

# The transition from paediatric to adult health care services for young adults with a disability: an ethical perspective

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## Abstract

*Young children with disabilities and their carers or parents tend to form a long-term dependent relationship with a paediatrician throughout childhood. At some stage when the young person with a disability reaches early adulthood, the relationship is severed. This paper draws upon recent research undertaken by the authors that describes the difficulties experienced by young people with disabilities as they go through the transition from paediatric care to adult mainstream health care services. The purpose of this article is to present the argument that the dependent, paternalistic relationship that tends to exist between young people with disabilities (and/or their carers) and paediatricians throughout childhood does not facilitate the successful negotiation of adult mainstream health care services, nor optimally promote the well-being of these young people with disabilities. It is proposed that the promotion of autonomy (or self-determination) via a well planned transition program will increase the likelihood that young adults with disabilities and/or their carers will be empowered to successfully negotiate the current mainstream health care system in Australia, and will enhance the well-being of young adults with disabilities.*

## The transition from paediatrician to adult health care services

Most children with disabilities and their carers engage the services of a paediatrician, and many carers come to depend, over a period of time, on their paediatrician to provide information and advice about appropriate services, including various health-related services and educational opportunities. A recent study (O'Connell et al. 2002) that examined carers' perceptions of the health and related services available to young adults with disabilities found that carers valued highly the services provided by paediatricians, particularly because the paediatrician acted as a kind of de facto case manager, assisting carers to negotiate an often complex health care system. This type of relationship may be described as paternalistic, because the paediatrician is closely involved in advising, facilitating and, to some extent at least, controlling the health and related care of the young adult. In most situations, it is likely that the carers of a child with a disability become used to this kind of relationship and depend on the paediatrician for advice about accessing and negotiating various health-related services.

Once the child with a disability enters adolescence, questions arise about when, how and if the transition should be made from pediatric services to adult mainstream health care services. Some experts recommend that care should be provided for an indefinite period of time by a paediatrician to a young adult with a disability on the basis that paediatricians have established a long-standing relationship with the adolescent (Fulginiti 1992). However, others disagree with this perspective and state that mainstream health care providers are best able to cater for adult health care needs (Blum 1995).

It is apparent that pediatric services may not cater comprehensively for all of the health care needs of an adult with a disability. Needs such as reproductive and sexuality counseling, and women's health concerns may well be neglected. In addition, pediatric services tend to be paternalistic in nature, and despite the fact that the patient has become a young adult, the paediatrician may continue to treat the young adult with a disability as he or she was treated as a child. For example, children do not generally participate in decision-making about their health and related care. Instead, decisions are made on their behalf based on beliefs about their best interests. In contrast, adult health care generally assumes that the person seeking the service is an autonomous individual with a right to privacy and a capacity to make decisions.

There appears to be no consensus amongst paediatricians and other appropriate health care professionals about an optimal time or stage for young adults with disabilities to make the transition from pediatric to adult mainstream health care services. Instead, decisions about when the transition should be made seem to be made on a case-by-case basis. In general, the timing of the transition from pediatric to adult health care services depends on the adolescent's development and the willingness of the paediatrician to relinquish his or her patient (Bowes et al. 1995). There are anecdotal reports of some persons with a disability who have reached the age of 40 years and who remain under the care of a paediatrician, while other young people with a disability have moved on to adult mainstream services.

An associated concern with the transition from pediatric to adult mainstream health care services is that programs designed to promote a successful transition seem to be very rare in Australia. As many young people with disabilities and their carers do not have the opportunity to participate in such programs, the transition period may be very difficult and stressful. The difficulty and stress is related to being thrust into the position of having to independently negotiate the adult mainstream system after having been protected and guided within the confines of the care of a paediatrician for many years. For example, a young adult of 18 years of age with a disability may have been under the care of a particular paediatrician for all of his or her life. As has been suggested, it is likely that such a relationship is paternalistic in nature, underpinned by the young adult trusting in and depending on the paediatrician over a long period of time.

This type of relationship between paediatrician and carer does not, in itself, facilitate the successful negotiation of adult mainstream health care services and therefore the well-being of young people with disabilities may be compromised. This article presents an ethical argument in support of a structured transition program that is underpinned by the need to transform a professional relationship based on paternalism to one based on respect for the autonomy of the young adult with a disability and/or his or her carer. This argument is based on the proposition that violation of the autonomy of a young adult with a disability will lead to future negative consequences for the young adult and/or the carer. To clarify, in the situation where the young adult with a disability is mentally incompetent, it is the autonomy of the carer that is, at times, violated, again with negative consequences to the young adult and the carer.

For the purposes of this article, "disability" is defined according to the Disability Services Act (1991) as an altered functioning that is attributable to an intellectual, psychiatric, sensory or physical impairment or a combination of those impairments; that is permanent or likely to be permanent; and that results in a substantially reduced capacity for communication, learning or mobility, and the need for continuing support services which may or may not be of chronic episodic nature.

