

**Over-protection in the lives of people with an intellectual disability in
Malta: research findings**

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This research was funded by the University of Malta Research Grants

November 2017

Introduction

There is a tendency in Malta for persons with an intellectual disability to be over-protected by their parents, other family members and even professional who work with them¹. It is a fact that many people with intellectual disability do require support in their daily lives; however, this does not mean that they are unable to make choices and take decisions about their own lives. They need to have the support they need to make their choices and decisions. Rather than having someone taking decisions on behalf of people with intellectual disability, parents, or other people, should provide support people with intellectually disability to take those decisions.

People with intellectual disability can live more independently. Because being independent does not necessarily mean that one does everything on one's own.² It means taking decisions and making choices and then being provided with the necessary support to help you carry out those activities which one can't perform on your own. More often than not, people with intellectual disability are not provided with this type of support. Frequently, parents, or others looking after people with intellectual disability are afraid that the person is too vulnerable and that they may come to harm if they are allowed to do as

¹ Callus A.M. (2013) *Becoming self-advocates: people with intellectual disability seeking a voice*. Oxford, Peter Lang.

² Finkelstein, V. 1981. *Disability and the helper/helped relationship. An historical view*. In A. Brechin, P. Liddiard, and J. Swain, eds. *Handicap in a social world*. Milton Keynes: Hodder and Stoughton in association with the Open University Press, pp 58-63; Morris, J. 1997. *Care or empowerment? A disability rights perspective*. *Social policy and administration*, 31 (1), pp. 54-60.

they please. In fact, it sometimes happens that people with intellectual disability run into problems and difficult situations. Because this is a real possibility, parents will not want their intellectually disabled offspring, even if these are adults, to take part in activities outside the family home, unless, that is, they are accompanied by their parents or some other person of trust.

The fact that in Malta people with intellectual disability go on living with their parents indefinitely adds to the problem of over-protection. More often than not, as a culture, we assume that parents will go on caring for their intellectually disabled offspring until they are no longer able to do so, or until death. The general belief is that these offspring will go to live in a residential service once the parents, or other family members, can no longer care for them. Few seem to understand the principle, expressed in the Convention on the Rights of Persons with Disability Article 19 (a), that intellectually disabled adults have the right to residential services because they want to live a more independent life than the one they lead with their family:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.³

As these research findings show, over-protection impacts on every aspect of an intellectually disabled person's life as well as that of their family.

³ UN 2006. Convention on the Rights of Persons with Disabilities. Available from <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

Research aims

The main aim of this research was to carry out a study focusing on over-protection in the lives of people with intellectual disability in Malta, the factors which lead to over-protection, and what needs to be done to address the problem of over-protection.

This research project also has the following specific goals:

- to investigate the effect that over-protection has on the lives of persons with intellectual disability;
- to identify what impels parents and other persons who care for people with intellectual disability to over-protect them;
- to identify models of good practice which demonstrate how one can take care of people with intellectual disability and provide them with the support they require without any over-protection;
- to develop recommendations for those who design and offer various services about how to provide support services to families of people with intellectual disability in order to ensure that they do not encourage over-protection;
- to give a voice for persons with intellectual disability, including a voice in the research process itself.

This research has been designed on the principles of inclusion. This means that one works, at the outset, on the assumption that people with intellectual disability are capable of developing many practical skills if they have the opportunity and are provided with the support they require. Moreover, inclusive

research is based on the social model of disability which focuses on socially constructed barriers which constrain disabled people⁴.

Another very important principle worth keeping in mind regarding inclusive research is ensuring the full participation of people with intellectual disability in the research process⁵. In fact, the present research project was designed by a person with an intellectual disability and a university lecturer. They then proceeded to carry out the research itself together. People with an intellectual disability were also involved in the discussions which took place during the research process, especially as part of focus groups, during the discussion and presentation of research findings and in the production of the present report.

Besides all this, inclusive research methods lay great emphasis on the importance of the life-experiences of people with intellectual disability. Therefore, very often this type of study uses qualitative research methods because this has been found to be a suitable method for examining different aspects in an individual's life.

⁴ UN 2006. Convention on the Rights of Persons with Disabilities. Available from <http://www.un.org/disabilities/default.asp?navid=12&pid=150>.

⁵ Nind, M. 2014. *What is Inclusive Research?* London: Bloomsbury; Walmsley, J. & Johnson, K. 2003. *Inclusive research with people with learning disabilities: past, present and future*. London: Jessica Kingsley.

How we carried out the research

The research took place through the use of focus groups:

- three focus groups made up of people with intellectual disability: two in Malta and one in Gozo. Seventeen people with intellectual disability in all.
- three focus groups made up of parents of people with intellectual impairment: two in Malta and one in Gozo. Fourteen parents in all.
- four focus groups made up of people who work with people with intellectual disability: three in Malta and one in Gozo. In all, eighteen representatives from non-government organisations.

Focus group meetings took place between September 2015 and September 2016, after the researchers had been granted permission to proceed with the research process by the Ethics Research Committee (UREC) of the University of Malta.

In this report, participants are referred to by pseudonyms, as follows:

- persons with intellectual disability are referred to by a first name (Pierre, Helen, etc)
- parents are referred to by a title and surname (Mrs Fenech, Mr Zammit, etc)
- staff members are referred to by a name and surname (Alice Gauci, Damian Pisani, etc)

What did the research show us?

The world of work

Of the people with intellectual disability who participated in the focus groups, a few said that they work full-time, and a few said they work part-time. Many participants attended day centres and a few said they stayed at home watching television. This was repeated by parents' groups and people involved in organisation working with people with intellectual disability. All the people who took part in the research worked and lived in Malta. Some of the persons living in Gozo said that they had had work experience through various schemes, but that they were not retained at their place of work. It is possible that there are some persons with intellectual disability in Gozo who do work but who did not participate in the present research project.

Opportunities for people to find work

During the last ten years the type of work undertaken by people with intellectual disability has changed. In the past they mostly found employment in factories, but nowadays, especially in the last two years, there were job opportunities in offices and in the tourism sector. There are also people who work in construction, as receptionists, as office help, manual labour, kitchen help, and

shelf-stackers in large shops and supermarkets. The vast majority of those with jobs are in part-time employment.

Those people with intellectual disability who participated in this research project and who are employed, work in the following areas: factories, hotels, hospitals, homes for the elderly, sheltered workshops, disabled persons' organization. One individual was undergoing job-training during the time the focus groups were meeting.

One point which was raised and which may provide an added incentive and increase opportunities for disabled people seeking productive employment is the fact that now disabled people who work can still benefit from the disability pension. Another point raised was the enforcement of the 2% Act, in other words the law which states that anyone employing more than 20 people must employ at least one disabled person, or at least 2% if they employed 100 people or more. On the other hand, some people observed that certain disabled people are being employed purely to ensure that employers fulfil the required quota. Thus, these people are given repetitive work which offers no opportunities for career advancement. In the words of Steven Farrugia: 'we just park them there'.

It helps a great deal when an employer has a person focused on inclusion and diversity, because this provides a positive basis on which to build.

