



ORIGINAL ARTICLE

# Reluctant 'Jailors' speak out: parents of adults with Down syndrome living in the parental home on how they negotiate the tension between empowering and protecting their intellectually disabled sons and daughters

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## Accessible summary

- This study looks at the issue of the social lives of adults with Down syndrome who are living at home with their parents.
- Sometimes, for the very best of reasons, the parents of adults with Down syndrome try to prevent their adult son or daughter with Down syndrome from going out on their own, from having a boyfriend or a girlfriend etc.
- In this study, I talk to a group of parents about how they feel when they think about the kind of social life their sons and daughters with Down syndrome have.
- For example, I ask them are they happy with the amount of friends that their son or daughter has, whether their son or daughter has a boyfriend or girlfriend, whether they would like to see their son or daughter get married etc.
- Because of the role played by parents in the social lives of their intellectually disabled adult son or daughter, it is very important for everybody concerned with the quality of life enjoyed by adults with an intellectual disability to understand why their parents think and act the way they do.

## Summary

While the language of empowerment and human rights have taken centre stage in both the disability literature and disability service provision for adults with intellectual disabilities. One area where there exists a disconnect between theory and practice, in the Republic of Ireland at any rate, lies in the parental home and the role played by parents of adults with intellectual disabilities (this study focuses specifically on adults with Down syndrome) in acting as gatekeepers of their son or daughters social life. For the best of paternalistic reasons, many parents of adults with Down syndrome severely restrict the life choices of their adult sons or daughters. This is particularly the case when it comes to the regulation of their son or

daughters sexuality, a possible effect of which may be to effectively deprive their intellectually disabled son or daughter of the opportunity of ever entering into an intimate sexual relationship with another human being. So are parents of adults with Down syndrome actually playing the role of 'reluctant jailors'? If yes, how do they navigate the enormously tricky terrain that characterises the Scylla and Charybdis like tension between trying to empower their adult son or daughter with Down syndrome while at the same time doing all they can to insure they come to no harm? This study interviews ten parents on the earlier issues, to gain a greater phenomenological understanding on the predicament that many parents of adults with Down syndrome believe themselves to be in.

*Keywords* Autonomous adults, down syndrome, family and sexuality, perennial children, the parental obligation to protect, the right to a sexual life

## Introduction

According to Cacioppo & Patrick 'when people are asked what pleasures contribute most to happiness, the overwhelming majority rate love, intimacy and social affiliation above wealth or fame, even above physical health' (2008, 5). While transient loneliness is something that most people feel at some stage of their lives, a central proposition this research project set out to investigate was whether Irish adults with Down syndrome living in the parental home are leading, at some fundamental level, very lonely, vicarious, emotionally impoverished lives when it comes to the extent of their close friendships be these platonic or sexual in nature.

Regarding these questions, the academic literature indicates that adults with Down syndrome are not leading the kind of emotionally satisfying lives that they want and need (Bond 2009; Carr 2008; Craft 1987; Knox & Hickson 2001). Furthermore, for the best of paternalistic reasons, it is very often the parents of such adults who play a key role in perpetuating this state of affairs (Baron *et al.* 1999; Carr 1995). With this phenomenon in mind, this study set out to explore how parents of adults with Down syndrome who are living in the family home try and find the right balance between protecting their offspring from possible harm, while ensuring that they are not deprived of the opportunities to form intimate relationships.

Owing to an array of factors adults with Down syndrome in the Republic of Ireland are a group whose lives have dramatically changed for the better over the last two decades. This ongoing process has seen the natural parental desire to do their best by their son or daughter with Down syndrome bolstered by a paradigm shift in the general intellectual climate regarding who people with Down

syndrome are and what they can achieve. To differing degrees, the social model of disability, the philosophy of normalisation and the growth of person centred planning within the disability services have all played a pivotal part in producing this change in societal attitudes and policy prescriptions. Although in many respects playing different language games, the family resemblance linking all of the above a concern with issues of self-determination, autonomy and assisted decision-making, and by extension the propagation of the belief that people with learning difficulties have the right to act and be treated by society in an age appropriate manner (O'Brien & Lyle O'Brien 2006; Oliver 1996; Wolfensberger 1983).

