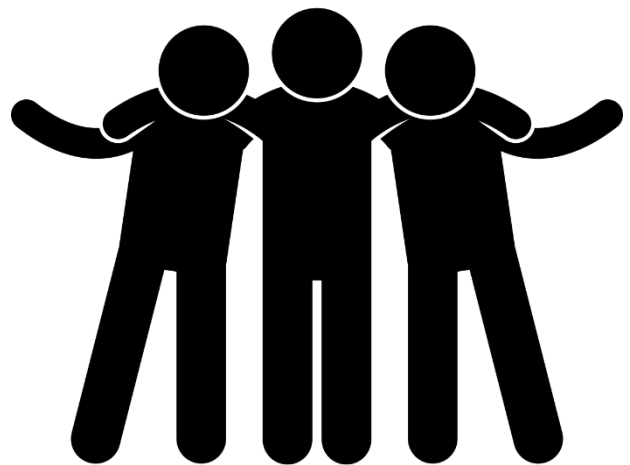




MALE CARERS RESEARCH PROJECT

INSIGHTS REPORT

*"There's no greater rewards.
It's easy to want all those
material things, but actually
the reward of loving and caring
for someone is great and it's
having the support to do that
effectively which is a very
important thing"*
-Primary Carer



Written by Lottie Elliott, Research and Development Coordinator
April 2020

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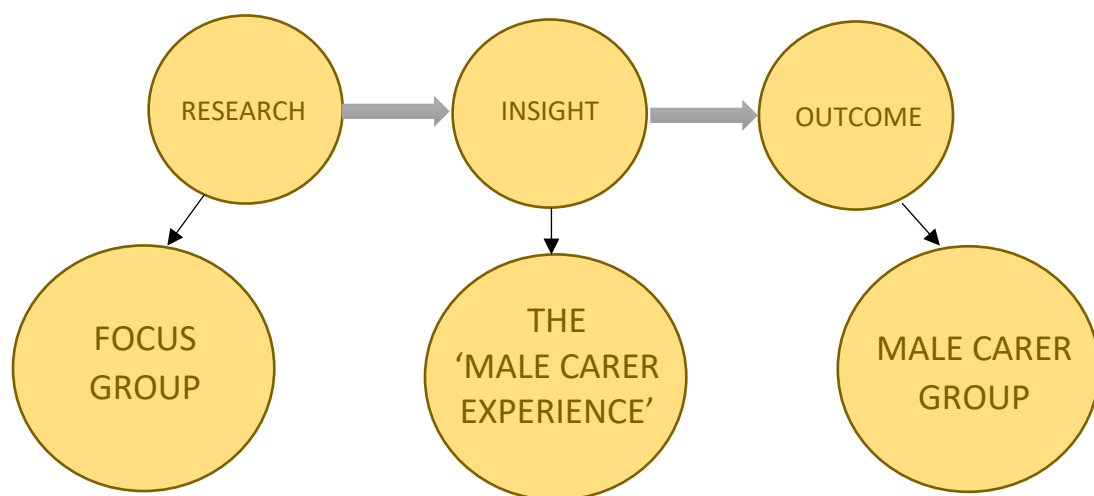
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*With special thanks to the male carers who took the time to participate and contribute to this short study, and who continue to share their experiences and support with others.
Centre 404 is highly grateful.*

1. Introduction

Male and carer are not two words that are commonly heard together. Men can sometimes be under-prepared for caring and often under-recognised. We want this to change. 42% of carers in the UK are male and this includes those of people with a learning disability, however only 12% of carers that engage with Centre 404's carers' services are male. Centre 404 wants to provide the best possible support to all carers. In aid of this, the purpose of this report is to present some of the experiences and needs of male carers of people with a learning disability in Islington, London. We want this report to inform thinking about service delivery and assumptions about male carers. The research was led by the Research and Development Coordinator at Centre 404 and conducted with assistance from three male carer volunteers in October 2019. The aim of this research was to:

- Acquire a better understanding of the needs and experiences of male carers
- Inform a new bespoke group specifically introduced to benefit, involve and engage male carers
- Develop Centre 404 services more generally to meet the needs of its beneficiaries



The report concludes by highlighting recommendations as to a need for:

- Provision when the caring role reduces and/or provision to support the preparation of this eventuality
- Managing carers' expectations
- Support with Personal Budgets
- Partnership working with public services
- Public awareness raising
- Advocacy during safeguarding enquiries
- Bespoke social/support groups
- Personal care advice and support
- Quality, reliable support for the cared for person to reduce stress for carers
- Innovative involvement & engagement strategies
- Support with identifying as a carer and communicating their needs
- Support to recognise, understand and manage guilt

It is important to note that the findings throughout this report may not necessarily be exclusive to the experiences of male carers alone, as many of the insights are likely true and relevant to carers of different genders and outside of learning disability. There is much common cause and experience amongst all carers. Rather, this project enabled the opportunity for male carers to come together exclusively to explore and contribute their experiences and locate any arising themes to inform the way in which Centre 404 understands and develops services for male carers and ultimately improve engagement with this client group.

2. Methodology

Phase One: Phone Questionnaires

In phase one of the project, the Research and Development Coordinator and Caseworker/Family Involvement Officer conducted a short questionnaire over the phone with seventeen male carers. This included nine primary carers who are the sole carer for their loved one and eight co-carers who care alongside someone else (usually a relative, partner or spouse), in order to identify any similarities and differences between the needs and experiences of these two groups. Purposive and convenience sampling was used for both phase one and two of the project.

These phone calls were also a part of the participant recruitment process for phase two of the project and allowed us to collect initial data about these carers; their caring role, who they care for, their interest in attending a future group and initial feedback on how to better engage and involve male carers at Centre 404.

Phase Two: Focus Groups

Phase two of the research involved two focus groups; one with primary carers and the second with co-carers. The aim was to confirm 6-8 participants for each focus group. This was inclusive of three male carer volunteers, two of whom co-facilitated the groups and one who provided administrative support – all of which contributed to the focus groups based on their own experiences. The participant facilitators were recruited based on their roles as carers (one primary, one co-carer) and therefore ability to engage and relate to other participants, their familiarity with Centre 404 services and their ability to effectively facilitate a group. A lunch was also provided between the two focus groups to provide an opportunity for participants from each to informally meet and socialise, with the hope to initialise a male carers network which would form the core of a future male carers group.

Due to availability and illness of dependents, fewer participants were able to attend than expected. Three primary carer participants attended group one (making a total of four primary carers, inclusive of one facilitator) and one co-carer participant attended group two (making a total of 3 co-carers inclusive of one facilitator and the admin assistant volunteer). A total of seven male carers participated in the focus groups. Although this number was lower than we hoped and anticipated, the richness of discussion did not appear affected and data collected was insightful. One way in which these low numbers did affect the research was at analysis stage, in the ability to highlight significant variances between the experiences of the two sample groups; primary and co-carers.

The Research and Development Coordinator provided a focus group guide for the facilitators to follow, which outlined the aims and objectives, ground rules, questions to guide discussion and quick tips on facilitation. The questions were developed with input and feedback from the male carer facilitators, CEO and the Centre 404 Supporting Families team prior to the groups being held. A total of 20 male carers were engaged with for this research project overall.