The benefits of employment

Another point raised during the discussion on employment was the fact that an individual doesn't always just work for a salary, although paid employment does give the individual more independence because they have more money to spend. Joseph Borg explained that more emphasis should be laid on the social aspect of employment, and not always focusing only on the economic aspect, 'it isn't just a question of money'. Participants observed that, among the advantages attached to employment, was the possibility of building on lessons learnt at school, otherwise what was learnt at school may be lost. Furthermore, employment also encourages the development of other skills, such as the person learning to travel alone by bus in order to get to work.

Some observed how important it was that parents are taught to understand the advantages to be had when their children are employed.

Different experiences in the world of work

Those who were employed said that they were happy at their place of work because they worked with people who loved them very much. Their colleagues treat them well and some also mentioned that their colleagues even looked

after them. For example, Mrs Aquilina mentioned the fact that her son's workmates saw to it that he didn't over eat.

But participants also spoke about different negative experiences. For example, an intellectually disabled person observed that he had had a number of jobs, but that he was never kept on; another person who was on a job scheme is not looking for work. People who are on a job scheme or undergoing training but are then not employed feel very dejected. A member of staff, Josephine Carabott, also spoke about this issue. She recounted how a client of hers had wept bitterly when her employment was terminated after the scheme she was on expired. Josephine Carabott asked: "What do you do? Crush their hopes and dreams completely? Or give them a glimpse of what they can have?". Mrs Borg said that her son had been given job and had even bought a work uniform, but then he wasn't accepted. Naturally, he was extremely disappointed.

Participants also observed that placement opportunities within a job scheme are plentiful largely because they are unpaid. But the moment it is suggested that the employer employs and pays the disabled person a salary, then they bring about all kinds of excuses, such as: 'because we use a lot of machinery here, because they may injure themselves, and similar excuses. It may be that the employer is being sincere when they mention these issues', but, as seen state later, employers need more awareness concerning this sector.

Another problem which was mentioned with regard to placements was that very often these take place within a very sheltered environment. For instance, individuals may be placed in local councils, or parishes where the individuals live, thus the individual would be surrounded by people who know them and who take care of them. On the other hand, the placement may take place in sheltered workshops where disabled persons all work together. Of course, all this is very good, but, as focus group members observed, the fact remains that disabled persons continue to live and work always and ever in an environment of over-protection. Consequently, one must take good care that these employment opportunities do not consist simply of 'make-believe' jobs.

Another point that was mentioned in one of the focus groups in Gozo is that the work experiences offered should reflect the employment opportunities that exist in reality. For example, in Gozo many jobs are in the tourism sector but disabled people are offered very few placements and training in this sector. Instead, they do factory outwork tal-fabbriki when in reality there are very few opportunities in manufacture.

Among those who work, many are employed doing repetitive tasks. This type of job doesn't offer the scope of furthering one's career. Other people, with different disabilities, also fail to advance in their careers. One of the reasons for this is lack of training, which often means that disabled persons in employment will not have the opportunity to develop their skills. Or else, the

disabled person themselves, or their colleagues, do not believe in the individual's potential and therefore the person is never provided with the opportunity to develop that potential. This is known as the 'self-fulfilling prophecy'⁶.

Some participants raised the point that some employers do not know that an intellectually disabled person has the potential to advance at their place of employment, or else employers may not know how to adapt the workplace to cater for the disabled employee's needs, or how to provide the disabled person with training to help them cope with different work. The focus is, very often, on what the person cannot do, rather than what needs to be done in order to help the disabled individual to achieve more.

There are also disabled people who have to leave their place of work because they will have been badly treated, especially by their work colleagues. Pauline Magro observed that people with Down syndrome are not bullied because they're '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.'

⁶ Merton, R.K. 1968. *Social Theory and Social Structure*. New York: Free Press.

An issue raised by Mr and Mrs Zammit highlighted the fact that an intellectually disabled person whose impairment was not immediately apparent often did not find any support at their place of work, whereas someone whose disability showed clearly usually found help immediately. On the same subject, Francesca Zarb observed that someone with a mild intellectual disability might find it difficult to reveal that they have an impairment: 'Because if they speak up they may be laughed at ... but if they don't speak up people won't understand their needs as disabled persons'. Annalise Scerri stated that these persons also experience more bullying because other people may not understand why the person is receiving more support.

Why more people with intellectual disability aren't in employment

A number of reasons have been given why so many people with intellectual disability are unemployed. As we saw earlier, some people with intellectual disability were in employment, but they may have had to leave their place of work because of bad treatment by colleagues. Some mentioned problems stemming from parents, while others identified problems created by employers. Another problem raised was that people with intellectual disability may not be working because they don't find work which is suitable for them, or else they may not be provided with modifications appropriate to their needs.

Where parents are concerned, some people raised the point that many parents do not believe that their intellectually disabled offspring are able to hold down a job. As Silvia Bonello put it, they say: 'What does he want to go to work for?'. Pauline Magro stated: 'very often it comes from the parents. They say so openly.' Or else they don't work because the parents are afraid that they may be abused, bullied or injured at their place of work. For example, they may be given more than their fair share of work 'because he won't complain'. So parents tell their intellectually disabled adult children: 'it's better if you stay at home.' Other parents may not be against the idea of their intellectually disabled children going out to work, but the same parents may be fearful of certain types of jobs, such as kitchen work, which involves using knives.

Others mentioned parents who were not interested in seeing their children work. Research participants noted how these parents didn't recognise the benefits of employment, because if they did they would be better motivated to help their children find work. They place their child somewhere and put their mind at rest, they opt for sheltered provision. There are intellectually disabled young people who go from one training course to another. As Annalise Scerri put it, 'the main thing is that they're somewhere sheltered'. Many participants pointed out that we need to remove the obstacles that exist in people's minds thanks to mistaken beliefs because this is the main reason why people with intellectual disability don't find work. Participants noted that we need to rid

ourselves of the culture of sheltering so as to enable disabled individuals to develop their own skills and abilities.

When parents don't come to terms with their children's impairment, it is the latter who suffer. A clear example of this was when a day centre representative explained that when clients from the centre were on a work placement, the person who completed the training with most success was the one whose mother told staff at the centre that her son was incapable of doing anything. Josephine Carabott said that sometimes you needed to be an advocate for the clients and you need to show parents that their attitude is holding their son, or daughter, back. 'You mustn't be afraid to push'. One other issue raised was that some parents objected to their offspring working alongside migrants from Africa.

Some other job-related issues raised included arrangements people with intellectual disability have to make in order for the individual to be able to go to work. One of these problems is related to transport. Their parents want to take give them a lift to work themselves but they won't be able to because the hours of work of the intellectually disabled person have to be adjusted to the suit the parent's particular timetable. Transport-related issues will also be raised later on in this report. Participants also declared that some parents want to choose their child's job, somewhere close to home and with hours convenient to them. There were even instances where parents stopped their son or daughter from

taking up a job opportunity because the former weren't happy with the arrangements, for example, the type of work, or because the place of work was too far away.

Then there were others who mentioned problems created by employers. One of the problems mentioned was the stigma which is still attached to persons with an intellectual impairment and because of which employers imagine that these people are incapable of working. There were participants who even went so far as to state that some employers are afraid of employing people with an intellectual impairment. This comes about because of lack of awareness about this type of impairment. As Joseph Borg said, employers argue: 'if something happens to him what shall I do?'

