

*family*

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Record

207

File Number

10181

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Title: We all need parents but not forever

Original source: Community Living Volume 5 Number 2

Resource type: Written

Publication Date: 01/10/91

Publisher info: Hexagon Press

### Abstract

In this short article, David Brandon argues that parents should not have to be involved in running services for their sons and daughters with disabilities. He likens it to continuing to run the lives of his two sons, now in their twenties, and says that the consumers of services are the ones who should be involved and that professionals should not neglect their responsibilities by pressuring parents.

**Keywords: Self Determination**

# We all need parents but not forever

Young people need a life away from their parents to develop their full potential and by standing back from their children's lives parents can be liberated



*Would you want your parents  
to plan your life?*

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A woman rang me the other day in great distress. She had been discussing the future of her ten-year-old son with learning difficulties with a local social worker. What would happen when she and her husband got older and were unable to look after him? Most grown up children left home, why shouldn't he? What did the local authority plan for the future?

The social worker was very sympathetic. She saw the problems and concerns but told the mother that due to rate capping and other financial restrictions, she didn't see that the local authority could help in the foreseeable future. There were too many children with disabilities and too few resources. Why didn't she get

together with other local parents to develop their own support services? With their combined resources, they could get the necessary grants and a suitable house from the local authority, pay workers modest salaries and run a very pleasant group home. Then they would have control over everything and certainly run them much better than the hard-pressed local authority. Doesn't it all sound rather seductive and flattering? Doesn't it sound like a way for long neglected people to get much more powers and influence?

In Lancashire, we have had a rash of such schemes. Concerned parents get together and develop modest supported accommodation projects. I don't care

for them. They move from one financial and management crisis to another. They mostly muddle along with a comfortable aimlessness. It's a sort of throwback to the days of the 1960s, of church halls and contract work pushing Woollies stamps in envelopes. These do it yourself services consisting of brilliant ideas like drive your own bus, make your own sandwich shops, develop your own photos, lack the valued option of having all those things done for you.

It is a form of abdication from professional responsibility, making a virtue out of gross neglect. We are not able to fulfil our professional

responsibilities so you must do it yourself. It pressures parents unfairly into becoming managers and innovators. It gives them additional burdens under the guise of more control. They may or may not have those skills or desires. Would you want to be compelled to help run your children's school? These parents may not want to have a full-time career as parents of adult children. They may have wanted to frequent restaurants; climb mountains; go to the cinema; have holidays abroad like the rest of us. All those activities have absolutely nothing to do with being the parents of a child with learning difficulties. If you have children, how would the prospect of looking after them for the rest of your life, running their supported accommodation or day centre service, appeal to you for no payment?

Such a policy not only forces back onto parents the responsibilities for running services it ignores several major

conflicts. There are marked differences between the roles of a manager of services and a parent. My two sons are in their 20s. As time has gone on, they have forced me to admit that increasingly I don't know what is best for them or, for that matter, anyone. Althea and I have become much less important in their lives and they are more influenced by girlfriends and teachers. They develop a life of their own in which we become just one of many influences. We have learned to value that detachment. It is good in one sense to be a non-parent again, or at least, for that important and long-term role to decrease in importance.

**Parental involvement is making a virtue out of gross neglect**

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Imagine if they had stayed at home. Imagine if we remained the central influence in their lives and the conflicts, which would emerge. We would want them to be safe whilst they

need to seek adventure and exploration. I won't even mention conflicts over sexuality. We would want to protect them from being exploited whilst they need to learn about crooks and shysters at first hand. Imagine if we ran the local disco, which they frequented. Wouldn't it be a safe but extremely boring place to go on Saturday nights?

The real issue here is who is the consumer? It is not the parents who usually attend ATCs or live in hostels. Their children do. If we are to involve anyone in the running of services, it must be the direct consumers. We want those services to reflect the needs of people with learning difficulties, not their parents. Parents don't necessarily know what is right for their children, disabled or not. "I know what is best for our Susan" is one of the most misguided and unpleasant of parental refrains.

Imagine the grim scene. It is an

average social services meeting looking a bit like Rembrandt's *The Nightwatch* but without its cheerful qualities. Your kindly parents are discussing you with earnest social workers, psychologists, nurses and doctors - all worthy if rather boring souls, the sort who commit adultery not because of lust but principle. It is your Individual Programme Planning meeting. They are planning your whole life. How does that appeal?

*David Brandon is an author and Senior Lecturer in Social Work at Salford College.*

My mother has been dead these last six years. I owe her a great deal but her understanding of my life and me was strictly limited. She always wanted me to get a real job, making money. She had no truck with this social work rubbish or writing books, Accumulating money was the only point of working so you didn't have to work for too long. If she had any involvement with my life plan, it would have frightened me. Does it frighten you?