Overprotection in the lives of people with intellectual disability in Malta: knowing what is control and what is enabling support

Anne-Marie Callus, Isabel Bonello, Charmaine Mifsud & Rosanne Fenech

Abstract

A study of overprotection in the lives of persons with intellectual disability in Malta was carried out on the principles of inclusive research. Focus groups were held with people with intellectual disability, parents of people with intellectual disability, and those working with persons with intellectual disability. Overprotection is a disabling barrier. Its effects were identified in employment, leisure time, intimate relationships, and the use of public transport, money, and mobile phones. People with intellectual disabil- ity who experience overprotection live very structured lives. They cannot develop their skills, abilities, and potential. Furthermore, they cannot live their life on their own terms, but on terms determined by others. This creates a sustained dependence on others, especially the family. It is important that a balance is achieved between protection and enabling support. Persons with intellectual disability should be given the support they need to express their wishes and act on them.

Points of Interest

- This article discusses a study that was carried out in Malta on overprotection in the lives of people with intellectual disability.
- The topic of overprotection was chosen by the person with intellectual disability who was a co-researcher in this inclusive research study.
- People with intellectual disability experience overprotection in employment, leisure time, intimate relationships and the use of public transport, money and mobile phones.
- People with intellectual disability should have the support they need to be able to do the things they would like to do.

Despite overt policies of 'rights' and an 'ordinary life' the trend of policy is thus for people with learning difficulties to lead lives of extraordinary regulation

(Riddell, Baron, and Wilson 2001, 200)

Introduction

In this article we reflect on the findings from an inclusive research project that we carried out in Malta about overprotection within the family and how it contributes to the 'extraordinary regulation' experienced by people with intellectual disability. The topic was chosen by one of the authors who is a person with intellectual disability. She chose it because in her experience many parents of persons with intellectual disability are afraid of allowing their adult children to do things on their own. We wanted to find out the reasons why this happens and the effect it has on the lives of these persons.

Background

The research literature

Relationships between adults with intellectual disability and their parents are complex and are affected by many factors. Parents are often the main source of support for adults with intellectual disability, as attested in many studies including the European research by Birtha and Holm (2017) and the US study by Hewitt et al. (2013). Hewitt et al (2013) also mention how parents support their adult children in various aspects of life. In many countries, parents of disabled people have also been at the forefront of the disability rights movement (Mansell and Ericsson 1995; Walmsley et al. 2017). Listening to parents can sometimes even be a matter of life and death, as the families of Connor Sparrowhawk and Danny Tozer, among others, would say (Ryan 2017; Laycock 2017).

On the other hand, Hendey and Pascall (1998), as well as Hemm, Dagnan, and Meyer (2018), discuss how adults with intellectual disability are restricted regarding the activities they can do and the places they can go to, with safety being an important consideration for parents. Beart et al. (2001) report on the limited range of opportunities for adults with intellectual disability in the United Kingdom, while Milner and Kelly (2009) explore how people with intellectual disability do not have many friends. Furthermore, one of the findings that emerges in a Greek study by Aroni, Hegarty, and Philalithis (2013) is that parents who themselves experience difficult situations tend to keep their daughters and sons with intellectual disability in a protective environment, such as a day centre or sheltered employment, since these are more practical options than supporting them to enter employment.

The lives that many people with intellectual disability lead within the shelter of the family environment tend to be correlated with experiences of overprotection. The issue of overprotection in the lives of disabled people is reported in the literature cited earlier as well as by Irazabal, Pastor, and Molina (2016) in research carried out in Spain and by Barron (2001) in Sweden, among others. Citing Levy (1943), Hollomotz describes overprotection as:

parental protection that is disproportionate, taking into account the developmental level and abilities of the child. It is characterized by excessive physical and social contact,

prolonged infantilisation, active prevention of independent behaviour and social maturity and excessive parental control. (2011, 44)

Adults with intellectual disability can enjoy autonomy and independence with support from their parents. Problems arise when there is a lack of agreement between what these adults would like to do and what their parents think they should do. Mill, Mayes, and Connell (2010) focus on how adults with intellectual disability in Australia negotiate autonomy within the family home. They note that:

[p]articipants who took passive or proactive approaches to negotiating autonomy within the family were generally satisfied with the level of autonomy they enjoyed and parental support/involvement in different areas of their life. Conversely, the one participant who took a defiant approach was not satisfied with either. (Mill, Mayes, and Connell 2010, 198)

As the research carried out by Patterson and Pegg (2009) in Australia shows, when support is provided, people with intellectual disability can successfully engage in community-based activities. An overprotective envir- onment, on the other hand, means that people with intellectual disability do not have the opportunity to develop personally and socially, and therefore to move into less protective environments, including work environments. This lack of opportunity is linked to a perception of these adults as not having the potential for development, and even of them as being vulnerable and therefore in need of protection. Friedman (2019) raises this issue in connection with money management – restrictions to accessing money are put in place not necessarily because of a person's inability to manage it but because of a perception of that inability. That restriction in turn does not allow the person to develop money management skills. People with intellec- tual disability may also successfully negotiate support that enhances their autonomy in some areas but not in others. Parents too seek a balance between 'ensuring autonomy and providing protection' (Barron 2001, 439). Overprotection, therefore, is not an all or nothing affair, with some parents being totally overprotective and others not at all.

On a final note, although the focus here has been on overprotection in the family home (in line with the aims of our research), as Hollomotz states:

 [o]verprotection may continue to affect people with learning difficulties in adulthood and is not merely executed by parents. It can be a defining feature of service structures, such as day centres and residential group settings, and it may guide staff action. (2011, 44–45)

Wherever it happens, as Hollomotz continues, '[o]verprotection is a hindrance to disabled people's self-determination' (2011, 45).