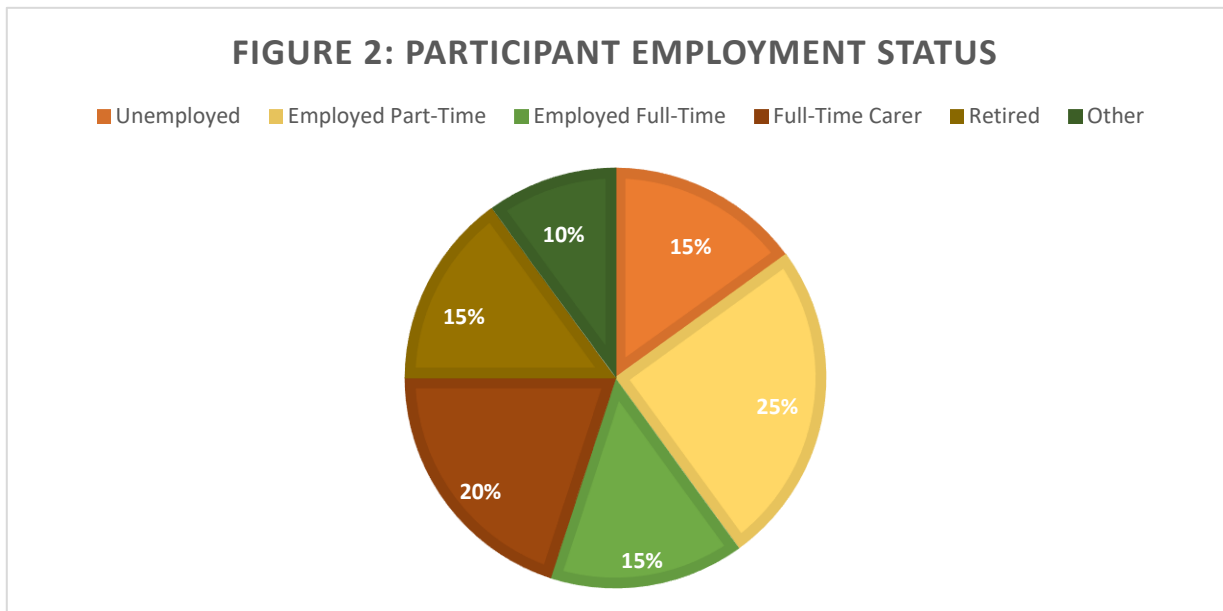
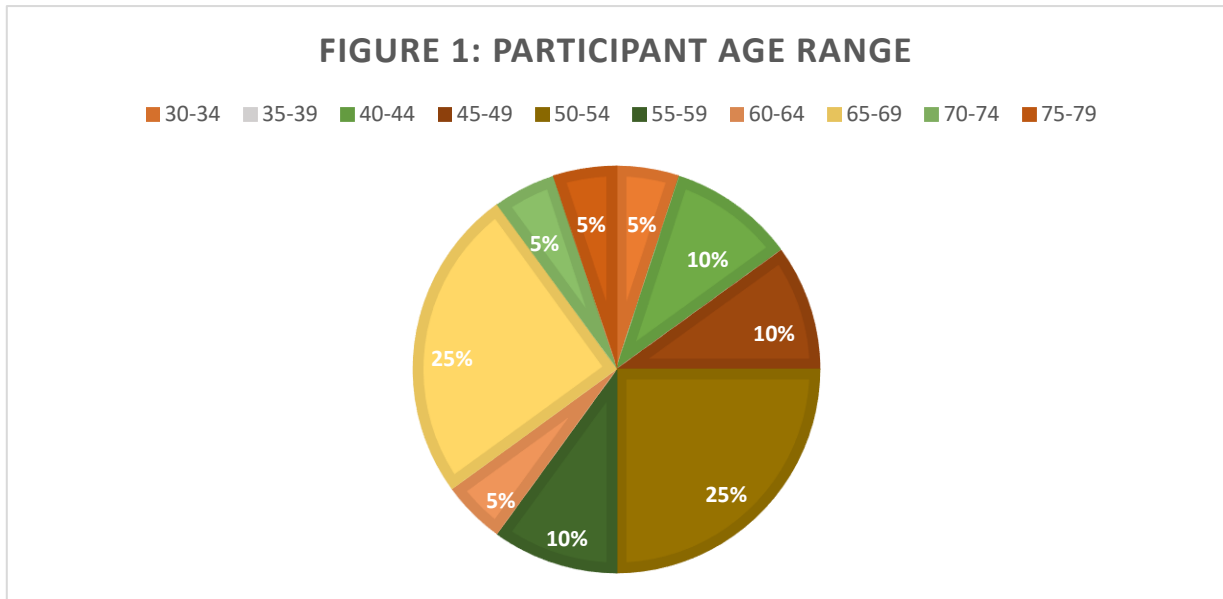
Phase Three: Participant Observation

This third phase of research was not within the initial methodology plan, but rather occurred during the writing of this report. As the first few male carer sessions took place and the group began to establish, the Research and Development Coordinator was able to conduct a small amount of qualitative work via participant observation and enquiry during sessions, which also provided insight to inform this report.

3. Demographics

Figure 1 and 2 illustrate the age range and employment status of participants. This data was collected in order to better understand carers' needs according to their age and availability, as well as in relation to their lived experience as carers in order to develop provision that meet these needs.