As a result, adults with Down syndrome in Ireland now appear to represent a group of people with intellectual disabilities who have been successfully integrated into the wider community and are leading in many instances very normal age appropriate lives. Many adults with Down syndrome are now brought up in families rather than in institutions, with the majority attending mainstream school at least at primary level. In addition on leaving school, many adults with Down syndrome go on to obtain paid employment, whether through sheltered employment schemes run by the disability services or less commonly in the private sector (Conroy 2003; Doyle 2003; Kelly *et al.* 2007). These policy initiatives are predicated on the belief that people with Down syndrome have the capacity to learn, develop and lead rewarding and relatively independent lives within a mainstream environment (Cunningham 2006; Newton 2004).

Yet, in spite of these positive changes, one area where the everyday lives of some adults with Down syndrome remain considerably different from that of their nondisabled counterparts, where the transition to adult status has effectively

stalled, is in relation to the degree of autonomy they enjoy when it comes to having more control over their social lives and by extension expressing their sexuality via the medium of intimate relationships. Unlike nondisabled adults, who control their own social and sexual lives, adults with Down syndrome living in the parental home are liable to be much more circumscribed when it comes to making those kinds of choices for themselves (Browne 1994; Emerson & McVilly 2004; Milligan *et al.* 2001). The limited research that has been carried out examining the situation in Ireland clearly indicates a wide gap between the desire expressed by many adults with learning disabilities to embark on a sexual relationship and the actual reality of their lives (Hamilton 2009, 303; Kelly *et al.* 2009). In spite of the evidence that has demonstrated that adults with Down syndrome have the same emotional and sexual needs as their nondisabled contemporaries, many of their parents tend to have ambivalent views in relation to their adult sons and daughters taking more control over their own lives (Schwier 2006; Shakespeare 2000; Valenti-Hein & Choinski 2007). Wanting to encourage independence in many aspects of life but reluctant, for example, to permit much freedom around unregulated socialising and by extension the opportunity to form intimate relationships, for fear that they will be abused or exploited in some way (Evans *et al.* 2009; Keith 2007). A fear, moreover which is vindicated by the available research evidence, which indicates that adults with intellectual disabilities are more vulnerable to abuse than their nondisabled peers (Hughes 1999; McCarthy & Thompson 1997; Murphy 2007). The essence of the autonomy/paternalism dilemma wrestled with by many parents of adults with Down syndrome living in the parental home is the fact that in spite of all the human rights talk about empowering adults with Down syndrome to become more independent the most important right they lay claim to is the right to ensure that no harm comes to their son or daughter (McCarthy & Thompson's (1997). A stance moreover typically adopted in the knowledge that a possible unintended cost of ensuring such safety is that they themselves effectively become 'reluctant jailors' with their adult son or daughter with Down syndrome in some cases reduced to the status of 'protected prisoners' (Caffrey 2004, 105).

## Methodology

A qualitative approach using semi-structured interviews was chosen as the most appropriate methodological approach to adopt in order to collect the kind and quality of data required. A key advantage in using this research technique when dealing with sensitive subject matter is that it provides the respondents with the time and space to answer in their own terms. In addition, it enables both the researcher and the respondent to react and to adapt as the interview unfolds; to pursue a line of reasoning that

emerges organically from their interaction, one which may otherwise have remained unexpressed and/or unthought (Robson 2002). To this end, a purposive sample of ten parents, broken down evenly along gender lines, of adults with Down syndrome living in the parental home were collected. The respondents, by their own 'admission' are all actively involved in campaigning for the rights of people with Down syndrome. They each replied to a leaflet drawn up by the author; one which was only made available at a public meeting in Dublin convened to discuss the implications of proposed government cuts to disability services. The respondents were interviewed about the degree of satisfaction they felt about their intellectually impaired adult son or daughter's social and sexual life and the role, if any, that they themselves played as gatekeepers regulating access into these mutually constitutive worlds. A topic guide covering socialising, issues of autonomy and sexual relationships was employed to structure the interviews. The interviews themselves typically took between 60 and 90 min to complete. With the consent of the interviewees, the interviews were tape-recorded and transcribed verbatim. After transcription, the NVivo qualitative software program was used to both code the data and generate key themes. The most salient of these are the following:

1. The parents perceived isolation of their adult son or daughter with Down syndrome.
2. The parents wish that their son/daughter was involved in an intimate relationship.
3. The fear of their son/daughter being subject to sexual abuse/exploitation in such a relationship.
4. The parents views on their son/daughter receiving sex education.
5. Whether the parents perceived their intellectually disabled son/daughter as having the same sexual needs and desires as that of their nondisabled contemporaries.
6. Whether the parents saw their adult son or daughter with Down syndrome as possessing the cognitive capacity to exercise more control over how they spend their leisure time.