The Maltese context

The discussion of our research also needs to take into account the Maltese context in which it was conducted. Although Maltese families have changed significantly over the past decades, as highlighted by Abela (2016), family ties prevail in contemporary Maltese society. Young people still experience very strong ties with their parents, as reported by Cassar (2016) and Abela et al. (2013). Significantly, these studies show that the relationship between young people and their parents is hierarchical, with parents remaining the figure

of authority. In a Eurostat (2015) study about young people in Europe, statistics about the estimated average age at which young people leave the family home show that Malta scores the highest average: 31.8years (in the United Kingdom it is 24.3 years). Additionally, the overprotective tendency of Maltese parents emerges from a study by Muscat (2017) with Maltese older teenage boys who leave the island to train as professional footballers. Muscat (2017) highlights how many of them identified themselves specifically as 'Maltese boys' who were used to finding everything ready and ill-prepared to strike out on their own.

The dependence of young Maltese adults on their parents impinges on the lives of disabled people too. Garland notes:

The small size of Malta and the close-knit communities that exist with these attitudes towards disability may make it more difficult for parents to avoid over- protection which society assumes is the correct way to raise a young person with disability. (2015, 44)

The tendency for people with intellectual disability to be cast into a prolonged adolescence (Shepperdson 2000) means that in Malta they find it more difficult to live independently. Another hindrance is the lack of comprehensive support services. While there are services for disabled persons to live in the community (Ag_enzija Sapport 2018), in effect they are geared more towards providing support when the family can no longer do so (Garland 2015). Many disabled people therefore depend on their parents – as well as other family members – for support in their daily lives (Garland 2015). The provision of this type of support can be problematic (Dun_er and Olin 2018).

Furthermore, in Malta it was parents who first fought for disabled people's rights (Camilleri and Callus 2001) and they continue to play a key role in campaigning for adequate services and the upholding of disabled people's rights (Azzopardi 2009; Garland 2015). Statistics from the 2011 Malta Census show that there is still plenty to campaign for – persons with intellectual dis- ability are amongst the least likely to be in the labour force, to have qualifications, and to be married (CRPD 2018).

The research discussed in this article asked whether and how people with intellectual disability experience overprotection in different aspects of life, especially through the actions of their parents.

Methodology

This research was carried out on the principles of inclusive research (Gilbert 2004; Nind 2014; Walmsley and Johnson 2003). It was also based on a social model understanding of disability (Oliver 2009), which informs the themes elicited from the analysis of the findings. People with intellectual disability were involved in all the stages of the research process. Isabel, a person with intellectual disability, identified the topic herself. She and Anne-Marie then designed and implemented the research plan, following approval from the University of Malta Research Ethics Committee.

Three rounds of focus groups were conducted, led by Anne-Marie and Isabel. They were audio-recorded with the consent of the participants. In the first phase, three focus groups were carried out with a total of 17 persons with intellectual disability, who still live with

their families and whose ages ranged from 18 to 55 years. Nine were male and eight were female. Transport was provided for these persons to make it easier for them to attend. These were followed by another three focus groups with a total of 14 parents. This number included three couples where both mother and father attended, a father, and another seven mothers. The ages of their children with intellectual disability ranged from 15 to 35 years.

For the second phase, four focus groups with 18 representatives of differ- ent organisations working in the sector were conducted. Of these, four were disabled persons and 10 were non-disabled persons who have paid employ- ment in the disability sector, one was a representative of a self-advocacy group led by persons with intellectual disability, and the other three were parents of people with intellectual disability who form part of parent-led non-governmental organisations. They referred to their own experiences as well as those of other parents they have close contact with. The focus groups with organisation representatives discussed the main findings from the focus groups held in the first phase. Thus, the experiences of persons with intellectual disability and their families were given primary importance.

At the same time, it was possible for us to gauge whether the personal experiences mentioned by the participants in the first-phase focus groups were typical of other families that the disability organisations come into contact with. This triangulation helped counter any biases in the first-phase focus groups, especially the possibility that the persons with intellectual dis- ability who were able to participate were the ones who do not experience a lot of overprotection; and the possibility that the parents who participated were also ones who tended not to overprotect.

For the first-phase focus groups, Anne-Marie and Isabel drew up the list of questions. People with intellectual disability were mainly asked about whether or not they go to different places and do different activities outside the family home, and whether or not they have any of the support they need to be able to do so. Topics included means of transport used, employment, continuing education, leisure activities, meeting up with friends and/or girlfriends/ boyfriends, having a mobile, and money. Parents were asked questions about the same topics regarding their adult children with intellectual disability.

Anne-Marie and Isabel then listened to the recordings of these focus groups together. We transcribed word by word the parts of the recordings we considered to be very important, and took notes about what was said in the other parts. Together then we analysed these notes and transcriptions to make a summary of the most important points that were mentioned. The questions for the focus groups in the second phase were based on this summary. The same method was used to analyse these focus groups.

Charmaine and Rosanne came on board after the focus groups were conducted, the data analysed, and the research report drawn up. We held a conference to present and discuss the findings with a wider audience. This article is based on our discussions and reflections on the findings. Anne- Marie took the lead in writing this article, putting together everyone's input, with the draft being revised and agreed upon by all four authors. We wrote the concluding part together. As mentioned in the following, a report of the findings drawn up by Isabel and Anne-Marie is also available, including an easy-to-read summary of

the main findings.

Summary of findings

In this section, we provide a summary of what the participants said in the different focus groups. For each topic, we start from the focus groups with people with intellectual disability, then those with parents, and finally the focus groups with staff. To identify the different roles of the focus group participants in the presentation and discussion of the findings, people with intellectual disability are referred to by a first name, parents by title and surname, and organisation representatives by name and surname. All names are pseudonyms.

Employment

Of the 17 persons with intellectual disability who participated in the focus groups, six work full-time and two work part-time. This number does not reflect the general reality. According to statistics from the 2011 Malta Census, only 7% of people with intellectual disability are employed (CRPD 2018). These eight persons are happy at work. Pierre said:

> my week is beautiful. I work with very nice people. They love me.

Another two persons with intellectual disability have previous work experience in training schemes, two stay at home all day, and the other five attend day centres.

Parents whose sons and daughters work reported different experiences. Mrs Aquilina described her son's employment as an overwhelmingly positive one. However, Mr and Mrs Borg said that their son's co-workers take advantage of him because he likes working and they shift their work onto him. Mr and Mrs Zammit also mentioned that their son's co-workers used to take advantage of him, especially with lifting heavy objects. Then, when their son hurt his back his employer sacked him because he did not want any problems:

> He [the employer] told us 'I prefer to give money to [a disability organisation] than employing someone like your son'.

