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Abstract

A paper presented in August 1986, at the 22nd National Conference of the Australian Group for the Scientific Study of Mental Deficiency (AGSSOMD) by Jeremy Ward, a parent leader from Queensland. Ward describes parent advocacy in terms of parents going beyond their personal situation and into group advocacy, and their ability to participate effectively with the pressures they have on them as individuals. Ward uses as references definitions of advocacy by Wolf Wolfensberger (the developer of Social Role Valorisation and founder of citizen advocacy). He also describes how Queensland Parents of the Disabled was founded, and how some difficulties parents face can recede by working collectively and supportively. **Keyword: Advocacy**

PARENT ADVOCACY: THE QUEENSLAND EXPERIENCE

Jeremy Ward

Paper presented at Twenty-Second National Conference of the Australian Group for the Scientific Study of Mental Deficiency (AGSSOMD), August 1986.

When I discovered Bob Dylan twenty years ago there was a song of his called 'Ballad of a Thin Man'. It seemed to capture a feeling of desolation that young people in those days liked to embrace, but I really had no idea what it was about. Part of it went like this:

"You raise up your head
And you ask 'Is this where it is?'
And somebody points to you and
says 'It's his'
And you say 'What's mine?'
And somebody else says 'Where what is?'
And you say 'Oh my God
Am I here all alone?'

Because something is happening here
But you don't know what it is
Do you, Mister Jones?"¹

Twenty years on and the parent of a child with a severe disability, those words have taken on a new meaning. From the first hint that something is wrong, through diagnosis and every subsequent milestone and setback, there is the feeling of utter isolation. With all the professional and family help imaginable, the decisions and the responsibility (at least while the child is young) rest solely with the parents. If they are advised to place a child in a residential facility for the sake of other children and the total family, it is their decision. If they decide not to embark on a potentially beneficial therapy programme because they believe they simply do not have the energy to go through with it, that is their choice. In the words of Jean-Paul Sartre: "The peculiar character of human reality is that it is without excuse."²

To talk about parent advocacy is to talk about parents. Whatever else it is about, it is advocacy by people who are always, inevitably, experiencing what it means to parent someone with a disability.

Parent advocacy would commonly be thought of as advocacy by groups of parents: it is group advocacy, or issue advocacy, by parents. Naturally, parents do a lot of advocacy for themselves and their children - all parents have to do this, to obtain better services from school authorities, the health system, other professionals and Government Departments. The difference when a child has a disability is largely one of degree, given the special

¹ "Ballad of a Thin Man", Bob Dylan, 1965, Warner Bros. Music Australia Pty. Ltd.

² Being and Nothingness, Jean-Paul Sartre, Washington Square Press, 1966, p.709

difficulties and needs and the lack of resources with which they may be addressed. For many parents advocacy on behalf of their particular child is all consuming.

Other parents see that strength lies in numbers, that a group may be able to effect change where individuals cannot. Such parents must be able to see beyond their particular situation. While never ceasing to be advocates for their particular child (at least while a child) they will be of little use to a parent advocacy group if they continually refer back to themselves, if they are constantly anecdotal.

Some parents never wish to go beyond their personal situation. But for those who do, it will often take time, and even then a crisis period, a milestone (e.g. child reaches school age) may stir up the old anger, anxiety, sadness so that, for a period, their ability to participate effectively in the group is reduced.

Members of a parent advocacy group will be aware of the pressures upon individual members. They will know the grieving, anger, chronic sadness, anxiety, guilt that rarely leaves them. They will know that time is a precious commodity, with feeding, bathing, toileting, dressing, supervision, monitoring services, home programmes to contend with. They will know the tiredness from the constant emotional overlay to the often sleep disturbed nights. They will know the financial burdens of special equipment, house modifications, clothing, medication, special diets, private therapy, on what will often, inevitably, remain one income families.

It is people with these pressures above those normally associated with life in the 1980s, that take on parent group advocacy. What does this involve?

I suppose we are all aware of some things that parent advocacy groups do. They lobby Governments; they write submissions; they represent parents on inter-departmental consultancy committees; they sometimes conduct or become embroiled in media campaigns. They may do other things dependent on the existence of other types of advocacy.