The majority (75%) of carers we spoke to were aged over 50 years and 65% of carers were either employed (25% on a part-time basis, 15% on a full-time basis) or a full-time carer. As a result, finding time for activities outside of work and caring was something most found challenging. This was explored and discussed further within focus groups, as outlined in the results section below.



4. Results & Recommendations

a. Answers to Key Questions

To structure the focus groups and encourage rich discussion, the facilitators asked participants six prepared questions about their experiences of caring. The following section reports on the key points and themes raised in response to these questions.

Q1. If you were unexpectedly given a whole day and night off from caring, what would you do with your day? What do you do when you are not caring?

Caring as 'A Way of Life'

The carers who participated in the focus groups all shared that caring provides them with a sense of purpose and makes them feel useful. Whilst caring responsibilities often create a challengingly busy lifestyle, these carers also told us they enjoy being busy and actively look to fill their time. Therefore when posed with the idea of being granted an unanticipated day off, the participants unanimously found it difficult to imagine this scenario and respond with an alternative to caring. Many discussed feeling lost without caring, or as though there would be something 'missing' if this aspect of their life was removed even temporarily. Therefore the notion of having time off, or needing time off, did not fully appear as expected as caring is so central to a carers everyday life and routine.

Of course, Centre 404 knows that being a carer does not mean you are simply a victim of disadvantage and unhappiness. Alongside the myriad challenges, caring also provides great joy and reward, particularly so if caring for a loved one. However the extent of this became more apparent during the focus groups, as every individual carer described caring as a whole "*way of life*". One participant when asked this question, responded "*oh I don't know [pause]... look for caring! It's sort of in me, it's innate*" (co-carer). The role of caring for the focus group participants we spoke with is completely bound into their identity, sense of self and purpose. This led to further discussion highlighting particular instances whereby this feeling of a loss of purpose and intention intensified for the carers, such as the transition period when the cared for person moves into supported accommodation and out of their full-time care. These insights draw attention to specific support needs during times where carers may be feeling particularly lost and isolated, where the intervention of a male carers group could be beneficial to rebuild social networks and new routines, whilst still focusing this around the part of their identity that has been so central to their life's direction and purpose.

Although being busy and sustaining this sense of purpose as a carer is important to those we spoke with, it is essential that carers are provided opportunities for respite where possible and suitable. The importance of supporting carers to maintain a life outside of caring was apparent, not only to reduce stress associated with their caring role but also to aid the transition away from caring responsibilities in future. Having assurance their cared for person was safe and happy during any periods of respite though, is key for these carers to fully engage and participate in a group that takes them away from their loved one. Therefore running a group for male carers alongside one for their cared for person, could assist in enabling this to happen.

Q2. Tell us about your experiences of receiving support/advice about your role as a carer and the person you care for. What type of support have you sought and has been provided? How did you seek support?

Managing Expectations

Some carers discussed feeling “*let down*” by other services and consequently disengaging with them to find other alternative organisations to help, such as Centre 404. These conversations emphasised the need for services to carefully manage the expectations of those carers it aims to support and maintain strong and clear communication around the support available to them, so as to reduce the likelihood of disappointment and resulting disengagement with these much needed services. In a more encouraging response however, all focus group participants reflected very positively regarding the quality of support received from Centre 404 and how well these relationships and expectations have been managed by staff throughout this care.

Support with Personal Budgets

Much of the discussions in response to this question focused around the need for financial support; a need that the Centre 404 Supporting Families team already recognise and deliver a great deal of provision in. In particular, the group discussed challenges around managing personal budgets for their cared for person and communication from the local authority on the processes and procedures that must be followed in line with this service, often leading to a breakdown in reliance and engagement with this scheme. The group discussed a tension between carers and council services in terms of knowing what is best for their loved one and therefore how personal budgets should be spent. This often left carers feeling undermined and in some cases being told they have done the wrong thing and asked to repay money they have spent for their loved one.

These discussions raised a potential gap in available and transparent information about personal budgets, or access to this information and guidance for carers, to enable them to utilise this support for their loved one if they need it. In response, Centre 404 could consider running workshops for carers to provide information on the direct payments system, in how to access and utilise it appropriately. Furthermore, this demonstrates the necessity for the Centre 404 Finding and Matching Service and the need for this to be promoted to carers who are trying to navigate the complexities of this benefit system themselves.