On the other hand, Mr Said said that his daughter has learnt how to skive, just like her co-workers.

In the staff focus groups, the participants said that most persons with intellectual disability do not work. Among the reasons mentioned was the reluctance of employers to take on disabled people, and especially people with intellectual disability. As Damian Pisani said:

> Physical disability? Alright, we'll manage somehow. Intellectual disability? No, not them.

The participants reported that employers accept persons with intellectual disability only while they are on a training placement. Josephine Carabott spoke about the dilemma that staff and parents face in these situations about whether to provide such opportunities at all. She said:

> What do you do? Crush their hopes and dreams completely? Or give them a

glimpse of what they can have? (Josephine Carabott)

Some people with intellectual disability experience protection within the work environment. Some work in a sheltered environment, such as the local council or parish. The focus group participants said this may be 'make- believe work'. Furthermore, after leaving compulsory schooling, some people with intellectual disability follow one training course after another. As Annalise Scerri put it:

the main thing is that they're somewhere sheltered.

Pauline Magro observed that people with Down syndrome are not bullied

because they are 'considered cute':

I think it's more that they are mummied around. That really annoys them. ... They look upon them more as their own children, rather than as equal colleagues. I think that that really annoys them.

Instances were mentioned where employment opportunities arise but are blocked by parents. The reasons given vary. Some of them are related to the workplace itself, for example fear of the person with intellectual disability being abused or bullied by their colleagues, or concerns that the workplace may pose certain dangers (e.g. knives in kitchens). These parents feel that their daughters and sons with intellectual disability are better off attending a day centre or staying at home.

Other reasons for parents holding adults with intellectual disability back are not directly related to the job. The most significant one is parents who do not want their sons and daughters with intellectual disability to use buses on their own, and insist on giving them lifts to and from work. If the working hours of the job do not fit into the parents' schedule, then the person with intellectual disability cannot take it up. This also happens if there is not an adequate bus service between the person's home and the workplace. Some parents underestimate the person's abilities and are convinced that they would not be able to work.

Leisure time

Whether or not they work, many people with intellectual disability do not tend to have much say over how and with whom they spend their leisure time. In all of the focus groups, there were many participants who mentioned that persons with intellectual disability go out only with their family. Very few persons with intellectual disability go out on their own or with the people they choose.

Some persons with intellectual disability said that they prefer to attend activities that are organised specifically for them, or go out with other peo- ple with intellectual disability. Nikita said that she does not go out with non- disabled people because she is afraid they will make fun of her. She said:

we have to wait because our parents tell us 'we'll see if you can go or not'.

Kevin said he opts to spend the weekend at home. He is very busy during the week and 'I

need my space.'

Leisure is sometimes structured around family activities. For example, Silvan said that in summer he can stay out late because his family stay in their second home in a seaside resort. He also described how he used to go clubbing with his friends but his parents stopped him when his friends left him drunk at a bus-stop. He said he understood why his parents did not want him to go out with those friends.

The parents said that when their adult children with intellectual disability are out on their own, they are very worried if there is no one supervising them. Mrs Zammit said that she trusts her son but not his friends. Parents whose children with intellectual disability are aged between 16 and 20 years consider them to be too young to go out without being supervised by a family member or a non-disabled adult that they trust. Only Mr Said mentioned that his daughter has a support worker who takes her out for leisure activities once a week. He said:

> I hate it that on this island they never go out with non-disabled persons.

This issue was also discussed in the focus groups with disability organisation representatives. Pauline Magro said:

> Once they leave school you never see their school-friends any more.

Some persons with intellectual disability meet with workmates socially, while others only attend activities held by disability organisations. Some may be forced to accompany their parents for the latter's social activities, such as dancing and bingo. The alternative would be for them to stay on their own at home, and the parents would be worried about that. But, as Silvia Bonello remarked, the disabled person:

> has to sit there staring at a bunch of 50-year old women playing cards. How many young people can enjoy something like that?

Joseph Borg mentioned a case of someone who was smoking in a bar and when the police entered he gave his cigarette to a person with intellectual disability who appeared to be the one doing something wrong. He said 'it's not easy to draw a line'.

Some said that parents need to overcome the fear they have of allowing their adult children with intellectual disability to do certain activities. For many parents, it is the first time that their daughter or son does something that is difficult. If all goes well, then they are allowed to do the activity again. A staff member of a day centre described how, when they organised a live-in, the parents of one service-user only agreed to her participation on condition that they could telephone her. The staff remarked on how on the first day the service-user's mobile phone did not stop ringing but on the second day they did not call again. Pauline Magro described parents, including herself, as having to struggle to give their son or daughter 'a certain amount of freedom'. This freedom, she says, is weighed against safety by parents:

> Perhaps if I trust her she will be more responsible. ... But I'm afraid that if something happens to her ... after all, she is my daughter ... That's why I struggle

within myself, because I can't keep them wrapped in cotton wool. ... But should I deny her these opportunities just because I'm afraid? (Pauline Magro)

Sometimes the activity is in a sheltered environment. Francesca Zarb, for instance, noted some parents' reluctance for their adult children to attend occasional evening activities organised by the day centre. She explained how the family settle into a routine and find it difficult to get out of it, partly because parents feel they have to make an extra effort to prepare their son or daughter for a change in that routine.

Some parents ensure that their adult children with intellectual disability enjoy mainstream leisure activities. For instance, they organise transport for their children to go out as a group. Or, as mentioned by Damian Pisani, a person with intellectual disability goes to a restaurant with their friends where they are known by the restaurant owner. Other activities are segregated. One parent-led association organises disco parties and the parents try to find young, non-disabled volunteers to keep an eye on things, but it is difficult to find such volunteers and often it is still the parents themselves who take care of things. Steven Farrugia raised a very important point on this matter when he asked whether people with an intellectual disability:

> prefer to do so because they're comfortable with that or is it because society out there isn't inclusive? ... I've got a lot questions in my mind about this subject and that's why I become very agitated. One needs to ask whether they go out in a group because that is how they feel safe, or if it is because they're happy to do so.