Parent advocacy is of course only one type of advocacy that ideally would sit neatly in a continuum, which included self advocacy organisations for people with disabilities, group advocacy by people with disabilities, citizen advocacy, specialised legal advocacy services, and adequate information and referral services. To the extent that any of these does not exist where a parent advocacy group does, that parent group may be asked and pressured to take on other functions.

More importantly, what does the advocacy part of parent group advocacy involve? Lawyers talk of advocacy being "the art of persuasion", but they would not see their advocacy to be more than speaking on behalf of another, however eloquently, however knowledgeably, however persuasively. They also place great importance on remaining detached, on not becoming emotionally involved. They see this (incorrectly in my view) as being "objective".

Writing about advocacy in the disability field, Wolf Wolfensberger claims that true advocacy must go further. He has complained that advocacy has become such a widely used concept that practically anything is labelled advocacy. "I personally call it 'Kraft Cheese advocacy'" he says, "in analogy to the Kraft cheese commercials that in essence

propose that one should take any kind of food and add cheese to it. Today, people would like to continue doing what they have always done, but add the word advocacy to it".³

For Wolfensberger there are three ways that advocacy must be more than merely speaking on behalf of someone else. First, there must be "vigor and vehemence. Speaking for someone in inaudible whispers is conscience-salving at worst and prayer at best."⁴

Next, there must be a cost to the advocate. This may involve "time that one would rather have spent on something else; wear and tear on one's emotions, such as one would ordinarily avoid; investment of one's material substance and possessions; sacrifice of rest, sleep and/or recreation; etc."⁵ The cost may even become a risk, of losing a job, of being rejected by colleagues and friends.

Finally, when the advocacy occurs in some sort of agency or group, it must be as free as possible from conflict of interest.⁶

It may be that Wolfensberger's views on advocacy derive from what has been called his "apocalyptic view of the future of human service systems".⁷ Nevertheless they do provide an interesting reference against which to assess the nature of parent group advocacy. In the complex maze of disability service systems, parent advocacy groups may well need to practise their advocacy Wolfensberger-style if they are to achieve the most humble of objectives.

Effective parent advocacy groups, then, must attract parents who already have substantial pressures in their lives, with limited time and resources; who are able to see issues beyond their own difficult situation; and who are prepared to take on tasks which may well be to their personal cost. How, you might ask, is this done?

I have no prescription for success, but I can tell you how Queensland Parents of the Disabled came about, how it has survived, and why I think it has every prospect of developing and growing.

Queensland Parents of the Disabled (Q.P.D.) has its origins in a national conference for women who had given birth to a child with a disability, convened in Brisbane in May 1980, by the then National Women's Advisory Council. Sue Needham, the founding President of Q.P.D. has said of that conference:

"It was an amazing, inspiring, frightening, and wonderful experience. The twenty Queensland women felt they couldn't let all that enthusiasm and energy die. So they formed Queensland Parents of the Disabled."⁸

Q.P.D.'s first major task was to organise a further conference, this time for Queensland parents. ACCESS '81, held in July of that year, aimed to bring together parents from throughout the State, whose children had wide ranging disabilities, and to allow them to

³ A Multi-Component Advocacy/Protection Scheme, W.Wolfensberger, CAMR, 1977, p.18

⁴ *ibid.*, p.19

⁵ *ibid.*, p.20

⁶ *ibid.*, pp.20-21

⁷ Guardianship of the Person, P. McLaughlan, NIMR, Ontario, 1979, p.20

⁸ Sue Needham, Opening Address, Parent Access Workshop, Parent Access Handbook, QPD, August 1983, p.4

discuss and formulate their special problems and needs. 132 parents attended, 42 per cent from country areas. From ACCESS '81 came Q.P.D.'s first publication, "The Future Should be Theirs..."⁹, a compilation of the major issues and recommendations from the conference. ACCESS '81 also produced the following directives:

"That in the future Queensland Parents of the Disabled should be regarded as a lobbying and co-ordinating group, concerned with the widest possible problems of the families of the disabled ...", and,

"That all members of Queensland Parents of the Disabled should see themselves as lobbyists for all families of the disabled, and as foundation members of a state-wide network; and become individually active in their communities".¹⁰

Perhaps the unique features of Q.P.D. can be traced to these early directives. It was to be primarily a lobby group and not engage in service provision. It was to represent all disabilities. It was to be genuinely State wide, a feature of particular importance in such a decentralised State as Queensland. It was to be an umbrella group representing smaller, local parent groups as well as individual members. It was to encourage and assist members in their individual lobbying activities.

