sharing of knowledge and skills.
- : assisting parents to identify a problem, and solve it within the I.S.G.
- : helping parents to understand the education system.

- : assisting parents to develop strategies and negotiation skills, particularly in the I.& S.G. process.
- : linking parents with appropriate support services and regional personnel.
- : networking with other disability groups, parent and school council organisations.
- : empowering parents with information and letting them decide.

PARENT ADVOCACY IS NOT:

- : legal advocacy
- : making decisions for parents
- : doing all the talking
- : making them dependent

QUALITIES OF AN ADVOCATE:

1. A strong commitment to integration.
2. An understanding of disability in children.
3. A strong sense of identification with the parent and shared values.
4. Recognition of the parent as an equal.
5. A desire to empower the parent, not to save them.
6. Ability to interpret hidden agendas and the games people play.
7. A good working knowledge of the education system, and its support services, particularly the integration process.
8. Ability to interpret abuse of the integration support group procedures.
9. Ability to negotiate successfully, win/win situations.
10. Knowledge and understanding of collaborative decision making processes and an understanding of difference between CONSULTATIVE & COLLABORATIVE process.
11. Good communication skills
 - : sensitivity
 - : integrating
 - : diplomacy

FORMAL/INFORMAL ADVOCATES

The INFORMAL advocate may be a friend who accompanies the parent to an I.S.G.

The FORMAL is a trained person provided by recognised organisations referred to on the lack of the I.S.G. procedures.

The formal advocate will have:

1. Experience in a range of I.S.G.s
2. A good working knowledge of the I.S.G. procedures and an ability to interpret abuse of the process.
3. Experience in negotiation skills.
4. Understanding of and experience in the education system.
5. Knowledge of support services.

Therefore the trained formal advocate will be in a better position to support the parent in the integration process and negotiate a successful outcome; but it is the PARENT who decides whether she needs a formal or informal advocate.

WHO ARE THE FORMAL ADVOCATES?

They are persons with a COMMITMENT to integration, who are prepared to work alongside parents and support them in the integration process. They are not paid persons, in fact they are not even reimbursed for travel or phone costs incurred in their supportive role.

THE GAMES PEOPLE PLAY

I need to share with TEACHERS some of the GAMES PEOPLE PLAY; because I want people to understand the STRESS being placed on parents who have already had to struggle and fight the battle of PREJUDICE STEROTYPING and DISCRIMINATION since their child was born. (Biklen)

1. PERMANENT PART-TIME "INTEGRATION" BETWEEN REGULAR AND SPECIAL SCHOOL

Integration restricted to art, craft, P.E., music.

Integration is not just SOCIALISATION, it is about ACCESS and SUCCESS to a broad range of curriculum and learning opportunities.

2. PSYCHOLOGICAL ASSESSMENT

During this latest round of applications for resources pressure has been put on parents to have their children "assessed". Home forms of assessment based on I.Q. has been discredited by professionals, but the education system continues to label children "mildly retarded", "within the moderately intellectually handicapped range", "at the upper end of the special school range" and this year we have a new category, "BORDERLINE" students who according to School Support Services criteria for Entry are not eligible for integration resources, however they keep on trying.

Do schools realise that once a child is assessed the child may be "labelled for life" - who needs labels? We label jars, not people.

Parents need to know that I.Q. assessment does not lead to an educational program, but it may lead to SPECIAL school placement, and that is to be avoided at all costs.

Parents need to know that if they have given permission for assessment they can withdraw that permission for assessment, they can also withdraw that permission for any further assessment and they need to put it in writing.

Integration is NOT CONDITIONAL on psychological assessment. It is the parents' RIGHT to refuse psychological assessment as it is their right to decline a recommendation for special school placement.

PARENTS need to understand that some teachers may never have had contact with a child with a disability before. Fear of the unknown is a powerful destroyer of confidence which may lead some teachers to doubt their COMPETENCE.

Teachers need information about the nature of the disability and the educational implications for teaching the child.

It is also important to let the teacher know that she is doing a good job.

3. FULL TIME ATTENDANCE

In some schools there seems to be a misunderstanding about the parents RIGHT to request full time attendance at a regular school, and that it is the responsibility of the I.S.G. to apply for the resources to support the class teacher.

In order to obstruct the process sometimes -

STAFF of a school refuse to accept a child with a disability and threaten STRIKE ACTION.

SCHOOL COUNCILS have been used to deny enrolment and admission.

ADMINISTRATIVE committees of schools attempt to overturn the decision of an I.S.G. about admission of the child and level of resources required and direct the PRINCIPAL (who is a member of the committee) to report back to the I.S.G.