Intimate relationships

Only three of the 17 persons with intellectual disability who participated have a boyfriend or girlfriend. But they do not always meet up as much as they wish to. Pierre meets his girlfriend for a coffee close to his home. But when he goes out with his parents, his girlfriend does not go out with them. Christine has a boyfriend but she only meets him once a fortnight when they go out with their group. Kevin said that his parents are willing to support him to get married but his girlfriend's parents are not. The others have mixed feelings about intimate relationships. For example, Silvan said that 'I would like to find a girl and start a family', but Tyler said his former girlfriend gave him too much trouble 'so it's better not to have anyone'.

Some parents actively support the relationship. When Mrs Aquilina is not at home and her son is going to meet his girlfriend, she sets the alarm for him so that he knows when it is time to go out. This reflects findings by Azzopardi-Lane (2011) that there are also people with intellectual disability in Malta whose relationships are taken seriously by those closest to them.

The organisation representatives mentioned how relationships of persons with intellectual disability very often are not taken seriously, as many focus group members remarked. Veronica Bugeja said that 'People say, "How cute!", "Aren't they sweet!" We go on seeing them as children'.

Public transport

The use of public transport has an effect on different aspects of life – being able to work, continue to learn, go out with one's friends, meet up with one's girl/boyfriend, and so on. Of the 17 persons with intellectual disability who took part, six said that they use buses on their own.

There are persons with intellectual disability who do not use the bus because of some difficulty. Mrs Aquilina said that her son only goes out on his own to places close to home. When he uses the bus, he gets distracted and does not know at which stage to stop. On the other hand, Mrs Fenech said:

> I never thought my daughter would be so capable of using the bus on her own. When she has to go to a new place, she never gives up. She asks people for directions and somehow she gets there.

The organisation representatives said that many parents do not let their adult children with intellectual disability use the bus on their own. Some parents ask about door-to-door transport before allowing their children to attend an activity.

Money

Whether a person with intellectual disability has enough money in their pocket is also an indicator of the degree of overprotection in their lives. Persons with intellectual disability cannot always spend their money how they like. Disability pension cheques are written out in the parents' name, which means that they cannot go to cash them on their own. There are parents who keep the pension themselves and give pocket money to the person with intellectual disability. Reactions to this arrangement varied. Nikita said that the money that her mum gives her is not enough, but for Eric and for Mark it is.

Some persons with intellectual disability have a bank account. Sandro said that he withdraws money on his own from his account but Tyler mentioned that he goes to the bank with his father:

> I can go on my own but the people at the bank tell me not to come on my own because there are certain things that I don't know ... I know certain things but not everything.

In the case of Mark, it is his mother who withdraws the money for him, and Silvan said that his salary goes into his father's bank account and then his father gives him money. He said this arrangement works because he always has enough money.

Some restrictions are motivated by the difficulties experienced by the person in managing money. Some parents mentioned that their adult chil- dren do not know the value of different notes and coins. Some parents pro- vide enabling support, for example by putting different notes and coins in different parts of their purse or wallet. Mr Schembri said that they have an agreement with their bank for their son not to withdraw more than e50. In Mrs Micallef's case, her daughter has a small amount on her debit card and she uses it when she goes shopping. That way she does not have to check the change. Mr Schembri's son and Mrs Micallef's daughter both work, so the money that is managed for them is from their wages. Mr and Mrs Zammit also said that they manage the money their son earns as he

spends everything he has.

The disability organisation representatives agreed that there are few persons with intellectual disability who have easy access to their money and who use money on their own.

Mobile phones

Mobile phones are seen as a good way for persons with intellectual disability to stay in touch with their parents while they are out. But there are some persons who, when they go out to meet their friends, their mum keeps call- ing to see if everything is all right. These persons feel that telephoning once is enough. Helen mentioned that her mum calls once 'so that they don't have to worry', while Paul calls himself, and also Tyler if he is going to get back home late. Silvan too mentioned that his parents call to see how he is:

> They tell me 'be careful' but they don't pester me.

But Nikita said:

> It's better if we have our own place. I don't like my mum calling me all the time to see where I am.

Pierre said his girlfriend's mother keeps calling: I cannot enjoy time with my girlfriend in peace. ... She keeps ringing her daughter

> to tell her to take care, as if I cannot take care of her myself.

The parents spoke more about the support that their daughters and sons with intellectual disability need to use their mobile phones. Some said that their children did not know how to control the credit on their mobile phone. Others that their children do not like being called because they think that this uses up their credit. Mr Schembri said that his son has two mobiles, one of which does not have a camera. This is the one who takes to work because he was taking photographs of his co-workers and putting them on Facebook.

On the matter of frequent phone calls by parents, many organisation representatives mentioned that parents also telephone their non-disabled offspring frequently when they begin to go out alone, but the calls generally subside. For example, Francesca Zarb said that when her non-disabled son went out alone by car for the very first time she rang him up constantly. 'And then gradually I didn't keep ringing.' Noella Schembri also remarked that she frequently calls her non-disabled daughter.

This section has presented a summary of the main findings. The full report and easy-to-read summary can be downloaded.[1] We encourage you to read the report and to make your own reflections on the findings.

Reflections on overprotection

Obstacles that hinder disabled people from participating actively in their communities and from living life on their own terms can be material (such as inaccessible physical spaces and

information) or intangible (such as negative attitudes). There are also other types of obstacles. One of these is the wish, of parents as well as others, to safeguard the well-being of the adult with intel- lectual disability in a world that is perceived to be largely hostile to them and inadequate to meet their support needs to make their way through complex processes and practices which those around them tend to take for granted, such as using public transport or checking the change in a shop. Thus, very often, overprotection is hidden behind well-intentioned actions aimed at sustaining the well-being of people with intellectual disability.

The following is what Isabel has to say about the need to find a balance between keeping a person safe and not overprotecting them:

> For me, protection means that parents do the right thing. For example, Mrs Aquilina doesn't allow her son to use the bus on his own for a good reason, since he doesn't know which stage to stop on. So she is protecting her son. But I believe that if her son can have a support worker who can teach him how to use the bus, he is capable of learning this if he gets the necessary support. In Malta we have very few support workers to teach persons with intellectual disability. I too need a support worker and am on a waiting list. I would like to learn how to do the housework but don't have anyone to teach me. It is not right for me and other disabled persons who would like to learn.