Given the opportunity, those who are able to work generally get on well. But there are employers who won't want to employ people with an intellectual impairment because they will have had a previous bad experience, because they may have been assured that the disabled persons was able to perform a task, whereas in fact they aren't able to. Consequently all people with intellectual disability are stigmatized. Damian Pisani put it like this: 'Physical disability? Alright, we'll manage somehow. Intellectual disability? No, not them'. Sometimes it's as though persons with an intellectual disability are forgotten. When you bring up the subject of employment, non-disabled people think

you're only referring to people with a physical disability and not to people with intellectual disability.

Mr and Mrs Zammit said that their son worked with a wholesaler and that he used to accompany the delivery man in his van, and that he did all the carrying because his friends used to take advantage of him. When their son hurt his back his employer sacked him because he didn't want any problems. He told the parents that he preferred to make financial contributions to non-government organisations that work with disabled persons rather than employing an intellectually disabled person himself.

Helping out at home

Helping out with chores in the home and running errands is important because it helps an individual become more independent. Almost all the parents said that their intellectually disabled adult children hardly ever helped out in the home. But there are disabled persons who help out with housework: they clear up, dust, make the bed, wash the floor, wash, hang out and bring in clothing, and some even help out in the kitchen. There are people with an intellectual impairment who go shopping to the grocer's, or their mother places an order, for instance, meat from the butcher's, and they'll go and collect it.

Some members of staff identified clients who help out at the centre, with support, if necessary and who, very probably, aren't given the opportunity to help out in the same way when they're at home. Some parents said one needed to know how to ask an intellectually disabled person to perform a task. And one parent said it depended on how they are taught, since non-disabled children were just as likely not to help in the home. Another parent observed that her experience showed that boys with an intellectual impairment had more of a tendency to help out.

Going out with Friends and Leisure Activities

There may be people with intellectual disability who work, but during the rest of the time they never have much opportunity to enjoy leisure activities. They go from work to home and from home to work and they only go out with the family. But, as Joseph Borg said, the social life is just as important as work.

Family outings

In fact, many focus group participants stated that many people with intellectual disability only go out with the family, because they don't have friends they can go out with. As long as they're at school they are invited to parties and other activities with the other children. But after school they spend their time in their restricted circle. In the words of Pauline Magro : 'Once they leave school you never see their school-friends any more. And you can't blame them.'

Many people with intellectual disability go out with their family, for example with their parents, or their non-disabled siblings and, in some instances, with their siblings' friends. Research findings indicate that this happens most frequently in Gozo where the majority of people with intellectual disability have a tendency to go out only with their own family groups. Of the people with intellectual disability from Gozo who participated in the focus group only one went outside his locality and has sometimes crossed over to Malta on his own. Parents and members of staff who participated in the focus groups in Gozo also confirmed

that people with intellectual disability hardly ever venture outdoors alone in Gozo. They added that these people usually stay within their 'comfort zone' and don't really have much of an independent social life.

Sometimes people with intellectual disability go with their parents so that parents can stay out late and at the same time rest their minds that their children are safe. This can raise problems, especially if the activity the parents are attending isn't of much interest to their children, for example, ballroom dancing, or bingo. In the words of Silvia Bonello, the disabled person "has to sit there staring a bunch of 50-year old women playing cards. How many young people can enjoy something like that?". But then there was also Helen who said that she enjoyed going out with her mother.

Going out with other people

There are other people with intellectual disability who do have friends, but their parents won't allow them to meet up, for instance at the local club. Other parents will let their disabled children meet with their work-mates, but not with other friends. Then there are those who go out with different groups who organize activities for disabled people, including activities organized by disabled people's organisations themselves, such as the Living Ability Not Disability (LAND) group and the *Grupp Flimkien Naslu* (the Together We Can Make It Group). Some people also mentioned the Special Olympics which, apart from coaching and other sporting activities, creates opportunities for various social outings.

But it seems that few disabled people have the opportunity to go out on their own, or with whoever they choose. Part of the problem is transport and money, topics we'll discuss later on in this report. As mentioned earlier, among those who go out alone, some just run small errands, such as going to a shop near their home. Some participants go to certain places on their own, and others are accompanied by family members. For example, one participant goes to church on his own, but is accompanied by his mother if he goes to the health centre.

Some attend scout meetings, drama, or the local band club (this was mentioned by two men), outings to Valletta and other places were also

mentioned. There are some who leave home alone, but then meet up with someone. In fact, when they go out with groups of disabled people they are always accompanied by someone non-disabled. For example, Nikita mentioned the fact that she goes out with a group of disabled people and that they have to helpers who accompany them. She said that she goes on her own to Mass in Valletta on Saturday evening and then she meets up with members of the group she belongs to. Silvan said that he often goes out alone but that he doesn't always meet up with someone. But he also added: 'I enjoy talking to everyone'. There are some participants who go out to meet their boyfriend or girlfriend as we shall see later in this report.

Some people stay out late, but this is rare. If they do stay out late they will be with their parents or older siblings. But there are a few exceptions too such as Tyler who said that he stays out late on his own. Nikita and Eric said they stay out late if they're with a group of other disabled people and if they have transport to take them back home. Silvan stays out late in summer when he and his family go to their summer residence. Helen doesn't come home late, when they have a party at work, her sister picks her up at midnight.

It is also worth noting that there are people with intellectual disability who don't go out, by choice. For example, Tyler explained that he didn't like to go out during the weekend because he goes out to work, and for other reasons, every

day, so on Saturday: 'I want to be alone to think over what I did during the week'.

Participants said that, to a certain extent, opportunities for going out alone depended on the individual, some were independent, while others were very severely disabled. Those people with a mild disability tended to go out more often and so, as Steven Farrugia said: 'we can't talk about disabled people as if they were a single group'.

Steven Farrugia is also of the opinion that: 'the more time passes, the trend is that more [disabled] people are going out'. Some participants noted the age of the parents was also a factor. Older parents make sure that their intellectually disabled sons or daughters go out with groups of other people with intellectual disability, whereas younger parents don't see that situation as appropriate and therefore the disabled persons ends up going out only with their family.

Going out also depended on whether parents trusted them or not. As Annalise Scerri said: 'There may be someone who is really capable, but is still not allowed [out]'. Nikita also raised the point that many people with intellectual disability have to have their parents' permission before going out. For example, when she herself wants to attend an activity, the first thing her parents tell her is 'now we'll see' and then she has to wait to see if she'll be allowed to go, or not.

There are parents who create many different opportunities to provide their intellectually disabled children with opportunities to go out. Damian Pisani mentioned an instance where the owner of a restaurant may know the disabled person, so the parents take them there for a meal in the weekend. 'They have an outgoing character, and they make friends. But then they always go to the same places. There's no choice. There's the danger of that happening too. Annalise Scerri explained that, often, if an intellectually disabled youngster is to go out, it has to be a parent who takes the initiative, 'someone who takes care to organise something'. Even when people with intellectual disability go out alone, it sometimes happens that parents take the initiative, for example, they organize the outing and transport.

