

# RASAID



## LETTER TO ANNE BRYCE

04/11/2008

Ms Anne Bryce

CEO, Achieve Foundation

Dear Ms Bryce

May I congratulate you on your forthcoming appointment as CEO of the merged entity of the Achieve and Crowle Foundations and may I wish the NewCo every future success. As a Crowle member (soon to be ex-member upon merger) allow me to welcome you and wish you well in your new role.

I am sure you agree with Belinda Epstein-Frisch when she points out that families have a natural authority in the lives of their disabled family members. This authority, she says, is sourced from decades of care and love, knowing their person over the longest period, having a stake in outcomes and advocating for services to meet their needs. This authority makes families best positioned to see the big picture, best witness to the performance of professionals and free from vested interests. She comments that the formal service system and the regular confronting of professionals and bureaucrats has a way of eroding the natural authority of families, but that this should not be so and that families must be empowered and proactive in the use of their authority.

In the same presentation, Dougie Herd points out that most of the services in the non-government sector (and this certainly applies to Crowle and Achieve) were initially started by parents. It's the parents who have the passion - the fire in the belly to make things better, he says. Belinda goes on to say that the right relationship is an ethical condition that exists between services and those they service when the people are seen and treated with appropriate respect, integrity and value and when they are enabled to be decisively influential in how they are assisted.

[www.nds.org.au/nsw/Conferences/2006seminars/S1\\_Belinda.pps](http://www.nds.org.au/nsw/Conferences/2006seminars/S1_Belinda.pps)

The Crowle parents have been exercising their natural authority and fire in the belly for many decades. Although most of the original parents have gone, family members continue to "confront" and bear "witness" and advocate for the needs of their people. It was fear of losing their services that caused them to vote for the merger but it was with assurances that their history, culture and uniqueness would be respected.

The Crowle families in the main have been outspoken critics of dispersed living arrangements. As one of the last service providers to withstand the trend towards devolution, Crowle has resisted long enough to see the policy come full circle, with the current acceptance of a wide variety of models. This passionately held view of the majority of Crowle members was underlined earlier this year in an outcry over the proposed sale of the Crowle land. The stated preference for a cluster development on the Belmore Street site is a response to what most family members see as unsatisfactory community living models. We see neglect masquerading as independence, dereliction of care dressed up as dignity of risk and isolation posing as integration.

While these viewpoints may not reflect those of yourself or your foundation, it is my great hope that they will be tolerated, respected and absorbed within the new framework of the merged entity. I am reminded of a conversation I had with Len Thompson a few years ago, in which he stated that the long-time residents of Sunnyfield were going nowhere at all, even if he had to fight for their right to stay (which of course would no longer be necessary). I am hoping that the same enlightened thinking will prevail within the NewCo.

It has become increasingly difficult for Crowle families to exercise their natural authority in the face of increasing bureaucracy and corporatization. There is a tendency to disparage their wishes for their family members or to represent them as "old fashioned" or "behind the times". In fact, the desire of the Crowle families for a cluster development is totally in keeping with the expressed wishes of the great majority of families with a disabled person across this country. It is somewhat difficult to support this statement, as the great majority of families, those still caring, have no forum at which to be heard and no representation. However, you will recall the debate around models of accommodation some years back which resulted in ninety percent of respondents favouring cluster style living. You may find a visit to the Carers 2020 Forum instructive, reinforcing the view that those advocating cluster living are the mainstream in this debate.

I hope the Crowle families will continue to be permitted to be "decisively influential" in their advocacy on behalf of their members. I hope they will go forward being "empowered and proactive in the use of their authority" with you at the helm to assist them to secure the services they need and must have. I particularly look forward to the securing of the promised respite facility.

With best wishes to you

I am Yours Sincerely

**Estelle Shields**