## Research findings

### *Social isolation*

In response to the question as to whether they were satisfied with the quality of their son or daughters social life, each of the respondents replied that they were not. They all expressed the belief that social isolation was and continues to be a major problem for their adult sons or daughters with Down syndrome, all of whom were over reliant on them as parents and other family members when it came to socialising.

For example, parent A explains how his adult son is almost totally dependent on him when it comes to getting

out of the house, 'socially he relies on me for his social outlet, he goes bowling with a bowling club on Friday nights, but generally after that he has nothing else'. In terms of identifying reasons for this state of affairs, he cites parental fear as a key factor in his sons 'failure' to establish a social network of his own, both in the past when he was a child, and presently as an adult. While this father subscribes to the belief that his intellectually disabled son is at greater risk than the normal adult in navigating the complexities of the social world. He made an attitudinal distinction in relation to his sons vulnerability in this respect between him and his wife, claiming that the latter would, in colloquial terms, 'pour cold water' on some of his tentative suggestions designed to expand his son's social horizons. According to parent A, 'my wife would be the one that wouldn't have the confidence in letting him away, she's nervous of him all the time that something will happen to him, so he would have been corralled all through his life.' This relative form of social isolation experienced by many adults with Down syndrome is also brought out by parent D's remark that her daughter 'while a gregarious character', who 'goes out on average around three times a week' in a group setting has, 'given the regulated nature of such outings' little chance of forming a 'close friendship' with one of her peers. This explanation refers to the fact that a lot of the socialising engaged in by adults with Down syndrome in Ireland takes place under the auspices of one of the disability day services that adults with Down syndrome in Ireland are usually affiliated with. According to most of the respondents, such events, where the emphasis is on engaging in concrete activities like bowling, coupled with the attempt by the professional carers in question to ensure that everyone in the group feels included, effectively precludes the possibility of close personal relationships developing.

### Sexual relationships

When it came to the issue of parental attitudes towards their intellectually disabled son or daughter becoming involved in a sexual relationship, the various respondents had broadly similar views. For example, a common theme that emerged in nearly all the interviews was that while all the respondents' sons or daughters had, at some stage in the past, or currently have a 'boyfriend/girlfriend'. These relationships bear little resemblance to what is commonly understood by this label when applied to their nondisabled counterparts. Parent B in talking about the experience of her daughter, explained how the latter, at the time of writing, has had two 'boyfriends', neither of which she saw very much, and when she did the two of them were very rarely alone together. The daughter in question currently 'has a boyfriend at the moment', yet effectively 'she doesn't go out with him... they don't go out'. Rather, their 'relationship' is one that is made up of infrequent phone calls and meeting

up as part of a monitored group referred to above. In summing up this aspect of her daughter's life, her mother characterises the relationship as 'more just friends than girlfriend and boyfriend', which as far as she knows is asexual. That this form of 'courtship' is typical among adults with Down syndrome in Ireland, is confirmed by parent C who when discussing his daughters relationships, qualified an earlier claim that his daughter had boyfriends in the past by adding that they were in fact 'more 'friends' though than 'boyfriend' and that in reality his daughter 'hasn't really been out', on a one on one basis with any man. Instead any contact between her daughter and a boyfriend would take place during one of the heavily regulated events referred to above. As parent D, whose daughter has had 'boyfriends' in the past' explains, such relationships are 'not really 'boyfriend and girlfriend' as they have rarely if ever 'gone out together on their own.'

### *Fear of a sexual relationship*

While expressing a principled belief that their adult son or daughter with Down syndrome had a right to lead a sexual life if they chose to, the ramifications of what this would involve in practice caused many of the parents to express worries about the possible consequences if their adult children ever actually embarked on a sexual relationship. Two of the most common fears expressed by the parents were that of their child getting pregnant and/or being subjected to some form of abuse and exploitation.