What parents think about going out

On their part, parents told us that when their intellectually disabled adult children are out on their own, they feel a certain anxiety unless there is someone there to look after them. For example, one couple mentioned the fact that their son likes to go to the local band, or football club. Parents said that they're happier when their children go out with someone who can take care of them. Mrs Zammit said that it isn't that she doesn't trust her son, but that she doesn't trust his friends to look after him. Wherever there is a negative experience, parents won't trust them to go out without someone to supervise.

Bullying is a great worry for parents too. Francesca Zarb pointed out that there is usually more concern over a girl than there is over a boy.

Parents' anxiety is at its greatest when their adult children go out with people who don't have an intellectual disability and who don't work in the disability sector. Mrs Zammit said that she tells her son what time he should go out, and not to stop and chat to everyone he meets so that he won't be late wherever he is going. This is because her son speaks to everyone and he looks upon everyone he meets as his friend. Parents of people with intellectual disability who are between 16-20 years old say that their children are too young to go out alone.

Silvan remarked that he used to go to Paceville, an entertainment hub, and get drunk and once his parents had to pick him up from a bus stop where he'd been left by his friends. Then he was told he wouldn't be going there again and he accepted that. Now, he said, his parents let him go out as long as it is with someone they trust. Therefore, there are situations where parents are right not to let their children go out with just anybody.

Another point raised was that some parents know that they have to overcome their own fears about letting their children do certain things. Pauline Magro said this: 'I'm very fearful ... and I fight against myself and I do understand that, sometimes, one has to give a certain amount of freedom. ...

The level of freedom depends on the ability of the child'. For example, if she doesn't cross the road properly, you can't let your daughter go out on her own. But then she added: 'Perhaps if I trust her she will be more responsible. Perhaps. ... But I'm afraid that if something happens to her ... after all, she is my daughter.' But, she went on to say: "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?" She observed that the most difficult time for many parents is the first time their children do something new – for example the first time they go to a live-in and until they return their parents hearts will be in their mouths. But if he goes once and everything turns out well his mother will send him again, even if she thinks that he won't be taking that much from it.

On the staff's side, efforts are made to ensure that their intellectually disabled clients become more independent, even within the family group. In one of the centres, activities are organised specifically to achieve this goal and to this end staff members work hand-in-hand with parents. One typical activity that was mentioned was that during Christmas, clients were given a voucher to spend in a shopping complex and they went together in small groups to choose something for themselves. For some, this was their first experience of paying for something on their own, but there were also some who were used to doing this already. One of the parents objected to her son's choice of a brightly coloured top, but her son was really happy with it. He can't communicate verbally, but

his facial expressions showed that he was happy with this top. The mother wanted her son to wear only conservative colours. The staff tried to reach a compromise and so the mother eventually agreed to let her son wear the top at home.

In fact, the staff at this particular Centre believe, quite strongly, that they should work hand in hand with parents and therefore they thought that they might repeat the same exercise next Christmas, this time involving the parents so as to show them just how much their children are able to make their own choices. They work step-by-step with parents because they know that, for the parents, the first step is always the most difficult one. An example of this is when the Centre organised a live-in, and the one client who most enjoyed being in the company of other people wasn't allowed to attend. In the end, the parents gave their permission so long as they could contact her by mobile phone. On the first day her mobile phone never stopped ringing, but on the second day it stopped.

Joseph Borg also spoke out about this and he pointed out that people with intellectual disability needed to be exposed to more risk in their lives. He went on to say: 'I'm speaking like this because we're on our own because if my parents could hear me they'd eat protest.' But then he added that being protected is important in certain circumstances, when in the company of other young people. As an example, he recalled an episode when someone was smoking inside a bar and when the police entered the young man passed the

cigarette on to an intellectually disabled person and it was the latter who got into trouble. Another issue he raised was if a young intellectually disabled person were being bullied and/or abused at their place of work. He concluded: 'it isn't easy to cut a clear line'.

This point was also raised by other parents who took part in the research, that is, only letting their children take part in an activity if they felt it would be a positive experience for their child, but they don't let them participate if they feel that it won't be a positive learning experience. The parents also want to see who is going to be with their children. Francesca Zarb remarked that many parents say: "They're not going to get much out of this", "It isn't worth sending him", "He'll be in the sun for too long" or "it will be a very long day". Parents seem to become passive and lethargic'. She maintained that when one changed an intellectually disabled person's routine one needed to prepare the person to cope with the change. Sometimes parents use different excuses to avoid sending their children to extra-curricular activities organized by the day centres, especially if these took place in the evening. She added: "When my son has an activity I make an effort to send him".

Going out: what do people with intellectual disability want?

People with intellectual disability want to do the same things that young people their own age do, for example, young people's activities if they're still young. For instance, Tyler said he goes to watch football, like other young men..

Since there are no support services in the community, people with intellectual disability remain dependent on the family, especially where going out is concerned. As a result of this, intellectually disabled are severely limited in their choices of where and with who they can go out because they don't have a support worker to help them. This situation is especially true for people who need support due to the severity of their impairment, because they can't go out on their own. It was only Mr Said who noted that his daughter had a support worker who went out with her once a week. Mrs Aquilina said her son used to ha support worker too, but the problem was that the service would begin but not continue. Focus group participants also identified the need for people with intellectual disability to be provided for some funds which they could use to socialise and to pay for personal assistance. It could consist of a portion of the disability pension, used exclusively for this purpose.

Pauline Magro said that some intellectually disabled youngsters aren't really keen on going out to places like Paceville. Loud music and the constant hubub upsets them. On the other hand, they don't want to stay with their parents. The

Down Syndrome Association, for example, organizes disco parties and the parents try to ensure that there are young, non-disabled volunteers to keep an eye on things, but it is difficult and often it is still the parents themselves who take care of things.

Steven Farrugia raised a very important point when he asked whether people with an intellectual disability prefer to go out with similarly disabled people '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.'

Going out: social changes that need to take place

In fact, the point raised by Steven Farrugia ties in well with remarks made by participants in the focus group about the social changes that need to take place. Some people mentioned the lack of awareness about disability among professionals and other personnel, for example, youth workers and people working in religious groups. Some people do involve disabled persons but only in a very limited way. For example, Vince Micallef mentioned disabled people's involvement in village festas and he said: 'it's always the same, holding up the big bass drum, or acting as standard-bearer, that's as far as they let them do'.

Participants noted that discrimination also exists between persons with different disabilities, because so go out more frequently and are more accepted. People with an intellectual disability and wheelchair users were identified as among the people least accepted in society.

Alice Gauci observed that the community made a difference, because if the disabled person was known in the community (for example, at the local club) they were likely to get out more. Therefore, there were more opportunities for going out in small communities. This was also mentioned in Gozo which is a small community where people get used to you, so if you need help its given to you; so one can take advantage of such a situation. Sometimes restrictions come about from the immediate home environment. For example, people with intellectual disability who live in streets where there is heavy traffic, are often not allowed out because of the danger of being run down by a car.

