



Mathew, me and David at Roath Park

Decisions, Decisions

Supporting your children to make life decisions as they move from childhood to adulthood is always difficult. If you have to make those decisions on their behalf then it becomes even harder Phil Harding explains.

Parents of children with autism and/or a learning disability will all recognise how it is often difficult to make some decisions regarding the welfare of your children; and those decisions seem to be necessary on an ongoing basis. The severity of the autism or condition that is affecting your children can also be a factor. When you have three boys and two of them are autistic then those decisions can become quite difficult and complex.

Information needed

If the level of autism affecting your children is severe, and both communication and comprehension is extremely limited, then parents need information and support to ensure that our decisions and choices on their behalf are the best

possible ones. One of our most difficult decisions concerned our eldest son David. When he was around 13 his care needs were so relentless and continuous that we barely had time to also care for his siblings. (younger brother Chris then 12 and our youngest Mathew then 5, who is also autistic.)

David's school, Ashgrove as it then was, provided a residential facility and respite, so we made the difficult decision that David would stay at his school from Monday to Thursday for 4 nights and we would have him home the rest of the time. That gave us a chance to recharge our batteries and make sure that Mathew and Chris had the quality of care and attention that they deserved. But it was an agonising decision to take! Although in hindsight it was the correct decision.

Bad choice

Then later, when David left Ashgrove at 19, we needed to make the correct choice for him to ensure his quality of life was good and that he was happy. We researched, questioned, liaised and generally did all we could to inform ourselves, eventually deciding that a local residential college was the best option. David's education and development could continue and the facilities and setting seemed very good.

That choice was a disaster for David his behaviour deteriorated and we soon realised that we had to get him out of there. So after a year at College he was home with us.

In hindsight we had made the wrong choice for David.

Supported living

Thus we had to start again and in liaison with Social Workers, Local Authority, Health and other professionals

we found an opportunity for David to move into a, supported living house in the community with his own tenancy sharing with another young autistic adult.

Since 2009 that has been David's home, although he is often home with us, and I often carry out some of his activities with him he is very much still an integral part of our family unit.

Supported Living has worked for David, although, in my opinion, it needs great commitment from family to ensure that all is well within the house and that his life is busy and fulfilled.

Being creative

Our next choice is on behalf of our youngest son Mathew, who is also now 19 and will be leaving Ysgol y Deri soon. Mathew has always lived at home with us, so any change in that routine will be challenging for him. Our aspiration is for David and Mathew to live together, just the two of them, in their own house in a supported living environment with their own tenancies close to where we live now in N.W. Cardiff. This would mean changes for both young men and it is also an aspiration that is not a common one within our Local Authority area and so we are in a constant dialogue with the Local Authority and Social Workers to try and work out a solution that is acceptable for everyone.

Recently I had to go through the process of filling in a form to put their names on the Cardiff Common Housing waiting List. We are also exploring the concept of a co-operative housing model, to see if that would suit their needs and our aspirations for them.

All in all the whole process is time consuming and intensive, but we think that rather than settle for the norm we should try as hard as possible to achieve a quality of life for our boys that is rich and full and gives them personal fulfilment.

So the quest goes on..... Wish us luck, we need it!!

Phil Harding



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Key Points

- **Phil Harding shares his experience** of making decisions on behalf of his children who are autistic.
- **Parents need information and support** in order to make the best decisions and choices.
- **Phil admits to making a bad decision** to send his son David to a local residential college. After a year David moved into a supported living house with another young man with autism.
- **Phil is now seeing whether they can get the local authorities support** to have David and his brother Mathew who also has autism to share a house or establish a co-operative.