In addition, the use of the term "carer" in this paper refers to the designated main provider of unpaid everyday care to the young adult with a disability. This will often be a parent of the young adult, but not in all circumstances.

## **The importance of autonomy**

The importance of autonomy (or self-determination) in health care is well recognised. In order to maximise the well-being of individuals (presumably the primary goal of health care), it is crucial to recognise the individual as the pivotal decision maker with regard to his or her own care and treatment. It is noted that autonomy, or self-determination, is valuable not only because it allows for the concept of subjectively defined well-being, but also because it is considered an element of personal worth and dignity (President's Commission 1982). Autonomy may be described as part of the moral basis of personhood (Young 1986). In other words, the possession of autonomy is important to us because it is a component of what it is to be a person.

In recognising and suggesting that patient autonomy ought to be respected, even in the situation where an individual has an intellectual disability, one is faced with questions about the possible extent of autonomy, and whether any expressed desire is actually an expression of the patient's autonomy. It is obvious that there are certain circumstances where particular individuals will not be able to act autonomously, particularly where the individual is young and has an intellectual disability. However, we argue that one of the goals of treating a young adult with a disability should be to promote self-management and autonomy whenever possible. The value of autonomy is related to its effect on self-esteem, which can be described as our sense of self-worth and self-respect (Bailey 2001). The possession of high self-esteem is related to the belief that one's life is of personal value. It is equally necessary to recognise the importance of promoting self-determination for carers in order to empower them and foster self-esteem. This is desirable of and for its own sake, but also in recognition of the interrelationship between the well-being and quality of life of the carer and that of the young adult with a disability. In any case, from a practical perspective, it would be difficult to promote and foster the independence and autonomy of a young adult without involving his or her carer.

## Paternalism and its limitations

To act paternalistically is to restrict an individual's autonomy in some way. In general, the relationship between paediatricians and young adults with disabilities and/or their carers is of a paternalistic type that emphasises the doctor's authority (Benbassat et al. 1998). In general, the rationale for acting paternalistically is to prevent the interests of a young adult and/or their carer being adversely affected. Of course, though, the autonomy of the young adult with a disability must be traded off against the perceived well-being of that young adult and/or the carer.

Such action taken to protect or benefit a person where there is considered to be some defect in the decision-making capacities of the person (for example, where it is considered that the person is incompetent to make a decision) is usually considered justified because it protects future opportunities available to the individual and the overall well-being of the individual. Many authors argue that justification is only warranted if the paternalistic action is compatible with respecting the individual's autonomy and the right of competent individuals to direct their own lives (Young 1986, Feinberg 1986, VanDeVeer 1986). In the case of young people with disabilities and their carers, particularly when the child is young and perhaps newly diagnosed (with a particular disability), paternalism may be readily justified as a means of protecting the interests of the child and his or her carer. However, as the child becomes older, grounds for questioning the appropriateness of paternalism emerge.

## Transition pathways

Transition pathways or models that facilitate the transition from pediatric health care services to adult services for young adults with disabilities are lacking in Australia, despite the need for such programs being recognised (Bowes et al. 1995). Some models are currently being implemented and evaluated in North America (Betz 1998) and the United Kingdom (Doyle et al. 1994). Evaluation of such models at this stage is not highly positive, and it has been reported that these programs do not achieve the goal of collaborative, coordinated and integrative services to young adults with disabilities (Scal et al. 1999). The findings of O'Connell et al. (2003) revealed that in the absence of a paediatrician who acted as a case manager, parent carers felt they lacked the knowledge and support to manage the young adult with a disability. In particular, a general lack of continuity of care between various service providers made it difficult for individuals with a disability or carers to negotiate the transition period, which resulted in an increased burden of providing care. Further, communication between service providers was identified by O'Connell et al (2003) as being problematic.

In the O'Connell et al. (2003) study (based in a regional geographic setting), paediatricians and general practitioners interviewed indicated that there was no equivalent adult mainstream service to the one that paediatricians provided for the continuum of care from child to young adult. Concerns were expressed about the difficulty of negotiating a health care system in which communication and coordination between providers was lacking. The paediatricians expressed particular concern about the outcomes for families once the young adult with a disability left their care. The families interviewed confirmed the veracity of the concerns expressed by paediatricians and general practitioners (O'Connell et al. 2003).

General practitioners interviewed in the O'Connell study argued that they were unwilling and unable to take on a similar role to that of paediatricians, as they lacked knowledge of the variety of specific services and resources available to young people with disabilities and their carers. The general practitioners seemed to suggest that the service they provided to individuals with a disability was less than optimal as a consequence of information overload, or perhaps a lack of time to sort through information. For example, one general practitioner stated that he amassed drawers full of information, but that by the time he accessed particular information it was often obsolete (O'Connell et al. 2003).

Further, general practitioners in the O'Connell study tended to believe themselves ill equipped to deal with specific complex disabilities and stated that they lacked confidence in managing some disabled clients. Some general practitioners expressed a lack of experience and knowledge about the management of (particularly) intellectual disabilities, which meant that they consequently focused specifically on the medical problem that was the primary reason for the consultation. It may well be that the time restrictions placed on routine consultations also negatively influence the ability of general practitioners to address issues other than the immediate medical problem presenting.