In relation to the former, the majority of the parents mentioned that one of the chief values of their disabled daughters receiving sex education would be the information they would receive in relation to how a woman gets pregnant. However, in spite of this many of the parents were fearful that even equipped with such knowledge something might go wrong if their son or daughter ever found themselves in a real sexual relationship. For example, parent E, when discussing the possibility of her 25-year-old daughter becoming sexually involved with a man worried, that if sexual intercourse was a possibility, whether her daughter 'would have the confidence to insist her boyfriend wore a condom'. Similarly, parent F expressed a concern that her daughter 'would remember what she had been taught in the classroom', and consequently 'refuse to have sex if her boyfriend wouldn't use contraceptives'. Parent H meanwhile when talking about some of the fears he would have in his thirty something son getting into a sexual relationship offered a completely different perspective on the issue of using contraceptives. This father was concerned that some of the images his son is exposed to on a daily basis via the media, plus the information 'he would inevitably receive' if given sex education, would condition his son into believing that to have sex he would 'need to become a good lover'. A possible result of which would be

to plant the idea in his sons mind that one manifestation of this skill would be the ability to effectively put on a condom when the moment came for him to lose his virginity. However, parent H was worried that the 'effort involved in putting on a condom in such a situation' was one that would be underestimated and/or overlooked by the sex education teacher, who in his view, 'would be more than likely female'. Recounting his own first 'fumbling sexual experiences', parent H expressed the view that a failure to 'properly put on the condom first time around' might damage his sons self-esteem creating a self-fulfilling prophecy 'that sex was not for him'.

The possibility of their adult son or daughter with Down syndrome becoming the victim of abuse and exploitation as a result of embarking on a sexual relationship was brought into sharp focus when the parents were asked to consider the hypothetical scenario of a sexual relationship involving somebody without an intellectual disability where there would be an asymmetry in relation to cognitive capacity between the parties. The consensus view on the part of the respondents was that such a relationship was one they could not and would not condone, even if their son or daughter 'was in love with the individual concerned'. For parent J, such a situation would be by definition exploitative given the power differential he deemed would necessarily follow from the cognitive imbalance between his son and a nondisabled suitor. Thus, 'as far as I'm concerned someone who doesn't have an intellectual disability has control over him and I wouldn't allow it, no matter how much he loves him, no way, I see my son having a relationship with someone of his own ability.' Parent G reiterates these sentiments when talking about her intellectually disabled daughter getting involved with a nondisabled man. 'I wouldn't be able to get my head around it'; 'the question I would be asking is 'why'? What apart from the obvious, apart from simply using her for sex would he want, what else would he get out of such a relationship?'

### Sex education

With one exception, all of the respondents stated that the day services their sons and daughters attend should be legally obliged to provide courses in sex education. Parent I was essentially talking for all the respondents when she stated that in her view 'every child should get sex education, whether Down syndrome or any other learning disability.' In terms of the content of such a course, there was also widespread agreement on what it should include. This included clear information on the mechanics of various sexual acts including those of masturbation and sexual intercourse. In the words of parent C 'let them mention everything, they have a right to know as well as the others have a right to know... I would just like her to be taught the basic things, as I say like disease, contraception, sex, oral sex

all of that, I have no problem with that.' Similarly, the view of parent B was that people with intellectual disabilities 'should know about everything... have it explained that if they did go into a relationship that they would understand what sex is about, and that if anybody interfered with them that they know that shouldn't happen, that they would have to know the difference if you know what I mean, that when its right and when its wrong'. While parent A, in his answer, essentially repeated the same inventory of topics that had to be covered mentioned by everybody else. Namely, that a sex education course for the intellectually disabled 'would have to cover protection, they would have to cover touching, masturbation and intercourse', but insisted however that such information should be taught 'in the context of a loving relationship'.

