

Partnership and marriage in Down syndrome

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This article looks at partnership and marriage amongst persons with Down syndrome. It does so within the context of a model of quality of life. It is recognised that people with Down syndrome are living longer and if they are to experience wellbeing over their life span then, at the outset to life, parents and professionals must have a concept of this huge change in possibilities and therefore priorities in education, work and social life. The paper provides examples of marriage and partnership and discusses the resources they provide for social and personal growth. If the possibilities of such development are not set at the beginning of life and through the childhood years self-image and opportunities are likely to be denied to a group of people who increasingly have opportunities for extended adult life.

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Introduction

This article, about partnerships and marriage for people with Down syndrome, would not have seemed a likely topic for a paper fifteen years ago. At the beginning of the century the life expectancy of people with Down syndrome was about nine years. Today, the life expectancy is above 50 years and one in ten is expected to live to seventy years of age. The data provided by Steele (1996) from the United Kingdom makes it quite clear, for example, that the majority of persons with Down syndrome are adolescents or adults, that is they are above fifteen years of age. In other words, it suggests that in "developed" countries most of the people with Down syndrome require a variety of adult services.

At the beginning of the century, when teachers, doctors and nurses would not expect babies with Down syndrome to live long, there was little point in talking about teenage and adult services. The accent now must be totally different. In stark terms we either prepare people with Down syndrome to spend their adult life in a state of care and protection, in institutions, supervised group homes, in lifelong care by their families, or we seriously set about the business of providing them with sufficient opportunities and education to enable them to function effectively within an adult society. I believe the latter speaks more highly to quality of life. It also has economic advantage, for people who can support themselves are less strain on the energies and resources of the community as a whole. If you accept this argument, then we need to discuss the ways in which we bring this about.

Development of Services

It is apparent that Down syndrome is following the trend of civilised populations in countries, that is, once the basic health needs of a group have been largely understood and dealt with, society then needs to develop educational and social services which gradually expand into the adult years, and interaction and reform of social services begin to take place. Due to diversity this becomes more and more complex bringing a need for multi and trans disciplinary involvement.

Quality of life - the model

Quality of life programmes are a means of bringing this about and in this context it is a matter of looking at various aspects of well-being in all aspects of a person's life, that is, it is an holistic approach. In this context, Felce (1997) talks about four areas of well being - physical, material, social and emotional well being. But there are other aspects to Quality of Life which also provide strong messages to the field of Down syndrome. Quality of life programmes which are effective deal with lifespan issues. It is restricting to start on the issues of adulthood when you have not dealt in the previous childhood years with the presenting challenges, because what develops in the early stages determines, to some considerable degree, what is going to happen later on. If you have lived a very protected life in your early years, and not had the advantages of a wide range of stimulation, then you are less likely to cope with high levels of stimulation and variation in adult life. For this reason, I am arguing that the best scenario, for adults who have Down syndrome, is to ensure that there are very effective services in the early years of their lifespan.

Even now, we do not have schools and communities which ensure total inclusion of people with Down syndrome. Frequently, they are deprived of regular stimulation over

language, and social issues, and the possibilities of developing community friendships - all of which are essential tools for adulthood. It is important that families recognise that inclusion is not just a matter of inclusion within schools, but is also an issue of inclusion within the home and community. For example, Timmons and Brown (1997) have indicated how teenagers who are disabled are required to go to bed much earlier than teenagers who are not so disabled. We have also been able to show that they have less friends, they are likely to eat meals with other children less frequently and they are likely to receive pocket money on request not on a planned or contributing basis. Indeed the whole care issue is one of keeping people quiet and tucked in, whether it is tucked in bed, or tucked in a special school, or tucked in a tightly circumscribed community. We tend to make them cosy and comfortable, rather than allowing them opportunities for exploration and stimulation. Such exploration plays an important role in the biological development of the brain and therefore the social and cognitive performance of people as they grow into adulthood.

There are other issues which are extremely important for developing adults. Denholm (1992) argues that disabled young teenagers have the same goals over friendships, relationships, dress codes, social morality as other people without disabilities. Their goals tend to be largely the same, though their opportunity to reach these goals are reduced. That has to be changed.