In Australia it appears that, in the main, children with disabilities (and their carers) have their health-related needs well met by paediatricians. However, upon reaching adulthood and leaving the services of a paediatrician, young adults with disabilities and their carers often have difficulty finding out about and, at times, accessing appropriate health and social services. The inherent implication related to entering the adult mainstream health care scene is that young adults (and/or their carers) are expected to independently and autonomously navigate the health care system. Sometimes, an inability to proactively exert some control over this system results in negative health outcomes for these individuals and a reliance on crisis services. A perceived lack of control may trigger a destructive and stressful cycle of negative health-related events and a reactive illness response that is difficult to reverse.

## **Preparation for the transition period**

The current paternalistic model of providing care to young people with disabilities in Australia does not prepare and empower these young people and their carers to self-manage the adult mainstream health care system in the future. Instead, it fosters dependence on an individual service provider – typically the paediatrician – during the childhood years. This dependence does not bode well for the probably inevitable time when this dependent relationship will be severed.

It has been shown in Australia and internationally that parents and carers of young people with a disability lack involvement in transition planning for their charge (O'Connell et. al. 2003) and actually desire greater involvement (Dempsey 1994). Dempsey (1994) argued that parents' satisfaction with disability services relates to their opportunities for involvement and communication with these services. This suggests that for parents, a sense of control over the health and related care of their child is of great importance.

While clearly the degree of involvement in planning and accessing health care services of young adults with a disability will be dependent on the abilities and motivation of the young adults themselves and their carers, we suggest that, all things being equal, young adults with disabilities and their carers ought to be afforded at least the opportunity to take on this role. This opportunity consists of at least two components. First, on a conceptual level, the dependent and long-term relationship that tends to exist between paediatricians and the young adult with a disability and his or her carer needs to be critically examined and subsequently readjusted with a view to empowering the young adult with a disability and/or carer to self-manage. This entails a change in the way paediatricians understand their role and responsibilities towards young people with disabilities and their carers. In other words, a conceptual change from the paediatrician–young adult with a disability relationship needs to occur from one of “doing for” or “providing with” to one of “facilitating independence” or “empowering”. From an ethical perspective, this would entail a change over time from the traditional paternalistic relationship to one that recognises the importance of autonomy.

Second, formal transition arrangements ought to be put into place that assist and facilitate young people with disabilities and their carers to negotiate the adult mainstream health care system confidently and proactively.

Such arrangements need to be implemented progressively and in a way that meets the specific needs of individuals – both young people with a disability and their carers. For example, transition programs need to consider the development stages of adolescence in the context of the specific disability (Pintz 2002). It is reasonable to involve the young adult in planning for the transition period wherever possible. It has been shown that even young children are capable of making informed, competent decisions about health care (Alderson 1992) and that young adults with disabilities value opportunities to learn about and access environmental supports, and to assume greater independence (Healy & Rigby 1999).

Formal transition programs ought to involve the paediatrician, the family general practitioner, the young adult with a disability and his or her carer, and other relevant health care professionals such as case managers, if appropriate. The program should promote the autonomy of the young adult (or, where the young adult is incompetent, his or her carer) by gradually decreasing the centrality of, and dependence on, the paediatrician; by gradually strengthening the relationship between the general practitioner and the young adult; and by slowly facilitating the assumption of personal responsibility for decision-making by the young adult (or, when necessary, the carer).

## Conclusions

Unfortunately, only cursory attention had been paid to ethical issues related to disability, as research and scholarship in bioethics tends to be focused on prominent high-tech issues (Kuczewski 2001). This paper attempts to address an important ethical concern – that of the predominance of paternalism at the expense of the promotion of autonomy in the relationship between paediatricians and young people with disabilities – that may be currently exerting a negative impact on the wellbeing of young people with disabilities and/or their carers.

Many young people with disabilities are capable of making informed decisions about their own health care, providing that they are afforded the opportunity to do so. The opportunity to be treated as an autonomous consumer of adult health care services requires that an individualised transition program be implemented for such young adults that is sensitive to their particular needs and capabilities. In situations where the young adult is not competent to make decisions on his or her own behalf, a parent/carer-focused transition program ought to be implemented that adequately prepares the parent/carer to independently and confidently negotiate mainstream adult health care services.

The individual interests of young adults with a disability and their carers must be recognised. While an on-going paternalistic model of care provision will be necessary and justifiable for some individuals who are not able to act autonomously, for many others, their interest in self-determination ought to be respected and promoted. The promotion and facilitation of personal autonomy will assist young adults and/or their carers to successfully negotiate the current mainstream health care system in Australia. Successful negotiation of the health care system is, in turn, likely to enhance the self-esteem and well-being of young adults with disabilities, as well as to prevent the negative consequences of neglecting preventative health care measures.

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