### *Perception of their adult son/daughter as having the same sexual needs and desires as their nondisabled contemporaries*

In response to the question as to whether they considered their adult son or daughter with Down syndrome to have the same sexual needs and desires as that of their nondisabled counterparts, the majority view was yes they had. But in the case of many of the parents, this realisation was the product of a learning process. For example, both parents D and F talked about how their initial expectations were challenged both by what they read, and what they experienced first hand. The latter claimed that he 'used to be a practicing Catholic and I believed in that whole idea that she was a gift from God... I suppose an 'angel' of sorts but definitely asexual... but that changed as I read about what Down syndrome involved, and that taught me that my daughter has the same feelings, emotions and needs as any other human being and that includes sexual desires'. Parent D expressed similar type sentiments, initial ignorance as to her daughter's sexuality, a perception which however dramatically changed with the onset of adolescence. While not long lasting, this sense of cognitive dissonance on the part of parent D proved to be an ongoing source of tension between her and her daughter. 'I couldn't come to terms with it at that stage... for example when we went out with the family, she would approach random guys, or follow guys she was attracted to, so you had all that kind of behaviour going on, and obviously the potential for exploitation was huge so... taking her to the beach became more and more embarrassing because she would take off her towel and sit beside all the handsome guys... and of course they always laughed at her.' This shift in attitudes on the parent's part is also captured by parent F, when he talks about his wish that his daughter, who had a boyfriend at the time, was becoming, or at the very least had the opportunity to become intimate with the man in question. 'It was interesting, but for all sorts of different reasons she went on a contraceptive pill, and from that stage on I adopted a less

"hands on approach" when it came to regulating the time they spent alone together, so that would have been half subconscious and half conscious, do you know what I mean, it would have said well let them discover for themselves where their going.' Again, parent D concurred in a similar but slightly different way when in describing her daughters current relationship as one that 'seems really good for the two of them, they actually knew each other for a while before they started going out, they went to the same club and it just developed from there, I think its good for everybody involved'.

### The question of autonomy

While the majority of the parents interviewed believed their adult child with Down syndrome to be very independent, these claims were always qualified when certain issues arose, or certain dilemmas were posed. Consequently, it seemed that the autonomy they proudly attributed to their intellectually disabled offspring was a limited one. It applied in some cases, for example, to their sons or daughters making their way to and from work or spending the money they earned on whatever clothes they wanted. But when it came to issues of sexuality and relationships, nearly all the parents questioned were much less confident in the ability of their sons and daughters to navigate that kind of terrain. For example, parent F was effectively talking for most of the parents when he made a distinction between the head and the heart. One where the parent wants, in principle at any rate, their adult son or daughter with Down syndrome to have a sexual relationship but is ever conscious of what they see as the extreme vulnerability of their children to exploitation and/or emotional suffering should such a scenario come to pass. In explaining this dilemma, parent F describes how 'when your emotionally involved it gets confusing, but you see with the other daughters its their business, its their life, they have to pick up their own pieces, its not with X so much, I have control over her life, its not what I want but I don't have a choice in being still part of her life at 33, and that's the way it goes but, you have to keep coming back to the fact that they have an intellectual disability.'

### Discussion

The above study set out to get the views of parents of adults with Down syndrome in relation to their adult sons and daughters with Down syndrome exercising more control over how they spend their leisure time and enjoying more freedom around the area of forming intimate relationships.

However, hovering over these empirical questions is a more abstract concern with the ambivalent way in which adults with intellectual disabilities are generally perceived when it comes to their ability and/or right to make for

themselves the decisions which affect their own lives. In other words are they objects or subjects in the eyes of those who have the authority to exercise power over them? And, equally importantly, is there a mismatch between how adults with Down syndrome are viewed and treated and their status under the law?