Organising such a conference assisted in establishing a State-wide network of parents which has contributed so much to Q.P.D.'s success. Maintaining that network has always been a priority, and funding has been sought specifically to enable committee members to undertake extensive tours throughout the State. There are now branches or Q.P.D. contacts in all major centres and contact has been made with isolated families in many other parts of the State.

In 1983, Q.P.D. held another major conference, this time aimed at improving the skills of individual members. ACCESS '81 had determined the issues: The Parent Access Workshop was designed to help parents do something about them. Sixty parents attended, again from throughout Queensland, to learn from experts in the fields of lobbying, negotiating, radio and T.V. interviewing, public speaking, letter and submission writing and conducting meetings. From this Workshop came a second publication, the Parent Access Handbook.¹¹

Since then Q.P.D. has expanded and developed considerably. We are incorporated and have a membership of 600. We have representatives on various advisory and Government inter-departmental committees. One member has been appointed to the recently formed Intellectually Handicapped Citizens Council of Queensland (a five member Council with quasi-judicial powers to provide assistance in varying forms to intellectually handicapped adults). A former President is now the Australia-wide parent representative on the Disability Advisory Council of Australia (D.A.C.A.).

In 1984, Q.P.D. ran workshops for parents on communications skills and produced a booklet, Communication Skills¹² based on the workshop materials. Earlier this year

⁹ The Future Should be Theirs...: A report from Access 81, QPD, November 1981

¹⁰ ibid., p.65

¹¹ Parent Access Handbook, QPD, August 1983

¹² Communication Skills, Kate Smith, QPD, 1984

Q.P.D. ran another State-wide conference, ACCESS '86: Five Years up the Road, attracting over 100 parents. This conference looked to informing parents of current issues, policies and activities across a range of disability areas. Q.P.D.'s latest publication, the Parent Resource Manual¹³ was launched at this conference by Judy Ellis, the Director of the Office of Disability.

Until mid 1985, Q.P.D. operated without funding and with virtually no fund raising. Specific grants or sponsorships funded specific projects and administrative costs came out of membership fees. In 1985, a Commonwealth Employment Programme grant enabled us to establish an office with one full-time employee. This employee simply provides support in typing, filing, photocopying, answering the phone, keeping the office open, etc. and does not speak for, or represent, Q.P.D. at meetings or on committees. It is firm Q.P.D. policy always to have parents representing the organisation rather than an employee.

The C.E.P. grant was for twelve months only and the money runs out this month. Q.P.D. has been unable to secure further funding from the Federal Government but the Queensland Government Department of Welfare Services has agreed to fund Q.P.D. until the end of this year. Without further funding, the office will need to be operated by members of the Executive.

Since 1980, Q.P.D. has had a high turnover of committee members. None of the original committee remain and in six years there have been five Presidents. It has been a "committee" organisation rather than one carried by one or two strong personalities. Planning for changes in executive positions has occurred where possible and the incoming President introduced to important contacts and groups.

Planning has been emphasised in the organisation in other ways. In fact, Q.P.D. has its own management consultants who generously volunteer their services to facilitate regular planning sessions. The emphasis has been on setting realistic goals within the constraints of Q.P.D.'s functions and individual members' skills and resources.

Through this process, Q.P.D. has resolved to adopt four major roles:

1. Monitoring of services and legislation;
2. Consulting with service providers and decision makers on consumer needs, rights and expectations;
3. Liaison with other parent and consumer groups in the field of disability;
4. Parent Empowerment to assist parents collectively and individually to maximise their skills in all areas of communication.