Q3 & Q4. Discuss a time you have felt most stressed and under pressure in your caring role. What helped most when you were experiencing these challenges and worries?

Carers Under Scrutiny

A few participants discussed instances of feeling scrutinised and judged or under suspicion at times. As the health and safety of vulnerable people is constantly a concern and priority of health services, their carers are also commonly under the microscope and having to navigate difficult safeguarding discussions about the wellbeing of their loved one. Although these carers recognise and appreciate safeguarding enquiries and the crucial need for these by authorities and care providers, they also expressed how turning the attention to the capabilities of the carer can put great pressure on them which can cause heightened stress often in an already stressful situation. The ability of authorities to show compassion and a sensitive approach in such circumstances helps to minimise stress for carers. In addition, having an advocate who understands and knows the carer well who can help to explain their role could also assist in this scenario – Centre 404 caseworkers are well positioned to be this support if it's needed and appropriate.

Awareness & Training in Public Services

In connection with the above, carers further discussed positive and negative experiences of support from public services and schools. One carer shared how a lack of manual handling training at his daughter's school meant he was regularly called to attend when his daughter suffered an epileptic attack, where he would find teaching staff had not supported his daughter's physical needs appropriately and therefore compromised her health, causing intensified stress for the carer.

In a more encouraging discussion however, others spoke about positive experiences of the police service in dealing with situations involving their loved one. Carers praised the approach of police in regard to communication with the individual with a learning disability and reflected on the progress that has been made with awareness raising and training in past decades. In contrast to the sometimes difficult dealings with safeguarding authorities that scrutinise carers on occasion, carers spoke about the benefit of these developments in approaches by the police force which have worked to reduce the stress experienced by carers when having to interact with this public service. This highlights the importance of awareness raising and specialised training for public services in order to best support those with a learning disability, and equally their families and carers. To continue this important work, specialist organisations like Centre 404 should consider ways in which they can be a part of this progress within public services, for example towards training for police on how to communicate and work *with* family carers to best support and safeguard people with learning disabilities.

Similarly, carers mentioned that people with no experience of caring often "*find it genuinely impossible to understand the situation [of caring]*" (co-carer). To this end, the carers we spoke to explained it is for this reason they find it much easier to discuss caring issues with other parents/carers who have similar experiences and insights to them and therefore a better level of understanding. Again this emphasises the need for carers groups to exist for this means, and the potential benefit for bespoke groups such as our proposal for male carers.

Personal Care

“You end up as a carer doing things that otherwise you would never think of having to do as part of your life.”
-Co-carer

Another challenge raised during focus groups was in regard to providing personal care to the cared for person, particularly if this involved the male carer supporting a female loved one. Support with menstruation was an especially sensitive issue that carers found difficult to navigate and seek advice about. Delivering a workshop for male carers on personal care with a focused section on menstruation, would help to provide the information and guidance needed, along with a confidential space for male carers to ask potentially difficult questions and share experiences. By utilising Centre 404’s existing resources and using a male healthcare professional to deliver the session would aim to encourage engagement and open discussion, whilst also providing access to a supportive contact who carers can approach with related queries in future to ensure this support continues.

Putting it into Perspective

Less a situation of heightened stress and more a common emotional side effect of caring, carers discussed here feelings of loss and sadness felt upon realising their loved one may not experience the life and milestones these carers initially anticipated for them. This was discussed in relation to their loved ones reduced capacity for independence and the opportunities such as attending University or having a career this entails. In addition their capacity to establish relationships or experience intimacy was talked about in terms of a sense of loss. These expected milestones were often judged in comparison to their loved ones peers who do not have a learning disability. The carers expressed they found it hard to adjust their original expectations for their loved one and felt a recurring sense of loss when others were developing independence and gaining new experiences, whereas the cared for person appeared ‘behind’ in these life stages. This was also accompanied by concern and compassionate sadness for their loved one who they felt at times were becoming more isolated as a result.

The carers then spoke about ways in which they attempt to confront and ease these worries themselves. A prominent phrase repeated by carers throughout the focus groups was about *“putting things in perspective”*. As one carer explained, *“when you listen to other stories it puts things in perspective. You say ‘look, things are not so bad’, because other people are doing more difficult things, I should not be complaining”* (primary carer).

