

Leadership to Counter Congregation

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In ancient Greece and Rome the punishment for the most serious of crimes was often a choice – death or exile. In effect, the social death of exile was deemed equivalent to physical death. In our society, the worst punishment meted out is 15-20 years of exile from society through our prison system. In some cases we will also forcibly exile people with highly infectious diseases or for ‘illegal’ immigration. In all of these cases there is an element of protecting society as well as punishing the person through social exile. So how do we reconcile the forced segregation of people with a disability in institutions? What is the rationale for this incarceration without trial for the crime of having an impairment?

There is a subtler issue at play in institutionalisation – congregation. It may be possible to sustain an argument for short-term forced segregation for the safety of an individual or the protection of society while measures are taken to prepare the person and the society for their participation. However, as far as I can see there is no argument for forced congregation outside of administrative convenience. Arguments along the theme of ‘they are happier with their own kind’ are so patently prejudicial that they do not deserve serious rebuttal. It is as logical as rounding up all the members of the chess club and forcing them together in an institution as they will be ‘happier with their own kind’. Or perhaps rounding up the Jews...

In looking at how we congregate, we see that our congregations are normally short-term. In fact our lives are a continually changing pattern of congregations around different issues and interests. Spending too long in any one grouping is likely to be viewed negatively over time.

So what is wrong with the forced congregations of institutions? Just close your eyes and think of the one thing about yourself that you would least like others to know about you. It might be a well-concealed physical characteristic, a vulnerability, or a past mistake. Now imagine that this is how you were known to the world. Moreover, you were forced to live the rest of your life with others sharing your exposed secret characteristic. This is the reality of the institution. The grouping together around this negative characteristic amplifies it to the world and ensures that it will be seen before your individuality, strengths and talents. You will become known by the characteristic rather than as ‘Joe’ or ‘Helen’. As we all copy each other, you will become more alike in behaviour, enhancing the sameness. Expectations of others are likely to fall with a vicious cycle of lowered opportunities, lowered skills and further lowered expectations. And the staff – almost all of whom will have been drawn to the work through compassion and good hearts – slowly will be absorbed into the culture of sameness and lack of hope. The soul of staff is gradually sucked out until reflection leads to a realisation that apart from a rare and precious contact at the human level, most of one’s efforts have resulted in reduced skills and further alienation of the people from the society. The road to hell is indeed paved with good intentions.

Voluntary congregation is a somewhat different issue. All of us are able to choose our friends, associates, venues, activities and other aspects of life, even though our choices may carry some real risks physically, emotionally or in reputation. People with an impairment are in great risk of having their reputation damaged by congregating with others similarly impaired, so we would always look to avoiding such congregations where people are not able to make an informed decision. However, when people make an informed decision

to congregate with others similarly impaired that is of course their right as citizens, but the point cannot be avoided that even short term congregations are still harmful.

It is often stated that institutions provide a safe refuge. A reading of the regular abuse reports from institutions should put paid to any such notion. We are not made safe by having our lives controlled by systems and individuals with vested interests, often at odds with individual welfare. We are made safe by being surrounded by people who love us and will stand up for our welfare.

So the argument about institutions is not an idle academic one. It is a call to leadership. If the best that system planners and service designers can come up with is a life without hope in an institution, they should stand aside for those who can see a better way. We have decades of research showing that forced congregation of people with an impairment does considerable harm physically, emotionally, developmentally, and in reputation. What marvellous new development is now discovered that will stop this damage occurring and a positive result occurring? In searching the literature I can find no evidence of such remarkable developments. What I can find however are stories of people who are trying a different way and succeeding. I read of stories of people labelled 'untrainable' who are employed in real jobs with a career path. I read of communities transformed by the inclusion of people with very significant impairments. Individuals find that slowing down, considering others, joining together and helping someone traditionally rejected, profoundly changes how they view life and their community. I see children growing up together in their local school with a fundamentally different view about impairment to their parents and a social awareness that speaks well for the future of the planet. I see people with impairments living in the community sharing their life and interests with friends, partners and associates.

The new way is not easy. We do not overcome millennia of rejection with a new program or even in a single generation. However the choice is stark and calls for a stand to be made. Is it to be a return to a system based on rejection and social elimination? Or do we aspire to an ordinary life for all? It is a time for leadership from individuals, families and all citizens, as well as those in formal positions of power. There is a better way.