Parents and parent advocates need to know that neither STAFF, SCHOOL COUNCIL, nor ADMINISTRATIVE COMMITTEES of schools can make decisions about admission of a child with a disability, nor the level of resources necessary, only the General Manager of the region can decide about admission and the I.S.G. is charged with the responsibility of determining the level of resourcing required.

4. "PART TIME TRAP"

It sounds so logical, to suggest part time special part time regular school - but it is educationally UNSOUND. Why do we ask the child who requires CONTINUITY & STRUCTURE to cope with

TWO	different	sets	of	RULES	
"	"	"	"	BEHAVIOURAL	expectations
"	"	"	"	CURRICULUM	
"	"	"	"	PROCEDURES	

e.g. assembly for regular school }
lining up for regular school } none for special

a good recipe for creating confusion, then we become the victim. A common criticism is that the child is a SOCIAL ISOLATE, any wonder, s/he is not in any one school long enough to make friends, s/he remains as a 'visitor' to the regular school, and never experiences 100% togetherness.

Ask yourself, would you insist that any other Primary age child to go to two different schools?

It would be true to say that at the first I.S.G. meeting, everyone felt a bit uneasy, not knowing what to expect of each other.

In my experience over the last few years as a practicing advocate for 25 students (10 of whom have severe or multiple disabilities) ALL with the exception of ONE began I.S.G. negotiation with a NEGATIVE climate.

Two years down the track, ALL but TWO of the 25 are VERY POSITIVE because ALL members of the group trust each other, have a common GOAL, are sharing information and accept that IT IS O.K. TO MAKE MISTAKES and use the I.S.G. process as a problem solving forum, rather than a boxing ring with a winner and a loser. We have all learned to negotiate successfully with a WIN/WIN outcome, so that parents and school feel that the student is making good progress, and NOBODY is PLAYING GAMES.

PARTICULAR HANDS ON EXPERIENCE AS A PRACTICING ADVOCATE WITH STUDENTS WITH IMPAIRMENTS AND DISABILITIES.

The majority of students for whom I act as advocate have severe or multiple disabilities. Some have been misdiagnosed by use of IQ testing used by systems psychologists, and inappropriately 'placed' in segregated settings, where their life chances have been diminished.

Some have little or no speech, and have been denied access to a means of communication until they had access to Deal Communication Centre, where they have been given a new lease of life. I shall confine my hands on experience to one student - John

I quote:

"My name is John. I am apraxic so I cannot talk. I am at a primary school. I don't like it because I work five hours. I get tired when I am working. I used to go to an S.D.S. I liked it better because I was yelling all the time and now I have to keep quiet because the teacher gets mad and I have to leave the room. After I leave school I want to go to university so I can help people like me. I am not getting on well at school because I am naughty and my main aide gets cross. I like my other aide very much because she does understand my idiosyncrasies."

John attended a conference on integration with his mother in March 88 where the Minister of Education was present. He asked if anyone wanted to ask questions or make a statement - this is John's statement -

' I WOULD LIKE MORE CHILDREN GIVEN A CHANCE TO
LEARN AND GO TO A NORMAL SCHOOL '

John

Extracts from Physiological Assessments

" I was unable to complete any formal assessment because of his inability to respond to questioning".

" It is evident from assessments that John's overall level of intellectual functioning falls within the range of severe retardation. Results of assessment suggested that at the age of 11 years 3 months John's receptive language was age equivalent to 2 years 5 months."

I want to know what in the hell are so called professionals in the system doing to our kids as Douglas Binlen says -
"Most decisions involving children and adults who have disabilities are not scientific questions for professionals to answer, rather most are political and moral decisions that the whole of the Society, and particularly the consumers (the parents and their children) should make".

It is, IMMORAL to go on 'assessing and placing' students in segregated settings thereby cutting off their life chances. Parent advocacy is the means by which parents are empowered with INFORMATION and SUPPORT in the fight for their child's right to have ACCESS to regular school and ACCESS to society, without that support they may be victims of systems control, and a lifetime of SEGREGATION, and for some, in their adult years victims of Sunbury.

I have a dream, that in the REAL world all people would embrace the 5 guiding Principles of Report - Integration in Victorian Education 1984 and BELIEVE that -

1. Every child has the right to be educated in a regular school (The right of the parent to enrol their child in regular school).
2. Non-categorisation - (children should not be labelled).
3. RESOURCES and SERVICES should to the greatest extent possible be SCHOOL BASED.
4. Collaborative (or shared) decision making processes.
5. All children can learn and be taught.