Although carers utilise this internal dialogue as a useful tool to pacify stress and emotional tension relating to some of the challenges of caring, it is as important that carers do not pacify these feelings to the extent of silencing them and reducing recognition of their own distress associated with the difficulties these individual carers sometimes experience. These insights further highlight the potential benefits of a male carers group; to provide a place to *“listen to others stories”* as part of the process of *“putting things in perspective”*, whilst also balancing this by allowing Centre 404 and other male carers to respond with recognition and acknowledgement of the difficulties that individual carers experience in their caring role, and consequently to address the impact of these on the carer.

Additionally, in relation to carers’ concerns about their loved one experiencing isolation resulting from a compromised capacity for developing independence and relationships, these concerns endorse the need for Centre 404’s Learning and Leisure services and appropriate signposting to these by caseworkers.

Q5. Tell us about what makes things worse and/or doesn't help when you are stressed about your caring role.

Wider Public Awareness and Understanding

As discussed on page 6, awareness and specialist training of learning disability within public services is crucial for people with learning disabilities and their carers to receive appropriate support. This was discussed further in answer to this question. The group identified that one of the most difficult things to deal with as a carer is a lack of public awareness about learning disability and specifically, the consequences of this upon their everyday lived experience, as well as for their loved one. Carers spoke of becoming very angry and frustrated when confronted with ignorant behaviour and attitudes towards them or their loved one in public, which exacerbated their levels of stress. A few carers also shared examples of this through their experience with schools, and others who they felt “*should know better*” (primary carer) and show more understanding given their role or knowledge of these carers’ situations. This was discussed particularly in regards to a perceived “*lack of sympathy*” demonstrated by some, both towards the child at school and the carer. As one primary carer explained:

“It’s always this situation of people who you think are capable, who can listen and understand, when they are just shocked, they are in a little box and don’t want to hear anything. This makes me very angry and frustrated and makes me want to fight for this boy because he can’t do it for himself. I’ve got to fight for him.”

The pressure of advocating for their loved one and raising public awareness of learning disability due to their experiences of a shortfall in knowledge and understanding, causes great tension and stress for these carers when they are trying to move through their everyday lives and routines. The unexpected nature of these continued public attitudes appears to heighten this stress and frustration further. Numerous carers even told of situations in which their loved one was financially abused due to their vulnerability, which further highlights an absence of public understanding and therefore compassion around learning disability.

These experiences demonstrate a continued need for public awareness raising around learning disability and also around the role of carers. This work needs to be propelled by organisations such as Centre 404 who have the resources to deliver campaigns on a more macro level in order to take some of this pressure off carers who are often forced to confront the public and challenge perceptions whilst trying to quietly get on with their everyday caring responsibilities. In addition, support to provide carers with these resources will enable them to feel better equipped in these situations and continue this work on a micro level through their interactions with schools and other public services.

Unreliable Support

Receiving support for their loved one either at home or within supported accommodation can be a huge help for carers in order to provide respite and also reassurance their loved one’s wellbeing is being taken care of. However, carers also spoke of times where external support has conversely caused increased stress. Examples such as bad punctuality or falling asleep during support were discussed, resulting in the respite for the carer being impacted and support for their loved one compromised. Carers explained that taking a step back from caring to allow another person to help can be difficult. So when the support then transpires as unhelpful and causes more stress, this can have a major negative impact on the carer and their ability to accept this essential support in future. The need for support services to recruit in a values-based way, provide quality training and supervision, and ensure lines of communication and feedback are constantly open for carers about the support they receive, are all crucial to ensuring that quality standards of care and support are met and maintained.

Q6. What would you like to see in a future Male Carers Group? What would you want to get out of it?

Running a Successful Group

Innovative Involvement

As presented in *Figure 2* (see page 3.), the availability of male carers is limited. The majority of carers we spoke to are either employed or caring full-time, which shows that a significant amount of their time is spent either working or caring. Through existing work, Centre 404 is familiar with the financial difficulty many caring families face and the associated pressures regarding employment. Taking time away from work was another strain discussed by the carers we spoke to. As such, finding the time to take part in any other activities or social life is a particular challenge. This was also very evident when attempting to recruit participants to take part in the focus groups, with many who although wanted to join in, were unable to commit the time in advance due to these existing commitments. Moreover, 2/9 participants were unable to attend on the day due to unexpected illness of their cared for person, which further highlights the difficulty in planning time away from these responsibilities.