The staff who work with people with an intellectual disability do encourage their clients to have a social life, but it still depends a great deal on many other factor, as we can see in this report. There are also certain place which, of their very nature, have many limitations. For example, they may not be provided with good public transport facilities. In the case of Gozo, people also remarked that because the island is so small it offers limited opportunities for going out, as we have seen before.

Public Transport

We can observe that the public transport sector also presents certain problems for people with an intellectual disability. Transport is a key allowing entry into the world of work, continuous education, free movement and leisure activities. In the words of Francesca Zarb, 'that's where we need to start – being able to get to work.' But there are parents who are afraid to let their children board a bus on their own. Some people mentioned the fact that certain parents ask whether transport will be provided for their children to attend a course, or a meeting. It doesn't occur to them to let their children use public transport. Participants mentioned a post-secondary college where intellectually disabled student were using public transport independently to come and go for lectures. But then a parent made sure that they had specialised transport by van and that skill of using public transport independently was lost.

Out of the 16 intellectually disabled person who took part in the focus groups, 6 said that they used public transport on their own: 4 in Malta and 2 in Gozo. In case of those people who don't use public transport independently, they either go out accompanied (very often by members of the family), or else they go out alone, but only to places within walking distance from home. These situations arise because the person may not know how to use a bus, or because the bus routes aren't convenient, or else because the timetable is not adhered to, for example the bus may arrive too early, or too late. People who

live in more central areas don't experience these inconveniences as much as those who live in more out-of-the-way places. But sometimes it happens that the individual is quite capable of using public transport, but the parents still give them a lift. Francesca Zarb said, 'there are people who are quite capable of learning to use it [public transport]. But they are not taught how, because the parents are lazy'.

There are people who don't use public transport on their own because of some sort of difficulty. For instance, Mrs Aquilina said that her son goes out alone to places close to home, let's say the gym; but if he needs to go further afield his mother, or father, take him because he won't know which bus stop to get off at, and he also becomes distracted and just misses his stop.

Some people may want to go somewhere new by public transport and the parents wouldn't want them to go on their own. But they're not discouraged, they ask for directions from people and eventually get there. When she was discussing the issue of transport Mrs Fenech remarked that her daughter was a lot more independent than she herself ever believed she could be. As some of the participants remarked, the fact that few people with intellectual disability use public transport could be due to Maltese culture, where people prefer to travel by private car. Moreover, because of inefficiencies in the public transport system parents end up taking their children themselves. Furthermore, the public transport system isn't completely accessible.

Money

Some persons with intellectual disability make use of money on their own, but from what was reported in the focus groups it seems that these are few in number.

Out of the people with intellectual disability who took part in the focus groups, Sandro said that he drew money from the bank on his own. Tyler, for his part, said that he goes to the bank with his father. He said, 'I'm capable of going to the bank on my own, but personnel at the bank tell me not to go alone because there are certain things which I won't understand, so it's better if I'm with someone. I know certain things, but not everything.' Mark's mother withdraws his money, and Silvan said his salary is deposited into his father's account who then gives Silvan cash. Silvan is happy with this arrangement because he has enough money.

Those who are on a disability pension receive the cheque in their own name or in the name of one of the parents. The latter group can't cash their cheque on their own, but their parents give them pocket money. Nikita said that her mother gives her money from the pension, but it isn't enough. Eric, on the other hand,

is satisfied with the amount of money from his pension that his mother gives him. Salvu said that he has pocket money given to him by his brother.

The parents also spoke about money issues. Mr and Mrs Zammit said that they control their son's money because he doesn't know how to look after it and that he spends anything he has. Some parents said that their children didn't know how to control their mobile phone credit. They use it all up straightaway.

Other parents observed that their intellectually disabled children didn't know the value of money, or didn't recognize the difference between money denominations. For example, two parents said that their children like to have a lot of coins because they think that the heavier their purse is the more money they have. As for those who don't recognize money, there are parents who help them distinguish visually. For example they divide different coins and paper money into different purses. But there are also persons with intellectual disability who do recognize monetary denominations and their parents give them small amounts of cash and then they go shopping on their own.

Parents find different ways to help their adult children when these don't know how to manage money. There are some who keep the money themselves and give their children money according to their needs. Mr Schembri said that they have an agreement with the village bank so that when his son goes to withdraw cash, he is never given more than €50. In the case of Mrs Micallef's daughter,

she always has a small balance in her debit card which she uses when out shopping; like that she doesn't have to keep checking for change. Mrs Micallef also said that, at first, her daughter was scared of withdrawing cash from an ATM on her own, that is until she began to help her learn how to do it independently.

Unfortunately there are also parents who abuse. For example, some participants mentioned parents, or other relatives, who take all their intellectually disabled offspring's disability pension and give them nothing in return. As Pauline Magro said, 'they have to have money in hand. If necessary give them cash a little at a time, and also advise them on what to buy, but in the end they should have some cash in hand'.

Another problem which was highlighted was that there are few people with intellectual disability who are able to shop on their own and to check for the right change. As Annalise Scerri said, their knowing Maths isn't enough, because you have to know how to check your change quickly, while there are other people behind you waiting to pay. She said that many people with intellectual disability prepared the denomination closest to their needs. For example, for a €1.50 bus ticket, they prepare €2 in hand.

There needs to be training in money management, and also how to use the credit card. Sometimes the training that is given is undermined by other people,

even when these have the best of intentions. Noella Schembri was one of those who mentioned that, when she's teaching someone with an intellectual disability how to shop, the shopkeeper will want to give the disabled person the item for free. As Noella Schembri herself said: 'some attitudes reflect the 'poor thing' mentality'.

Mobile telephone calls

Mobile telephone calls are a good way for people with intellectual disability to keep in touch with their parents, or other carers, while they are out of the home.

But some people with intellectual disability experience problems when using a mobile phone and the calls made on it. For instance, individuals who go out to meet friends, have their mother ring them constantly to see if everything's all right. They feel it doesn't matter if she rings once, but ringing frequently isn't right. In fact, there are parents who do ring up, just once and no more. Helen said that that's what her mother does, 'so as not to keep worrying'. Some members of staff also said that that there's nothing wrong with ringing once. Annalise Scerri said, 'I don't see anything wrong in their ringing once, especially when they use public transport. There's nothing wrong with a system where one rings once to make sure they arrived safely.'

Eric doesn't have a mobile phone. His parents' minds are at rest because they know where he is. He attends activities organized by disabled people's organisations. Mark said that when he goes on a Day Centre outing his mother keeps phoning him up to see if everything is OK.

It's worth noting that where people with intellectual disability never go out alone, no one thinks that they should have a mobile phone. Clearly, the

tendency is to look upon a mobile phone as a means for parents and/or carers to keep in touch with the disabled when s/he is outside the family home.

On the matter of frequent phone calls by parents, many members of staff mentioned the fact that parents also phone their non-disabled offspring frequently when they begin to go out alone, but the calls generally subside soon enough. 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.

There are also disabled people who do the phoning up. Take Silvan who said that when he goes out he either rings once to let his parents know that all's well, or else they call him and he lets them know where he is. Tyler rings home when he is going to be back late.