Having blown Q.P.D.'s trumpet, let me return to Wolfensberger's three principles of advocacy. Having reflected on Q.P.D.'s activities since 1980, I can say that I think we could satisfy him that Q.P.D. is a true advocacy group and no "Kraft Cheese" imitation. It may be for others to judge whether we have embraced our task with sufficient "vigor and vehemence", but looking from the inside I think we have, and we have certainly made our presence felt in some quarters. I know that Q.P.D.'s activities have been at cost to individual members. That explains the high turnover of active membership. And

¹³ Parent Resource Manual, edited Colette Tucker, QPD Inc. 1986

perhaps clearest of all, Q.P.D. is totally independent both of Government and non-Government organisations, political parties and of any service provision. Our firm policy never to engage in providing services of any kind is so that we minimise potential conflicts of interest. There are some who would like us to provide a comprehensive information service, for example, but that is a service and Q.P.D. has strenuously resisted going down that road.

It is through maintaining their independence that parent advocacy groups will derive their strength. Individually parents owe allegiance to no one but themselves and their disabled family member. They will find strength in that commitment. But they will also often be fearful to press too hard for changes in services when they know there is no alternative for them. When dealing with their own situation they will often experience conflict: to press for change and risk losing a service, or to cop it because there is no alternative. But collectively those difficulties recede.

It is part of disability folklore that many advances worldwide in the last thirty years have been due to parents getting together, organising their forces, finding strength in numbers. Many voluntary organisations that groups like Q.P.D. now lock horns with from time to time, were started by parents. But there are some who conclude from this history that real change will only be effected by parent groups, forgetting that there are roles for many other advocacy groups. There are some who, on a more basic level, expect parent groups to do what they believe cannot be done from within their own organisations or Government departments. So professional people within non-Government organisations want the parents to lobby for change; so Government employees want parents to take up issues with their own Minister. On a more basic level still, there are those in organisations and Government agencies who simply refer on parents to parent groups when they may have been able to sort out the problem or request quite easily themselves.

Parent advocacy groups will always have their limits; limits which will be largely self-imposed if they plan and set realistic goals. Q.P.D.'s experience shows that. It must therefore be remembered when raising expectations about a parent group, that it need not, and it may not, by choice, take on what is being asked of it.

Parent advocacy groups will therefore need to brace themselves for what is, at the same time, a most desirable development: the recognition, apparently soon to be enshrined in disability services legislation, of the need for consumer input in service delivery. "New Directions" made recommendations to this end,¹⁴ and the recent Budget papers reveal that these will be implemented.¹⁵ Parent advocacy groups may soon become the service providers' new best friends.

My point is simply this: if responsible informed consumer participation in decision-making is expected, consumers will need support. Parents cannot be expected to participate equitably and sensibly with full-time service providers and all the support they have, and who understandably have their own interests and priorities to preserve, unless those parents also have the resources to enable them to be equally well informed and equally skilled. They will not be able to devote their precious time to meaningful consultation, if they have no support in running their organisations, if their base is a committee member's living room, and their time spent chasing up information, in typing, folding newsletters, collecting mail from post office boxes. Unless the disability

¹⁴ New Directions: Report of Handicapped Programs Review, AGPS, Canberra 1985, p.132

¹⁵ Detailed Summary of 1986-1987 Budget Initiatives for Community Services - Statement by the Minister for Community Services, Senator Don Grimes

services legislation allows funding to give support to parent advocacy groups, and other consumer groups, the "consultative process involving people with a disability, parents and advocates, and service providers" (Minister's post budget Statement)¹⁶ will be a hollow process indeed.

The disability field is going through exciting times. New initiatives in the proposed legislation are said to allow greater flexibility in services, greater accountability, and consumer participation in review and evaluation of programs. Little benefit will be derived from these initiatives unless they bring improvements in the quality of life of individuals. It will be for parent advocacy groups and other consumers to stringently monitor these changes, however welcome they may appear, and to take care that their participation in the review and evaluation process is meaningful, and pursued with the "vigor and vehemence" so dear to Mr Wolfensberger.

¹⁶ *ibid.*, para 25