When it came to parental answers to these questions, in most cases, especially in relation to the 'tough issues' that really test ones commitment to the principle of autonomy or self-determination, as previously mentioned a split between the heart and the head was a reoccurring motif. An example of this 'typology' in action can be clearly seen in the sometimes contradictory replies that the respondents gave. Thus, while the parents were in agreement that their adult son or daughter with Down syndrome had the same rights and needs as their nondisabled peers; a view which was expressed most forcefully when it came to the right to have access to sex education programmes. When it came to questions such as whether they as parents should play a more active part in creating the conditions which would increase the likelihood of their adult son or daughter becoming involved in a sexual relationship. Whether they believed their children had the right to enter into consensual sexual relationships with who ever they so choose, or whether they would approve of their adult son or daughter with Down syndrome becoming parents in their own right. Then, various caveats were introduced to dilute their heretofore principled stance when the implications of such behaviour became clearer. While the reasons proffered by the parents to justify their respective positions were formulated in a number of disparate ways, their propositional content can be subsumed under the general belief that the decision-making capacity of their adult son or daughter with Down syndrome is impaired. One consequence of which is that all of the respondents felt it was their duty as parents to sometimes adopt the role of surrogate decision-maker for their adult son or daughter in question. Ironically enough, given that many of the parents interviewed were for the most part unaware that people with intellectual disabilities do not enjoy the same rights as those Irish citizens who do not have an intellectual disability. Many of their beliefs about the intellectual capacity of their intellectually disabled son or daughter, either explicitly stated and/or inferred from what was, or was not said, corresponds to a large extent with the 'legal capacity' enjoyed by the intellectually disabled in Ireland. The concept of legal capacity refers to whether the decisions one makes are protected in law. Irish law as currently constituted discriminates against people with an intellectual disability in that it makes it a criminal offence for an individual with a 'mental impairment' who is not living independently to engage in sexual relations unless they are married (Johnson *et al.* 2010). However, having said that, it is doubly ironic that in many of the scenarios discussed the parent does not actually have the 'legal authority', whatever

about the moral obligation, to act in such a paternalistic fashion. The law as it is currently constituted in Ireland makes it illegal for the parents to do what they said they have, or would do, if the situations in question arose; namely to make such decisions for their adult offspring, especially if that entailed overruling a decision already made by their intellectually disabled adult son or daughter (Inclusion Ireland 2009; Namhi 2003).

### Limitations of study

The main limitation of this study, as with any small-scale qualitative research project, is with the ability to generalise from the findings. In strict methodological terms, one cannot generalise from a sample of ten parents of adults with Down syndrome living in the parental home to this population as a whole. Nevertheless, with this qualification in mind, if one grants the following two premises:

1. All parents of adults with Down syndrome living in the parental home are concerned with the quality of their son or daughters social and sexual life.
2. Parental views on their adult son or daughter with Down syndrome living in the parental home entering into a sexual relationship can be arranged on a conservative/liberal spectrum.

Then one can argue, on the basis of inference to the most plausible explanation, that the insights gleaned from the respondents, all of whom identified themselves as holding liberal views on the issues under scrutiny, offer some support to validate the original hypothesis; namely that a large percentage of adults with Down syndrome living in the parental home are leading largely asexual lives.

### Recommendations

Whether one accepts the above conclusion or not, given the paucity of Irish research into this area, it is imperative that more work be performed to provide interested parties with data as to what the key players (namely the relevant experts, the parents of adults with Down syndrome and obviously the adults with Down syndrome themselves) think about the general issue of increased freedom for adults with Down syndrome around the areas of unregulated socialising and the formation of sexual relationships. Hopefully such conversations will in turn lead to the production of various blueprints, which coalesce around the objective of providing optimal opportunities for the formation of close personal friendships for adults with Down syndrome, be they sexual or platonic in nature.

In addition, one is also on relatively safe ground in agreeing with the respondents that there should be a statutory requirement on the disability services in Ireland to provide sex education programmes for people with Down syndrome. That the law which discriminates against

adults with an intellectual disability expressing their sexuality should be overhauled and that policies should be put in place, which will help close the knowledge gap which exists between the relevant professionals and some parents of adults with Down syndrome regarding the question as to whether adults with Down syndrome have the same sexual needs as their nondisabled contemporaries.

### Conclusion

However, as this study demonstrates when the issue involves parents who have all the requisite information then arguably social policy can go no further in terms of its prescriptions. If there is a hierarchy of knowledge which can help settle the matter in a definitive, objective manner as to whether parents of adults with Down syndrome living in the parental home should privilege one side of the paternalism/autonomy debate when it comes to 'allowing' their sons and daughters more freedom around the areas of unregulated socialising and sexual relationships it has yet to make itself known. To this end interested third parties, regardless of their 'expertise', who will not be personally effected by any decisions taken might do well to heed Wittgenstein's wise aphorism; 'whereof one cannot speak, thereof one must be silent,' and act accordingly (Wittgenstein, 1961).

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