Sometimes it isn't parents who ring up often. Kevin said his girlfriend rings him to see if everything's all right. He said she liked to call him a lot. Tyler also remarked that one girlfriend he had was too bossy and that she used to give him orders about what he should and shouldn't do. Pierre, on his part, said that his mother lets him go out with his girlfriend, but that *her* mother kept ringing her up. He said, 'I can't enjoy being with my girlfriend in peace. ... She keeps telling her daughter to be careful, but I can look after her'.

Technology

There are many people with intellectual disability who know how to use information technology. Almost all of the participants in this research project have a mobile phone and some of them also have tablets. Some participants don't know how to read, but they still learn how to use tablets, especially when they want to watch videos on Youtube. In one instance, one of the persons with intellectual disability has a computer but it's kept at the Centre which she attends so that the staff there can help her use it because no one at her home knows how to give her the support she needs to use it.

Pauline Magro observed that many people with intellectual disability don't get by without the use of technology. As Veronica Bugeja put it, technology has the advantage that the individual doesn't need to know how to read and write in order to use it, because s/he can make it work visually and aurally. Pauline Magro remarked that it is used for educational purposes 'but more so for Youtube, so I won't beat around the bush'. She noted that in her son's case, he tries to use what he's learnt. In fact he's capable of producing an SMS, but he doesn't know how to write using a biro.

One of the Centres, whose staff participated in these focus groups, had an offer where clients could buy tablets at a reduced price. Parents were included in

the training sessions on the use of the tablets. The aim was to improve clients' independence by working hand-in-hand with the parents and to involve them as much as possible. There was one mother who didn't want her son to have a tablet and when staff investigated to find out why, they discovered that once someone had given the son a tablet that didn't work and he opened it up to try and mend it. But his mother insisted that he had broken it. A representative of the Centre also reported that when they put up a presentation, together with clients from the Centre, one particular client had learnt to switch on the data projector and to work the powerpoint presentation himself.

Intimate relationships

As part of this research project we also discussed intimate relations, that is, we talked about boyfriends and girlfriends, and about marriage. Intellectually disabled participants raised a number of different points on this subject.

Those people with intellectual disability who have a boyfriend or girlfriend are confronted by certain obstacles when it comes to their enjoying this relationship. Many of them don't have opportunities to meet their boyfriend or girlfriend as often as they'd like. The fact that they're 18 years old doesn't mean that they are independent. There are some who just go out with their boyfriend or girlfriend, but there are others who also have sexual relations. Pierre meets up with his girlfriend to have a coffee together because they meet close by to where they both live. But when he goes out with his family, for example to go to a festa outside their town, his girlfriend won't be with him. On his part, Kevin said that his girlfriend's mother doesn't want them to get married. Christine has a boyfriend she meets every fortnight when they go out together as members of the same association.

There are also some individuals who are not, or are no longer, interested in having an intimate relationship, or else they want to be cautious. Silvan said he only wants friendships with girls, nothing more, because in the past, whenever he had a girlfriend they always ended by breaking up. Tyler too said

it was best if he didn't have a girlfriend. Nikita said there was a boy in the disabled people's group she's a member of, but for the moment they're just friends because she wants to see if she can trust him, because the boyfriend she'd had before had taken her money.

Certain parents support their intellectually disabled children in their quest to find a boyfriend, or girlfriend. Take Mrs Aquilina, for example, when she isn't at home she switches on an alarm to remind her son that it's time for him to go out and meet his girlfriend. But Mrs Aquilina also remarked that her son and his girlfriend want to get married and that they have planned everything down to the last detail, but they can't understand that it's difficult for them to get married and begin living together, because the support services they need to help them do that don't exist. Mr Schembri said that he and his wife wished that their son would think about the direction his relationship with his girlfriend is taking them. They are ready give them the support they need to get married, even if theirs is just a civil marriage, but the girl's parents don't want it to happen.

However, there are also parents who don't support their intellectually disabled children in their efforts to have an intimate relationship. Francesca Zarb said that some parents are afraid 'especially where girls are concerned'. On her part, Pauline Magro raised the point that relationships between persons with an intellectual disability are not taken seriously. 'They [non-disabled people]

don't see it as a relationship. It's seen either as an infatuation, or some game'. Veronica Bugeja too explained, 'They're not taken seriously. People say, "How cute!", "Aren't they sweet!" We go on seeing them as children'. This point was raised by a number of different people in the focus groups. Noella Schembri said that even when people ask them, 'who is your boyfriend?' it's clear that they're not being taken seriously but that they're being treated as though they were still children. Josephine Carabott emphasized the simple fact that by constantly exclaiming 'aren't they sweet!'" and using what she called 'standardized clichés' means that 'in our eyes we see them as children' and as a result of that, this complex issue is never addressed. Vince Micallef agreed when he said, 'that's as far as we can go ... this is always a closed issue'.

This is why there is never acceptance of the fact that people with intellectual disability can have these emotions. In fact, Steven Farrugia said that there's a mistaken perception that people with intellectual disability don't have sexual urges. He went on to add that this was a very 'hot' subject and he remarked that once, during a radio programme, he said that people with intellectual disability could have intimate relationships and on the following day he began to receive messages from parents who said that they disagree because their children would be abused. Then there's the perception that someone who is disabled isn't capable of having a family. Some disabled people do receive the support they need. But it isn't everyone who has the support necessary to overcome these obstacles.

Participants in the focus groups, especially those who work in the services sector noted the lack of education about sexuality among parents and among people with intellectual disability themselves. They said that it isn't common for parents to support their children's efforts to have a boyfriend, or girlfriend. In fact, they observed that many parents block their intellectually disabled children's efforts to go out with someone. Some parents even put up resistance to sex education because they find it difficult that their children may be talking about the subject. But, in the end, they do appreciate their children learning about sexuality.

How other people behave towards people with an intellectual disability

Most of the people who took part in the focus groups said that people usually behaved well towards people with intellectual disability. Disabled people said this themselves, as did their parents and people working in the sector. For example, Francesca Zarb said, 'People have become more aware'. But there were people who recounted negative experiences. There are people with intellectual disability who are made fun of and even bullied in society. Participants observed how you can still find people who laugh at them and mock them. You find positive and/or negative attitudes everywhere - the workplace, within different organisations and in society in general.

On a personal level, Nikita said that she doesn't go out with non-disabled people because she's afraid of them making fun of her. Helen remembered an incident when she'd gone to the dentist with her mother and they overheard the dentist say, she's handicapped ' and she argued that she doesn't feel pain. On his part, Mark, who had recently left school, said that he'd been bullied at school and that they used to call him 'retarded'. Some people remarked that people with an invisible disability are bullied and abused. But, on the other hand, Silvan pointed out that his friends had accepted him the way he was, they never laugh at him because he speaks like them and they didn't know what his disability was. Sometimes the people who do not treat the intellectually disabled person well are people working in the disability sector. For example,

some participants mentioned the fact that certain drivers of accessible vans behave arrogantly. And there were also some clients who don't get on very well with certain support workers at the Centre they attended.