> Our parents love us, but when they do overprotection it is bad. For example, if my friend wants to go out for a meal and return home late, she can take a taxi. But her parents are afraid that the taxi driver might do something, as she would be on her own with him. They have their reasons to be afraid – after all so many bad things happen to people. But these things can happen anywhere. Another example is another friend who can only meet her boyfriend in places close to her home. She would like to visit his hometown, but her parents don't want her to. They tell her it's too far away. Many parents of persons with disability are afraid of their children using buses. I can say that many parents do some overprotection, some more and some less. They are afraid something will happen to the disabled person. But they shouldn't be afraid.

Therefore, it is the response to the support needs that are experienced by adults with intellectual disability which is the key to avoiding overprotection and to promoting enablement. Examples have emerged from our research of people with intellectual disability who are supported by others, including by parents who use specific strategies to facilitate the social inclusion of their adult sons and daughters with intellectual disability and their ability to make choices and act on them, while safeguarding their well-being. Examples have also emerged of staff in various organisations encouraging parents to become less overprotective. But the pattern that consistently comes into view is of adults with intellectual disability being held back from being included in society, from participating in mainstream activities, and (most importantly) from living their own life on their own terms, in the name of keeping them safe from harm. As persons working in the disability sector, either in a professional capacity or as persons with disability ourselves, the issues raised by the participants in the focus groups are also ones that we have witnessed or experienced ourselves.

From the analysis of the research findings, three main themes have emerged on the issue of overprotection and regulation: living structured lives, hindered development, and continued dependence on the family. The following discussion of these themes sheds light on the factors that control the lives of people with intellectual disability in a stifling manner and the ones that promote enabling support.

Living structured lives

Even while they experience overprotection, people with intellectual disability do engage in various activities – including sometimes employment, leisure activities, and close relationships with their peers. But these activities are done under the watchful eyes of others within pre-determined structures. While these structures offer a degree of choice and self-expression, the options available are often limited and set by others – what they have is a menu of options to choose from, as Hollomotz (2011) argues. Various other images come to mind to describe the lives of many people with intellectual disability, such as the cotton wool mentioned by one of the parents in the focus groups. The research findings as well as our own professional and personal experiences also made us think of the image of a caged bird who knows how to fly and wishes to fly but unfortunately remains locked in its cage.

Many persons with intellectual disability attend day centres, which offer them opportunities that they greatly value. But for those who wish to extend their life experiences to engage in mainstream activities, the day centre can be restrictive. Interestingly enough, staff who work in day centres as well as with other service providers who participated in our research are very much aware of the need for the persons with intellectual disability they work with to become more independent and more included in mainstream age- appropriate activities. As seen earlier, there are instances where staff actively create opportunities for the persons they are working with to be given greater choice in their lives, including sleeping away from home, and working. This is in line with Witsø and Kittelsaa's (2018) discussion of the role of professionals in enabling people with intellectual disability to active adult lives.

In some cases, parents resist these opportunities for their adult sons and daughters with intellectual disability. But some of those who participated in the research spoke of their and other parents' struggles to ensure that in car- ing for their daughters and sons they do not provide the level of protection that is usually associated with young children, thus infantilising them (Capri and Swartz 2017). Significantly, as seen in the findings, it is usually the first time that parents are so reluctant. If all goes well, the person with intellec- tual disability participates in that activity again. This usually happens when there is support provided by staff or volunteers whom the parents trust. Existing structures can therefore also be used to provide enabling support. Furthermore, the change from controlling in a stifling manner to providing enabling support can be done in steps which enable persons with intellectual disability to acquire new skills, and their parents to get used to these persons being more independent.

Activities organised by non-governmental organisations were reported to play a vital role in enabling people with intellectual disability to have an active life. Sometimes these activities occur in a segregated setting. There is nothing wrong with this as long as it is what the person with intellectual dis- ability chooses to do. Making someone do something in the

mainstream of society because this is the 'normal' thing to do can create its own problems. This is shown by Wilson (2003) in relation to the obligation of finding 'real' jobs for people with intellectual disability. On the other hand, one must ask whether the person prefers to be in a setting specifically designed for people with intellectual disability because they find mainstream social settings unsafe. This reflects Steven Farrugia's observation, quoted earlier, that people with intellectual disability may prefer to go out in a group because that is how they feel safe.

Moreover, it is true that non-governmental organisations provide structured activities, but they are structures that are enabling. After all, even parents who promote an independent life for their adult children with intellectual disability provide a structure: Mrs Micallef's daughter being taught how to use the debit card, Silvan being told to socialise with people who do not take advantage of him, parents organising transport for a group of people with intellectual disability to go out together. These instances enable people with intellectual disability to have choices of what to do with their time and money, while ensuring that the necessary support is there.

Structures are enabling when they provide the support that is necessary for a person with intellectual disability to lead their own lives, providing a balance between autonomy and protection, as argued by Barron (2001) cited earlier. Parents who create these enabling structures or whose sons and daughters participate in enabling activities set up by different organisations are no less aware of their support needs than the parents who overprotect. For example, Mrs Aquilina supports her son in meeting up with his girlfriend, but puts a limit on his use of public transport since he does not know which stop to leave the bus at. What is key is the response to the difficulties faced by persons with intellectual disability.

Hindered development

For the parent of an adult with intellectual disability, responding to support needs by wrapping in cotton wool can seem like the natural and logical response, especially because of the duty of care that arises naturally from their relationship with their children. This can happen with parents of children with other disabilities as well, as shown for example by Holmbeck et al. (2002) and Munro et al. (2016). Such parents often continue to carry this duty well into the adulthood of their sons and daughters (see Birtha and Holm [2017] and Hewitt et al. [2013] cited earlier). In fact, this point was made by many of the parents who participated in the research.