There are other issues which are readily apparent. Several authors have shown how people with disabilities, and people with Down syndrome in particular tend to have less varied and less advanced leisure time and recreational activities, and that they start to decline much earlier in life than other people. Our own data, Brown, Brown & Bayer (1992), show this decline taking place during the mid to late twenties for people with Down syndrome which is somewhat earlier than people with other disabilities. As Read & Bloch (1996) have pointed out, it is generally accepted that recreational opportunities, motor competence and physical fitness are related to vocational and adult social skills, including the nature of development and final level of attainment. This certainly supports the data we found in our longitudinal studies of people with developmental disabilities, and people with Down syndrome in particular. Within the Down syndrome group there are variations. Females seem to perform more effectively over a wide range of activities than males. Yet within society, and particularly disability agencies, we have clear evidence that the females are protected and cared for rather more than the males. Of course some may argue that this care and protection would enable them to function at a higher and more emancipated level socially, but the overall evidence suggests the opposite is true. That is, with greater opportunities for expression of wishes and desires, and the ability to make choices within a more normal environment, people with Down syndrome would be better fitted for adult life. Choice is yet a further criterion within quality of life models (see Brown, R., 1997).

In this section I have underlined a number of features which are important for the development of young people with Down syndrome as they approach and enter their adult years. I have placed this within a quality of life model for several reasons, and stress the need for an holistic consideration, a lifespan approach, the development of choice and empowerment and, as we shall see later, the

need for the development of positive self image. The platform has to be set for adulthood - like any stage the scenery must be in place and the intended performance rehearsed many times under guidance.

Partnership and marriage

I now wish to turn to the issues of partnership and marriage. I am not advocating partnership and marriage for all persons with Down syndrome. I am arguing that the increasing lifespan of persons with Down syndrome and the development of social models of inclusion naturally leads to partnership and marriage. This view is supported by such writers as Jean Edwards (1988).

If people can develop a range of skills and go on to higher levels of performance, then this performance may be heightened even further through the possibilities of partnership and marriage. Traditionally there have been great concerns about persons with Down syndrome marrying, (a) because people have been worried about pregnancy and disabilities, and (b) with parenthood there is a possibility of reproducing children with Down syndrome. There is some evidence (see Edwards, 1988) suggesting that the chances of a Down syndrome mother having a Down syndrome child are noticeably higher (50% of their offspring are reported to have children with Down syndrome) than a mother without Down syndrome. About 50% of women with Down syndrome are fertile and the sperm counts of males with Down syndrome are less than males who do not have Down syndrome. However, interviews with parents of people with Down syndrome suggest another issue may be more relevant and of concern. That is, the parents of a Down syndrome adult are more concerned about issues relating to the potential stresses and pressures of parenthood and grandparenthood. However, in a modern, emancipated society there is advice and control over reproduction. My interviews with people in the adult range with Down syndrome suggest that many of them, who would be capable of entering into a partnership or marriage understand, are open to, and have a concern for regulating their reproductive patterns. They are often frank over these matters either indicating they will deal with them when the time is right, or they make it quite clear, because of their own condition, they do not want to have children (Brown, 1995).

What are the advantages of partnership and marriage? First of all, participants would have a close friend and companion with whom they could share a wide range of experiences and social learning and adaption can take place. This is relevant to motivation and emotional development, factors identified by parents as needing attention in quality of life studies (Brown, Bayer & Brown, 1992). Marriage relates to interests and language stimulation and its further development, the sharing of physical chores, stimulation between a couple which gives rise to opportunities for greater activity in social and physical events, therefore more motivation, and therefore growing physical reserves. It also opens the way to greater exploration of the environment. It is well known in the non-disabled population that partnership and marriage leads to greater longevity. This is probably not due to chance but due to some of the advantages and developments that I have listed above. The more disabled you are, the more you need support and guidance and support over a wide range of areas. It is through partnership that much of this becomes not only possible, but acceptable to the people concerned. There is little doubt, in talking to

teenagers and adults with Down syndrome, that many would like to marry. Of those I have interviewed, not many wish to have families, but the concept of being with someone and sharing with someone is extremely important. Why, because someone has Down syndrome, should they be condemned to a life of being single, when that is not what they wish?

Where I have interviewed people who are partners, the following tend to be the trend. Someone with Down syndrome is more likely to partner somebody else with a disability. I would suggest that by and large this is to be expected, because at the present time, the majority of people with Down syndrome frequently meet other people with disabilities. The data on friendship and partnership in the normal community indicates that individuals are likely to meet their partner in work environments, and in social and leisure time community arrangements (Firth & Rapley, 1990). Since in our societies, people with Down syndrome frequently attend sheltered workshops, it is more likely that they will meet and partner people who go to sheltered workshops or other training facilities. The more training that goes on early in life, the more likely the individual is to have vocational employment. A large number of young adults with Down syndrome now have part-time and full-time employment, and this increases the chances that they will relate to a wider range of the community and gradually make friendships. It is true that people with disabilities have been more easily sexually exploited than other people (Sobsey, 1995). Yet there is also evidence to suggest that even amongst quite severely disabled adults, the greatest factor against appropriate sexual relationships is the attitudes and knowledge base of the staff with whom they are involved (see Brown, H. 1997). The same statement can be generalised. It also depends on the attitude and knowledge of parents responsible for the upbringing of people with Down syndrome. Thus knowledge earlier in life brings both support and understanding and therefore further growth.