For these reasons, a male carers group requires innovative involvement methods in order to include and therefore benefit as many carers as possible. For example:

- Holding regular groups, whilst also offering flexible scheduling such as varied times/day of week or weekend, could go some way in providing a session convenient for carers who wish to be involved, even if they are unable to attend all sessions.
- Holding inclusive sessions whereby carers are able to bring their cared for person with them and take part in an activity together, could reduce the pressure of trying to balance their time between caring and respite whilst also enabling them to spend quality time with their loved one away from the day-to-day. However, it is important to note that participants also discussed the need for additional support with inclusive group activities (in the form of extra Support Workers for example), to help avoid any potentially stressful situations that could take the carer and their loved one away from the group.
- Holding online group sessions could allow participation from home, for those who struggle to step away from caring. It may also encourage involvement of those who are apprehensive about joining a group and create an easier transition out of social isolation.

A Secure Space for Sharing

All participants agreed that sharing their individual experiences of caring within a group setting was an extremely positive and beneficial experience. They expressed it helped to feel less alone in their experiences of caring and the challenges that accompany these. Listening to others' experiences put their own into perspective, which served to somewhat alleviate feelings of unfairness and hardship. It also provided a non-judgemental space to vent any frustration about the challenges they may have experienced, in a controlled and facilitated setting. In order to allow this open sharing to take place, participants felt it important to ensure that a secure, confidential space is provided to do so. A private, quiet, uninterrupted room is required. In addition, having the session facilitated by male carers assisted to create a welcoming and empathetic environment to share openly and honestly in the knowledge there was shared understanding between members. Male to male, peer to peer support was highly valued in the group, with participants commenting on the ease in which they were able to engage with their male peers. This was particularly in comparison to other carers' events whereby the majority of attendees were female carers – although these were also useful

and enjoyable to participate in, the male carers felt that having an all-male group provided a different dynamic to what they were commonly familiar with.

“One of the things that surprised me is, I was thinking ‘it’s a group of men, we are going to be sitting here staring at a wall’, and we’ve done nothing like that at all, it’s been very constructive. Very eye opening.” –Co-carer.

b. Other Key Insights

Support and Awareness at Work

Focus group one (primary carers) shared common experiences regarding the challenges faced during employment when explaining their circumstances to management and requesting time off to care for their cared for person. Participants described difficulty in approaching managers about flexible working and discussed perceived societal expectations around gender roles associated with caring that prevented a comfortable environment in which to have these discussions at work. The male carers we spoke to felt this was easier for women to negotiate at work due to social gender norms and views about caring. Group discussion tended to focus on carers’ interpretation of the external societal factors that may influence this, however the way in which male carers themselves identify with their caring role and how this is communicated to others’ could be to some extent useful to consider here – particularly when providing advice to male carers about their rights in the workplace.

A survey and subsequent report produced in partnership between Carers Trust and Men’s Health Forum (2014) that looked into the experiences and needs of male carers, highlights that over one quarter of male carers in employment are not as likely to identify or describe themselves as a carer to others and consequently their need for support might not be immediately clear and thus could result in them not receiving the required support.

As indicated in this discussion excerpt from three male carer participants during the focus group:

Carer One: *Maybe society has become more accustomed to the idea. Especially when it comes to children, it’s women looking after children, for centuries it has been that way and even if you start doing the job of looking after somebody, you find it a little bit odd too. I remember, I was working somewhere, it was always difficult to go and tell the line manager ‘look, I’m looking after my child and he’s not feeling well and I have to go.’*

Carer Two: *I’ve been in working environments where... if they [female carers] wanted time off, they would just need to say ‘I’ve got some issues that I need to resolve’, they wouldn’t need to go into detail about looking after someone or that they had an appointment somewhere. And the manager, who was normally a man, would go ‘oh alright, yeh whatever, how many days do you want?’. Whereas a man wouldn’t get that, he wouldn’t make that approach.*