A continued level of unnecessarily high protection has a negative effect on opportunities for people with intellectual disability to develop their abilities and fulfil their potential, let alone for them to be able to do so on their own terms. It also affects their confidence negatively – being told, directly or indirectly, that one is not capable of doing this and that can make one very insecure (Munro et al. 2016). The difference between protecting someone from risk and underes- timating their abilities is not always clear. To take an example from employ- ment, blocking opportunities for a person with intellectual disability to work can be motivated by a fear of the person getting hurt, through mistreatment or because of an accident, or the perception that the person is not capable of working. These concerns do need to be taken into consideration – occupational health and safety is important for all workers; and no worker, disabled or not, should be expected to carry out work which is not

within their range of abilities or for which they have not received adequate training. But when there is over- protection, rather than finding constructive ways of addressing these concerns, the reaction is to keep the person with intellectual disability out of employment completely. This reaction hinders the growth, on a personal and social level, of the person with intellectual disability.

Furthermore, as can be seen from the findings, when it comes to work, some parents aspire to a tailor-made job for their adult children with intel- lectual disability, with door-to-door transport, working hours that fit into their own timetable, and a job description that the parents are happy with. Some persons with intellectual disability end up working in sheltered environments – for example, vocational placements which are temporary, or in the local council or parish of their village where they are already known, and accepted by, their co-workers. There is of course nothing wrong with working in such places but when the jobs given only amount to 'make- believe' work, as quoted earlier, then the situation is problematic, even more so when the person is capable of working in more open environments and of doing other jobs, including better paid ones.

Another issue connected to hindered development is related to socialising, where people with intellectual disability encounter many barriers. Many of the participants in our research spoke of the frustration that these barriers cause. As described by Mirfin-Veitch (2003) in her literature review about the relationships of persons with intellectual disability, they have limited opportunities to go out on their own and to choose their own friends, much less to develop intimate relationships that are often blocked by parents.

Sustained dependence on the family

As can be seen from the discussion of the research findings so far, many people with intellectual disability in Malta tend to lead structured lives that hinder them from developing their potential and to be able to make choices about their own lives. This structuring also sustains the person's dependence on the family, and therefore also becomes self-sustaining: the more the person with intellectual disability is overprotected, the less they develop independence-related skills, and the more they continue to be dependent on others, especially the family and primary caregivers.

The strong ties of Maltese young people with their parents, discussed earlier, were also highlighted by the participants in our research. Within this context, it is not surprising that people with intellectual disability keep very strong ties with their parents, and vice versa. These ties are shown, for example, in the persistent checking on people with intellectual disability by telephone calls from or to their parents, especially when they go out with friends. The use of mobile phones by people with intellectual disability is in fact very interesting. Those who only go out with their families tend not to have a mobile phone. As Hemm, Dagnan, and Meyer (2018) cited earlier point out, parents are concerned about the safety of their adult children with intellectual disability. Therefore, mobiles become a means of keeping check on people with intellectual disability rather than for them to communicate with their peers.

Given that people with intellectual disability continue to need support in their daily lives, the strong ties that they have with their parents also become ties that sustain dependence

of the former on the latter. Another way in which the strong family ties come out clearly is that just because a person with intellectual disability works and uses the bus, it does not always mean that they are independent. There are those who use the bus to go from home to work and from work to home only. This happens when the parents tell them what they should do and where they can go. It also happens when the person with intellectual disability does not have any friends outside work.

Cultural factors can also continue to sustain dependence on the family in less obvious ways. Maltese people rely on getting around by driving them- selves in their own car to a much greater extent than they use buses (Malta Independent 2017). Young people are given lifts by their parents until they can drive and have their own car. For those who have an intellectual disabil- ity, this last option is hardly ever available and, if they do not learn how to use the bus on their own, they continue to be dependent on being given lifts long after their non-disabled counterparts have become independent in this respect. The lack of ability to travel independently has serious consequences on the person's autonomy more generally (Beart et al. 2001) – meeting up with friends, attending social activities, following training and educational courses, and working are seriously compromised. Where parents support their adult children with intellectual disability to use the bus on their own, the latter can lead freer lives. This can be seen from the example of Mrs Fenech who was surprised by how much her daughter managed to accomplish with using the bus on her own. It is significant that Mrs Fenech's daughter was provided with support from a personal assistant to learn how to use the bus. The need for such services came out clearly in the focus groups. And as Gauci states, there is a need for personal assistant services in Malta:

> that make it possible for the disabled person to live an independent life, perhaps not by doing everything on her own but by having the opportunity to decide and choose herself what she will do in her everyday life and how she will do this.
> (2017, 595; our translation)

Continued dependence on the family of origin undermines one's ability to achieve full adult status – in the eyes of society and in the practice of one's daily life. The tendency for adults with intellectual disability to be seen as adolescents, or even children, emerges clearly from our research, for example in the way they continue to depend on others to manage their money or be given permission to attend an activity. In the area of intimate relationships, the issue of people with intellectual disability being seen as childlike is highly emphasised. Given that sexual maturity (physically, psychologically, and emotionally) is one of the clearest markers of adulthood, it is significant that it is in this very area that adults who have an intellectual disability were identi- fied as being seen as children. This indicates a cultural resistance to consider them as adults that goes beyond the need for enabling structures and support.

In one of the focus groups, Noella Schembri described overprotection as 'another disability', and therefore a disabling barrier. Removing this barrier entails providing the services envisioned by Vic Finkelstein (1998) that enable disabled people 'to attain a greater degree of independence than otherwise might be possible for them if left to their own resources' (unpaged). People with intellectual disability cannot rely entirely on resources available within the family to live life on their own terms. They also need personal assistance services which, as Askheim (2003) and Williams, Ponting, and Ford (2009) discuss, need to take into

account their specific support needs, and ensure that the way the service is managed does not undermine the person's ability to exercise choice and control in their lives. With these points in mind, we conclude this presentation and discussion of our research with four ideas that we thought of together.

Conclusion

A tug of war

We could see how very often there is a constant struggle. Sometimes it is a struggle between persons with intellectual disability who want to do some- thing and their parents who are afraid that they might get hurt. Sometimes, it is a parent who struggles between the instinct to protect and the wish to allow their son or daughter with intellectual disability to follow their own wishes, especially when the latter wants to do something for the first time. We thought of these struggles as a tug-of-war

Getting the balance right

Parents are right in wanting to protect people with intellectual disability from situations in which they may be harmed. Parents are mostly afraid that their disabled adult children may be mistreated by those around them. Unfortunately, there are times when such mistreatment happens. But this does not mean that parents should lose all trust in society, and the need for protection does not mean that there should be overprotection.

