

RASAIID



SKIRTING THE FRINGE – FAMILY ADVOCACY

Family Advocacy presents a philosophy that could be best described as the radical fringe of disability thinking. In its view, inclusion of a person with a disability in every facet of normal life means that anything special is wrong. So it follows that special schools are anathema to Family Advocacy and so are special classes within normal schools. Special service provision that groups together people with a disability for residential, work or social reasons is denounced as "congregate" and even group homes have now been labelled with the dread "institution".

In fact, anything at all that sets people with a disability apart from the norm is condemned. At a recent workshop run by Family Advocacy, it was suggested that the extra few dollars paid to families with a disabled child was "compensation". Respite that takes children out of the family home is "segregating" families. Special doctors to treat people with a disability were criticised. Even Special Olympics took a caning. The philosophy is that disability is in the way we treat people with "impairment", but not intrinsically in their special needs. In other words, if we don't treat them as disabled, then they won't be.

The logical progression from this is in the stance taken on providing accommodation for a person with a disability. Here, Family Advocacy take a D.I.Y position. They maintain that families should buy or rent a house or unit for their family member and surround the person with "circles of support" in the form of extended family, friends and neighbours to assist with "independent living". They encourage "formal" support in the form of H.A.C.C services and are angry that what little assistance is available from the disability department goes to group homes rather than in "flexible packages" to families.

It can be seen why governments encourage this point of view. It lets them off the hook nicely. While the disability community is crying out for funding and services, Family Advocacy is suggesting an alternative that requires little or no funding. With their "don't wait - create" position on disability accommodation, they are urging families to go it alone. Families who cannot see how they would be able to do this are clearly short on vision and belief in their person and unwilling to try innovative solutions.

It must be said that for a number of families, the independent option is a viable one. For those people whose disability is in the mild range and who can manage on just a small number of hours of support each week, the Family Advocacy solution is a possibility. It is also a possibility for wealthy families or people with a large compensation payout who are able to self-finance care. One such family has costed the future care for its family member at seventy-odd thousand per annum plus the purchase of a property. This is a modest projection when one considers that it costs the department much more than this to fund an average supported accommodation package. However, there are not too many families who can get their hands on this sort of post-tax money for the ongoing care and accommodation of their disabled member. It is for this reason that they look to governments to provide.

Family Advocacy admonishes caring families to permit their person his or her "Own Home". They concede that this achievement will take "imagination, hard work and courage" but they are short on detail when it comes to the daily provision of care (care is not a word used by Family Advocacy). Apart from a few hours of H.A.C.C service and relying on family and friends, another possibility promoted is the non-

disabled flatmate. Attracted by a reduced rental, this flatmate is required to assist the person with a disability and be a companion. They are, apparently, quite difficult to attract in this less than perfect world.

There are only a very small number of case studies in Family Advocacy's portfolio. Incidentally, most seem to be situated in country towns, where housing is less expensive and communities are smaller. Most families are stretched to the limit caring for their disabled member while under their own roof. They cannot imagine how they could move their person out and still be responsible for the daily welfare. They cannot see themselves paying city rentals, asking friends to do personal care, asking neighbours to supervise, asking extended family to sleep over. They cannot visualize how it could function practically.

This is where Family Advocacy gets SMUG. They have all the correct words: inclusion, integration, independence and families who will not travel the suggested path have no vision, no innovation, no courage. They are denying their person a bright future and self-determination. In fact, families want exactly the same thing for their person as Family Advocacy is promoting. They want their person with a disability to have a good life and they want to be able to set in place influence and safeguards around that life. It is just that in the vast majority of cases they need government assistance with funding to make it happen.

I have allowed that for people with an intellectual disability in the mild range or for families with a bank balance in the millionaire range, Family Advocacy's suggested modus operandi may be possible. Now, will Family Advocacy allow what I envisage for my son as the ideal to meet his needs and give him a good life to be an equally valid solution? I see a cluster residential complex where my son can live and interact with his best friends, who are people with a disability similar to his own. I see it here in my local area in an ordinary suburban street but purpose built to fully accommodate special needs. I see the highest level of family input and influence and those families drawing in their friends and families, the local community. I see ongoing future care provided by a government department and staff informed and guided by families. I see the howls of delight as my son and the friends he has known all his life rejoice in each other's company.

There is no way that Family Advocacy will accept the validity of my vision. It will scream "institutionalized" and "congregate" and "segregate" and "non-inclusive" and all the other correct words to describe what I see as the ideal for my son. There is no place in the FA philosophy for people with a disability to form relationships with other than non-disabled persons. But I will defend to the death my right to choose because I believe that parents always know what is best for their own person. Those parents who can afford to pay privately for care are to be applauded for going it alone. Those families who can informally provide drop-in support for a person with a less severe disability are to be congratulated. Those families who have been able to secure some funding for formal supports are to be considered lucky. The rest of us wait, in no position to create anything at all except patience and hope for a long life.

This is where I come to my problem with what I see as betrayal by Family Advocacy. In a landscape with glaring and disgraceful neglect and failure by governments, it would be fair to expect that a funded systemic advocacy agency calling itself "Family Advocacy" would be crying from the rafters about the disadvantage and misery experienced by people with a disability and their family carers. It would be fair to expect that such an agency would be not just representing the vast majority of families but organizing them, unifying them and spearheading a massive campaign for the services they need. After all, one of the main reasons that families are in the situation they now are is that they have had no voice, no union, no representation and no clout. Rather than seeing themselves in this role, Family Advocacy has chosen to walk an alternative path and put all their resources and energy into this route. Only a very small number of families are able to follow them there and yet they present as though this is the way forward - and the only way.

Estelle Shields