It is of interest to look at some of the partnerships between people with Down syndrome and also the partnership between others who have disabilities. When I interview people in partnerships I try to visit them in their home environment. The couples have been partnered over several months to ten or more years. What I find frequently, is a great deal of personal contact between partners, with obvious affection and support. There is often great pride in collecting memorabilia about their life together. There joy of life is expressed through pictures and other treasures, (wedding rings and photos, wedding presents). They are proud of their marriages and see themselves as truly joining the adult community. Some of them have external support systems such as a landlady, who might provide some back-up support, and who may have been chosen because she has knowledge and experience in social or other services for people with disabilities. Others have an apartment within the parental family home. On one occasion, when I asked the landlady and her husband what it was like having someone with Down syndrome and another disabled person as married partners living below them, they replied, "Well they are the same as any other married couple, except they are happy all the time." Although we see this as a humorous remark, in many of the cases that I have interviewed, that would probably be a fair statement. But adults with Down syndrome vary like other people in the community, and fixed generalisations should probably not be made. I have also interviewed people who have partnered and married and the marriages have broken down. In some of these

instances, the individuals have become stronger, recognising that there are socially acceptable barriers between themselves and others, and to infringe on those barriers is unacceptable (e.g. sexual or other physical abuse). This type of development can only take place if people gain the necessary experience - hopefully through experiences which are not abusive. There are risks involved, just as there are risks in the partnership of non-disabled people in the general population.

Frequently, I have found that family duties are shared amicably and sensibly between the partners, each making use of the others skills either through planning and awareness, or because the situation simply works out that way - He does the cooking because he is good at cooking, they do the shopping together because it is fun doing shopping together. He always walks ahead of her when going up the road because he walks faster than her. If someone walks faster than you then they set the pace, and in practice you get better exercise than if you were on your own and did not have this challenge. In another partnership, between two women, one was employed and the other worked in the home because of the social implications of physical disability. So partnership is about stimulation, it is about adaptation, it is about sharing and supporting. It is about learning and improved memory, greater motivation, improved status and improved self-image, and the fact is that it can and does work for people with disabilities.

However, I am not arguing that everybody with Down syndrome is ready for such relationships. But because of the greater longevity of people with Down syndrome, from the very inception of life the possibility of a relationship must be borne in mind, not as a vague idea, but as a prospect that with the necessary experiences and steps this will become a desired achievement. In one of my interviews, a mother from the Ups and Downs Association in Canada, who had a young son born a few months earlier with Down syndrome, asked if she could accompany me on one of my interviews. Afterwards she said, "Thank you for involving me because this is the first occasion since my son was born that I had had any concept that my son might have a future." Yes, parents needs to perceive the reality of a long term future - for without it, they cannot provide an environment which enhances the opportunities to learn the necessary skills for an adult lifestyle.

One of the major features of people with disabilities, and this is clearly true of people with Down syndrome, is that their own notion of future planning can often be limited. And yet in various walks of society amongst parents who are determined that their children will have a future, one sees all sorts of skills being applied, developed and expressed as they become young adults. Most of us will know of young adults with Down syndrome who have become actors, who have become dancers, who are painters; some do it for amateur interest, but they have a goal about it and a direction they want to follow. Others are employed part-time or full-time in those roles. Others, perhaps less adventurous, have part-time jobs working in supermarkets, or working in the recreational industry. The point is that people with Down syndrome are growing, they are taking on adult roles and now we must recognise that one of the adult roles they need to take on is that of partnership. No doubt, as with all adult partnership, there will be frustration and difficulties, but from what I have seen there are also successes. It is imperative that parents and professionals remember that many, if not

most of the people with Down syndrome will now start out life living with their parents. Planning for the future of their children, wherever possible, must involve the idea of developing relations with others so that they can support one another to live long and enjoyable lives. They will need support in that they will need help, but the evidence to date, though relatively small is nevertheless positive.

Concluding comment

Our image is of one where the lifespan of people with Down syndrome will approach that of the normal population. No doubt in older age, they will be faced with the diseases of older age and yet, from what we know of the non-disabled population, frequently it is partnership which helps people to live successfully during those years. Even then, there are accidents and people who do not cherish marriage or partner relations become damaged and then often grow again, and this will happen in the field of Down syndrome. But we must never prevent those opportunities taking place, because someone has Down syndrome. We should not be surprised if sometimes it does not work. The challenge now is to prepare people through life so that such possibilities of partnership and marriage can take place, believing the gains will outweigh the limitations - that the rewards will outnumber the set backs.

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