What people with intellectual disability need is support. They need support to learn how to do things on their own as much as possible, and support from personal assistants who accompany them to do those things they cannot do on their own. If the person with intellectual disability has a personal assistant, the parents do not worry.

Parents also need support. They may need support to better under- stand their fears and how to deal with these fears in a balanced way rather than also making their disabled daughters and sons afraid. They also need support to understand the difference between looking after the well-being of a person with intellectual disability and being overprotect- ive. It is important that they have guidance, for example from social work- ers, who can help them get out of overprotecting. Parents can also meet to learn from each other about how to achieve a balance between protection and enabling support. It is also important that they listen to what people with intellectual disability say about the support they would like to have.

Working together

When persons with intellectual disability and their parents have the type of support that they need, they can work together instead of being in a strug- gle with each other. This benefits everyone because working together means that people with intellectual disability have the support they need to make their wishes a reality, and that their parents' concerns are listened to and any action that is necessary is taken. Therefore, everyone works together for the same aim.

The homing pigeon

18

When everyone works together, and when there is a balance between protection and support, people with intellectual disability can live their life on their own terms. This does not mean that they are free to do exactly what they want all the time. Nobody lives like that. But it means that they have support and structures which promote their independence instead of making them continually dependent on others. It also means that these support and structures promote empowerment and enable people with intellectual disability to follow their own wishes. These structures include self- advocacy groups, personal assistant schemes, and community-based services. This made us think of the homing pigeon, who is not kept in a cage but is free to fly while always having a home to go to where it is cared for.

Note

1. Available from 31st August 2018
https://www.um.edu.mt/socialwellbeing/disabilitystudies/projects/inclusiveresearchproject

References

Abela, A. 2016. Family Life. In M. Briguglio and M. Brown (eds), *Sociology of the Maltese Islands*, 17–48. Luqa, Malta: Miller.

Abela, A., R. Farrugia, C. Casha, M. Galea, and D. Schembri. 2013. *The Relationship between Maltese Adolescents and Their Parents*. Malta: Department of Family Studies, University of Malta.

Aġenzija Sapport 2018. *Biennial Report* 2016-2017. Santa Venera, Malta: Aġenzija Sapport.

Aroni, D., J. Hegarty, and A. Philalithis. 2013. "Expectations of Greek Parents about Employment Opportunities for Their Child with Learning Disabilities: Implications for Social Workers." *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community* 27 (4):357–73. doi:10.1080/02650533.2012.732045.

Askheim, O. P. 2003. "Personal Assistance for People with Intellectual Impairments: Experiences and Dilemmas." *Disability & Society* 18 (3):325–39. doi:10.1080/0968759032000052897.

Azzopardi, A. 2009. *Understanding Disability Politics in Malta*. Saarbrucken: VDM Verlag Dr Muller.

Azzopardi-Lane, C. 2011. *Sexuality and people with learning disability in Malta: Realities and potential*. Ph.D. thesis, University of Kent.

Barron, K. 2001. "Autonomy in Everyday Life, for Whom?" *Disability & Society* 16 (3): 431–

47. doi:10.1080/09687590120045987.

Beart, S., D. Hawkins, B. S. Kroese, P. Smithson, and I. Tolosa. 2001. "Barriers to Accessing Leisure Opportunities for People with Learning Disabilities." *British Journal of Learning Disabilities* 29 (4):133–8. doi:10.1046/j.1468-3156.2001.00109.x.

Birtha, M., and K. Holm. 2017. *Who Cares? Study on the Challenges and Needs of Family Carers in Europe*. Brussels: Coface Families Europe. Retrieved from http://www.coface-eu.org/wp content/uploads/2017/11/COFACE-Families-Europe_Study-Family-Carers.pdf.

Camilleri, J., and A. M. Callus. 2001. "Out of the cellars. Disability, politics and the struggle for change: the Maltese experience." In L. Barton (ed.) *Disability, Politics and the Struggle for Change*, 79–92. London: David Fulton.

Capri, C., and L. Swartz. 2017. "We Are Actually, after All, Just Children': caring Societies and South African Infantilisation of Adults with Intellectual Disability." *Disability & Society* online. 33(2): 285–300. doi:https://doi.org/10.1080/09687599.2017.1409102.

Cassar, J. 2016. Youth. In M. Briguglio and M. Brown (eds) *Sociology of the Maltese Islands*, 69–82. Luqa, Malta: Miller.

Commission for the Rights of Persons with Disability (CRPD). 2018. *Statistics on persons with disability from the 2011 census*. Retrieved from http://crpd.org.mt/research/.

Dun_er, A., and E. Olin. 2018. "Personal Assistance from Family Members as an Unwanted Situation, an Optimal Solution or an Additional Good? the Swedish Example." *Disability & Society* 33 (1):1–19. doi:10.1080/09687599.2017.1375900.

Eurostat 2015. *Being young in Europe today – family and society*. Retrieved from http://ec.europa.eu/eurostat/statistics-explained/index.php/Being_young_in_Europe_today_-_family_and_society.

Finkelstein, V. 1998. *Re-thinking care in a society providing equal opportunities for all.* Discussion Paper by Vic Finkelstein, The Open University. Retrieved from https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-finkelstein2.pdf.

Friedman, C. 2019. "People with Disabilities' Access to Their Own Money." *International Journal on Disability and Human Development* 18 (1)

Garland, R. 2015. *The impact of the family, church and state on the aspirations of young people with disability in Malta: A cultural perspective*. Unpublished Masters dissertation, University of Malta. Available from https://www.um.edu.mt/library/oar/bitstream/handle-/123456789/6519/15MADIS005.pdf?sequence1⁄41&isAllowed1⁄4y.

Gauci, V. 2017. Konklużjoni. In F. Bezzina *Xejn Dwarna Mingħajrna: 25 Sena Ta' Ħidma Fejjieda u Tibdil Radikali mill-Kummissjoni Nazzjonali Persuni B'Diżabilità. 1987–2013*. Malta: Horizons.