There are some individuals who are accepted in groups and others who are not. There are disabled people who can go out alone as often as they like, but when they join groups, such as (non-disabled) youngsters, they end up being ignored. For example, Tyler said that he was in a youth group and there was a girl helping him, but he had to leave. The group leader told him 'you're creating big problems for us'. But then he said that he goes to drama with non-disabled people and they get on very well together because 'our tutor has brought us together like one family ... there isn't any of that ignorance'. Pierre said that when people stare at him, he asks them, 'How can I help you?' and then they go away. Mrs Camilleri mentioned how her daughter used to go out using a walking-frame, but one day she heard someone pass a comment about her and so she didn't want to use the frame to go out with ever again. Now she will only go out holding on to her mother's arm and so there's a limit to how much she can walk.

Some people remarked that it was more a question of people not knowing how to behave towards people with intellectually disability more than a question of their being shunned, or else they're patronising and treat them as though they were still little children. This happens most especially with people who have

Down syndrome, who seem to have become the icon for people with an intellectual disability. Josephine Carabott raised a similar point when she said that 'there are individuals who are like their village mascot' because people think they're cute.

Veronica Bugeja said that sometimes the attitude is, 'I take care of him because I pity him'. In fact, the 'poor thing' aspect was brought up by many participants in the focus group. Noella Schembri noted that in the past more people used to laugh at disabled people and that nowadays the mentality is more protective, 'they look after you to see you don't get hurt'. But, as she said, this is still part of the 'poor thing' mentality.

Some participants observed that people with intellectual disability are expected to be quiet and not create trouble. Whatever is done for them, it's as though they're doing them a favour. But, as Silvia Bonello said, 'This isn't about whatever it is they're doing for them. This is an obligation'.

Among those people who find it most difficult to be accepted are those with different behaviour. Where people with autism are concerned, some people tell the parents that they don't know how to look after their children. Silvia Bonello mentioned an example where an intellectually disabled person has an invisible disability and he has a badge that says: 'I've got different needs, please bear with me'. This is so that people will realise that his behaviour is different.

Therefore we can see that whereas negative attitudes towards people with intellectual disability are decreasing, but a great deal still needs to be done to ensure that these people are accepted as equal citizens. The general tendency is that while they are not hidden away or treated badly, they are treated like children and not like adults. All this hinders people with intellectual disability from being equal members of society.

Expectations for the Future

Finally, we asked members of the focus groups, how they would like to see the future for people with intellectual disability develop.

There were some people with intellectual disability who expressed wishes on a personal level:

- Some people with intellectual disability would like to have their own house, or flat, and if they need help they can ask their mother or support workers to help them.
- Someone would like to get married or live with her boyfriend, but her mother won't let her; then there's someone else who would like to find a girlfriend and have a family.
- There are some who would like to find work.
- Some participants said they'd like to travel abroad, some alone, others with a group from the day centre.
- In Gozo there's someone who would like to go to live in Malta.
- Also in Gozo, there's someone who said they'd like to go on more frequent trips to Malta.

Many members of the focus groups emphasized the importance of listening to what people with intellectual disability themselves have to say:

- It is important for us to see what the intellectually disabled person wants, even when it's difficult for them to make their voices heard because they might have complex dependency needs. At the moment some people with intellectual disability are being heard more than others.
- It is also important the people with intellectual disability are better able to speak openly about their disability, so that non-disabled people will become more about disability. Intellectually disabled students need to learn about their impairment from the time they are at school.
- It is equally important for people with intellectual disability to have good self-esteem and that they are provided with support when necessary.
- More opportunities need to be provided for people with intellectual disability to express themselves in public fora and in private spaces. Steven Farrugia also added that feedback needs to be collected not just from disabled activists, 'but even from the person who's always sitting at the back'.
- Joseph Borg pointed out that 'we should listen to what we have to say, not just the experts'.
- Steven Farrugia said that when we design services for disabled people we shouldn't just proceed according to what the system dictates, but 'we must see what the [disabled] person's needs are'.

- Steven Farrugia also noted that we should focus on 'needs that are important to young people, such as, going out, friendships and the use of social media'.

Participants also raised points about changes that need to take place in society in general:

- Greater respect for people with intellectual disability.
- More independence for people with intellectual disability.
- Not to look upon people with intellectual disability as objects of pity, but as whole people.
- More awareness and education about people with intellectual disability. Manuel Baldacchino said that there was need 'for more education in society'.
- Josephine Carabott identified the need for us to 'eliminate the distance between 'us' and 'them'. More real inclusion ... We need to go on learning. And educating society”.
- Steven Farrugia said that we shouldn't speak to them in a patronising tone. 'Do we need to use that pitiful voice? ... It annoys them'.
- Noella Schembri expressed a wish for 'the day to come there would be no distinction between disabled and non-disabled people, when we are all the same'.

- Joan Azzopardi also expressed a similar wish, that 'disabled people will be independent ... not to look at them as us and them but as us'.

People emphasised the need for more services for people with intellectual disability:

- Agenzija Support⁷ needs to be strengthened in the very important role it has in helping to design the future for people with intellectual disability.
- Plans involving people with intellectual disability need to be designed for the long-term, and, as noted earlier, always based on what people with intellectual disability themselves actually want.
- More and varied activities for persons with intellectual disability.
- More support to enable people with intellectual disability to go out, especially during weekends.
- More support to enable people with intellectual disability to meet their friends.
- More support to help people with intellectual disability find more friends.
- More support to enable people with intellectual disability to go out with their boyfriend or girlfriend.
- Parents want to see more housing and flats made available so that when they are no longer able to care for their intellectually disabled children, the latter can go to live in these residences without being a burden on

⁷ <https://fsws.gov.mt/en/support/Pages/welcome-support.aspx>

their siblings. As Veronica Bugeja said, 'the burden of care needs to be taken off the shoulders of parents and family and the service provided well and truly in the community'.

- More opportunities for independent living.
- The importance for people with intellectual disability to be in gainful employment.
- It is essential that day centres don't revert to being institutions catering for large numbers of clients, which is what is actually happening. When this happens, support works ensure that the client's basic needs are met but that leaves them with little or no time to provide a personalized service and organize activities aimed at personal development and inclusion in the community.
- There is also the concern that the inclusion skills learnt at school are being reversed. There is a good beginning at school, but afterwards everything is lost. As Francesca Zarb said, after school there's 'a big vacuum ... a mistake in investment ... in a few years everything is lost'. Pauline Magro added that 'it's almost worse because one moment they have friends ... School shouldn't stop at the age of sixteen because they still won't have reached a certain maturity'.
- There's a great need for real inclusion. We shouldn't be creating enclaves for people with intellectual disability. For example, youth centres should practice the principle of inclusion more.

Over-protection

While almost every issue discussed in the focus groups touched on the subject of over-protection, there were some points raised about over-protection in a more general way which, until now, haven't formed part of the main themes of this report.

Focus group participants discussed the reason why over-protection happens. They remarked that there were certainly occasions when parents had every reason to protect their children, but that there were other occasions where this became over-protection. This sometimes happens because parents are worried that their intellectually disabled children may come to harm, or may be mistreated or excluded by others. Situations like these make them interfere in what their children should, or shouldn't, do. Sometimes parents do both, that is, sometimes they protect in the right way and at other times they over-protect. Sometimes you'll find, in the same family, one parent who's over-protective while the other isn't. Noella Schembri described over-protection as 'another disability' that the individual has to experience over and above their existing intellectual disability.