Gilbert, T. 2004. "Involving People with Learning Disabilities in Research: issues and

Possibilities." *Health and Social Care in the Community* 12 (4):298–308. doi:10.1111/ j.1365-2524.2004.00499.x.

Hemm, C., D. Dagnan, and T. D. Meyer. 2018. "Social Anxiety and Parental Overprotection in Young Adults with and without Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 31 (3):360–8. doi:10.1111/jar.12413.

Hendey, N., and G. Pascall. 1998. "Independent Living: gender, Violence and the Threat of Violence." *Disability & Society* 13 (3):415–27. doi:10.1080/09687599826713.

Hewitt, A., J. Agosta, T. Heller, A. C. Williams, and J. Reinke. 2013. "Families of Individuals with Intellectual and Developmental Disabilities: Policy, Funding, Services, and Experiences." *Intellectual and Developmental Disabilities* 51 (5):349–59. doi:10.1352/1934- 9556-51.5.349.

Hollomotz, A. 2011. *Learning Difficulties and Sexual Vulnerability: A Social Approach*. London: Jessica Kingsley.

Holmbeck, G., S. Johnson, K. Wills, B. McKernon, S. Erklin, and T. Kemper. 2002. "Observed and Perceived Parental Overprotection in Relation to Psychosocial Adjustment in Preadolescents with a Physical Disability: The Mediational Role of Behavioral Autonomy." *Journal of Counseling and Clinical Psychology* 70 (1):96–110. doi:10.1037/ 0022-006X.70.1.96.

Irazabal, M., Pastor, C. Molina. M., and C. 2016. "Family Impact of Care and Respite Service: Life Experiences of Mothers of Adult Children with Intellectual Disability and Mental Disorders." *Revista De Cercetare Si Interventie Sociala* 55:7–18.

Laycock, M. 2017. *Concerns over Man's Death in Care*. The Press 19th June 2017. United Kingdom, Retrieved from http://www.yorkpress.co.uk/news/15355244.Concerns_over_ man___s_death_in_care/

Malta Independent 2017. Wonder Why There's Traffic? There's One Car per Adult on the Road. *The Malta Independent* 1st August 2-17. Malta, Retrieved from http://www.inde-pendent.com.mt/articles/2017-08-01/local-news/Wonder-why-there-s-traffic-There-s-one-car-per-adult-on-the-road-6736177307.

Mansell, J., and K. Ericsson. 1995. *Deinstitutionalisation and Community Living – Intellectual Disability Services in Scandinavia, Britain and the USA*. London: Chapman and Hall.

Mill, A., R. Mayes, and D. Connell. 2010. "Negotiating Autonomy within the Family: The Experiences of Young Adults with Intellectual Disabilities." *British Journal of Learning Disabilities* 38 (3):194–200. doi:10.1111/j.1468-3156.2009.00575.x.

Mirfin-Veitch, B. 2003. *Relationships and Adults with an Intellectual Disability. New Zealand: National Advisory Committee on Health and Disability and Donald Beasley Institute*. Retrieved from: http://www.donaldbeasley.org.nz/assets/Uploads/publications/NHC-Relations.pdf.

Milner, P., and B. Kelly. 2009. "Community Participation and Inclusion: People with

Disabilities Defining Their Place." *Disability & Society* 24 (1):47–62. doi:10.1080/ 09687590802535410.

Munro, M. P., Maricela M. M. Garza, J. R. Hayes, and E. A. Watt. 2016. "Parental Perceptions of Independence and Efficacy of Their Children with Visual Impairments." *Journal of Human Services: Training, Research, and Practice* 1 (1)Article 3. Retrieved from https:// scholarworks.sfasu.edu/cgi/viewcontent.cgi?referer1⁄4https://www.google.com/&httpsredi r 1⁄41&article1⁄41002&context1⁄4jhstrp.

Muscat, A. 2017. Action research: *Preparing Maltese football players for migratory based transitions*. Ph.D. Thesis. Liverpool John Moores University. Retrieved from http:// researchonline.ljmu.ac.uk/7141/.

Nind, M. 2014. *What Is Inclusive Research*? London, England: Bloomsbury.

Oliver, M. 2009. *Understanding Disability: From Theory to Practice*. (2nd Ed.). London: Palgrave.

Patterson, I., and S. Pegg. 2009. "Serious Leisure and People with Intellectual Disabilities: benefits and opportunities." *Leisure Studies* 28 (4):387–402. doi:10.1080/0261436090 3071688.

Riddell, S., S. Baron, and A. Wilson. 2001. *The Learning Society and People with Learning Difficulties*. Bristol: Policy Press.

Ryan, S. 2017. Justice for Laughing Boy: *Connor Sparrowhawk – a Death by Indifference*. London: Jessica Kingsley.

Shepperdson, B. 2000. Negotiating adolescence. In D. May (ed.), *Transition and Change in the Lives of People with Intellectual Disabilities*, 55–74. London: Jessica Kingsley.

Walmsley, J., and K. Johnson. 2003. *Inclusive Research with People with Learning Disabilities: Past, Present and Future*. London: Jessica Kingsley.

Walmsley, J., L. Tilley, S. Dumbleton, and J. Bardsley. 2017. "The Changing Face of Parent Advocacy: A Long View." *Disability & Society* 32 (9): 1366–1386. doi:10.1080/ 09687599.2017.1322496.

Williams, V., V. Ponting, and K. Ford. 2009. "I Do like the Subtle Touch': interactions between People with Learning Difficulties and Their Personal Assistants." *Disability & Society* 24 (7):815–28. doi:10.1080/09687590903283407.

Wilson, A. 2003. "Real Jobs', 'Learning Difficulties' and Supported Employment." *Disability & Society* 18 (2):99–115. doi:10.1080/0968759032000052770.

Witsø, A. E., and A. M. Kittelsaa. 2018. "Active Adult Lives for Persons with Learning Disabilities—the Perspectives of Professionals." *British Journal of Learning Disabilities* 46 (1):10–6. doi:10.1111/bld.12207.