For over-protection to end and for people with intellectual disability to have more opportunities to make choices in their life, these are not things that will

happen at once. The change has to happen gradually, as much for persons with intellectual disability to develop and acquire the skills they need, as for parents to give the intellectually disabled children more freedom. All this may need to happen slowly. Alice Gauci mentioned the fact that parents don't realise that their intellectually disabled offspring go through the same development process as their non-disabled children, 'and, where intellectually disabled children are concerned, parents are not provided with the support they need to deal with that stage of letting go'. Silvia Bonello agrees that parents experience a lack of support from professions and this support needs to be provided early on. This is also important because parents don't always have the skills themselves to help their intellectually disabled children to become more independent. On the other hand, if there is a training programme, persons with intellectual disability, together with their parents, will both be able to develop the necessary skills which will then translate into a reduction in over-protection.

Maltese culture has a tendency to be over-protective and this also applies to people with a physical disability. And over-protection doesn't just stem from parents. Damian Pisani gave as an example the situation of two men who developed a physical disability and their wives treat both of them like children.

Because of all this, there is a tendency for parents of people with intellectual disability to go on looking upon their offspring as if they were still young

children, even when these have grown into adults. So, for example, parents still have a tendency to associate post-secondary colleges with a school environment. They go on using the contact book system, or else they persist in phoning the school. There are also parents who see their role as controllers of their intellectually disabled children's lives because they feel they know what's best for them. As Joseph Borg remarked, parents tell them, 'as long as you're under my roof you'll do as I say'. Noella Schembri also brought up this point. She observed that we teach people with intellectual disability many skills, but then we don't give them the freedom to use those skills. She said that they're like 'ducks without legs. How are they going to swim?'

People remarked that we cannot put a limit on what people with intellectual disability are capable of doing and how far they can go. Very often they will be absorbing whatever it is we are trying to teach them, but it takes them a long time to express what they will have learnt. Everyone moves forward at their own pace. Sometimes there is sudden spurt in an individual's development after what seems like a long period of stasis. As Damian Pisani said, 'everyone needs their own plan, which has to be reviewed after two years... You can't just stop and say "that's as far as he can go". You can't go forward if you don't have a plan. You can't dictate and say "this is how s/he will progress"'. Moreover, as Steven Farrugia remarked, 'we practically have to use a different measure for each individual. It's important that we treat the individual in an age-appropriate manner'.

Some parents have an open mind. Some participants observed that these sort of parents are often younger, but that isn't always the case. Others said that it also depends on the character of the parents, but it also depends on the character of the intellectually disabled person. There are parents who would like to see their children become more independent, but they sometimes find people who hinder their efforts. Mrs Aquilina believes, very strongly, that her son should speak for himself. If they go to a restaurant she makes sure he tells the waiter what he wants. If the waiter tries to ask her she lowers her head into her menu so that the waiter will have to speak to her son. When her son had an assessment, the assessor began ask her question, and she told the assessor to ask her son.

In the focus groups held in Gozo, it transpired that there's a greater tendency towards over-protection on this island. This is partly due to the inevitable limitation of such a small place which suffers from double insularity. We discussed this issue earlier on. But there also seems to be a tendency for persons with intellectual disability to be kept always within the family. Members of staff who have worked in both Malta and Gozo also noted this tendency. Personnel who work in Gozo try out different initiatives in order to increase intellectually disabled person's independence.

All this shows us that over-protection is a complex phenomenon. There is no one single solution which works for everyone, or some other solution which will remove over-protection in the short term. Steven Farrugia put it very well when he said, 'you have to dig very deeply to discover where over-protection comes from'. And to find a solution you have to work hand-in-hand with every intellectually disabled person and with their family.

Afterword

After we had finished the research and drawn up this report, we organised a national conference in order to discuss the findings of the research and the subject of overprotection with persons with intellectual disability, their parents and staff working in various organisations. The following are the main points raised in the discussion.

Protection is needed to ensure that people with intellectual disability are safe. People with intellectual disability and their parents have to face situations where the former are bullied - at work and in society in general. They also face situations where their abilities and potential are not acknowledged. But we need to be careful so that protection does not create unnecessary restrictions in their lives. It is also important that, when providing protection, the reasons why are explained clearly and in a friendly manner.

There are good ways of providing protection. In fact, there are parents who keep an eye on their sons and daughters with intellectual disability while ensuring that they have a lot of freedom in their lives. Parents should also allow their sons and daughters do things on their own, even if they struggle, and help them only when they absolutely have to or are asked for help. Reducing overprotection starts from the home.

Avoiding over-protection while still ensuring the safety and well-being of persons with intellectual disability means using resources that already exist - in the family, in society, and also thanks to technology. When it comes to shopping, debit cards are very useful especially for those who do not know the value of different notes and coins, or do not know how to check the change. This is a good example of finding ways of enabling adults with intellectual disability by using technology and community resources to give them choice and control without being based at risk.

While most parents have the wellbeing of their adult children with intellectual disability at heart, unfortunately there are those who are abusive. It is important that where such cases are known they are reported and that when there are suspicions the right organisations are alerted so that they can take the necessary action. It is also important to keep an eye on those people with intellectual disability who are at risk because they find it difficult to speak for themselves, which can make it easy for the abusive situation they may be in to go unnoticed.

Overprotection is also created by society in general, by patronising attitudes, such as speaking to adults with intellectual disability as if they were still children, or speaking to the persons who are with them instead of addressing them. For example, in a restaurant the person with intellectual disability is not

given a menu because it is assumed that it is the parents who will choose for them.

There are already many examples of good practice - in families, in service-provision, and also in society. It is important to keep on working towards the goal of removing over-protection. We need to challenge misconceptions and over-protective practices, both on an individual as well as a collective level. If we are consistent, the message will eventually go through.

One participant said:

'They don't see what we are capable of.

Give the person a chance.

It isn't always the parents who have to speak on our behalf.'

In fact, it is important to remember that people with intellectual disability themselves have an important role to play in any effort to remove over-protection. They should speak out about what they would like to do, and also if people behave in an unacceptable manner with them. They should fight for their rights. For instance, if they would like to join a club or if they are bullied at work. This also means that the adults around them must be willing to listen to them, and provide support for them.

People with intellectual disability should also not accept the patronising attitudes of others. They should see themselves as adults who have capabilities. But people with intellectual disability cannot do this on their own. They need support. They also need to be given the time and space to come out with ideas, and support to refine these ideas and to discuss the best ways of making them a reality.

It is important for people with intellectual disability to be in the mainstream of society and be involved in mainstream education, employment and leisure opportunities. However, the opportunities provided by organisations that work with persons with intellectual disability are also very important. These organisations are a lifeline for many because they provide opportunities to develop one's potential, to socialise with non-disabled people as well as with other people with intellectual disability, and not to simply stay at home in front of the television or on Facebook or YouTube. But for many people with intellectual disability it is not even possible to join these organisations and their activities.

People with intellectual disability need respect and to have their dignity acknowledged. As one of the participants said:

'We are not objects. We are people.

We need to be accepted not tolerated.'