Carer Three: *And I think it’s often unintentional as well. I think a lot of the time when a man finds himself as the main carer, it’s not, well certainly it wasn’t my plan to be a main carer, and I think I would have had an assumption early on that I would not have been a main carer. And in fact, I probably tried not to be the main carer and the assumption was that my son’s mother was naturally going to go into the role because of our gender roles. And then it didn’t quite manifest that way so I found myself as the main carer. But I don’t think I prepared myself, and I didn’t start with the expectations that I would be the main carer.*

Although it is likely that male carers already engaged with and accessing Centre 404 services identify more explicitly with their role as carers, this research could indicate a continued need to support their communication with others about this and their related individual needs within certain circumstances such as employment discussed here. In addition, providing information about carers' rights, specifically to male carers, is essential to ensure they receive services and benefits in line with these needs and feel comfortable and confident to ask for them.

Understanding and Managing Guilt

A number of the male carers who participated in the focus groups talked of experiencing feelings of guilt. Guilt could feature when spending time away from the cared for person or taking part in an activity to benefit the carer, seemingly unrelated to the wellbeing of the cared for. It was also discussed in relation to getting frustrated or sad about the carers own circumstances and feeling guilty about complaining (both internally and expressly) about these circumstances. This would on occasion be accompanied with feeling as though the carer 'should' be feeling happy about the rewards of caring, rather than sad about the challenges. Feelings of guilt also appeared when thinking about the situation of other carers; putting their own circumstances "in perspective" in comparison to other carers who appear to be worse off than themselves. The depth and recurrence of these feelings of guilt identified by these carers indicate a potential need for practical and emotional support to manage this. Centre 404 may want to consider delivering a workshop to benefit carers who experience this guilt in order to improve wellbeing. A safe space where carers can openly discuss and share these experiences, and learn ways to understand and manage them could be useful. This may also go some way in raising awareness about and challenging the taboo of carers' guilt.

c. Summary of Recommendations

Some of the insights raised by the male carers and discussed throughout this report are already recognised and also addressed by Centre 404's existing services. This provides reassurance that Centre 404 is very in touch with the needs of its beneficiaries, whilst also reconfirming the continued need for existing provision. In addition however, some insights have highlighted additional needs and areas for growth and development within our services. A summary of recommendations in line with all these insights as discussed above, are outlined here:

- i. **The need for provision when the caring role reduces and/or provision to support the preparation of this eventuality.** A male carers group could be beneficial for [re]-building social/support networks and new routines for carers during times when their caring role is reduced and they are open to feeling lost or lacking in purpose/direction as a result of their caring role reducing. For example, referrals of male carers to the group when they are preparing for or going through the process of transition of the cared for person leaving home. Providing respite for these carers should also consider their need for reassurance their loved one is being cared for well in their absence, so as to enable the carers to fully engage and participate in a group.
- ii. **Manage carers' expectations.** From the moment a referral is made and a carer is in touch with Centre 404, it is important for caseworkers to discuss and remain transparent (as much as is possible) about what Centre 404 are able to support with and the possible outcomes of this support for the carer and their family. This includes areas where there is a chance Centre 404 may not be able to provide support or may try and not succeed, such as in relation to benefit

applications for example. Communication with the carer should be maintained to continue to manage any expectations or where circumstances may change.

- iii. **Support with Personal Budgets.** There is a potential gap in available and transparent information about personal budgets, or access to this information and guidance for carers to enable them to utilise this support for their loved one if they need it. Centre 404 should consider running workshops for carers to provide information on the direct payments system, in how to access and utilise it appropriately. Furthermore, caseworkers should ensure they promote and refer carers to the Centre 404 Finding and Matching Service, for those who are trying to navigate the complexities of this benefit system themselves.
- iv. **Partnership working with public services.** Through its specialism, Centre 404 is well positioned to aid public services with training and awareness raising for their workforce. Centre 404 should consider how it can partner to help public services and authorities learn how to work with people with a learning disability, and equally with their families/carers to support them in the right way and work collaboratively together to safeguard people with learning disabilities. This work would also go some way in demonstrating Centre 404 as experts in the field and raise its own profile locally. In addition, equipping carers with the tools to raise awareness themselves and develop better ways of communicating their needs, for example in schools, will aid this process further.
- v. **Public awareness raising.** Similarly to the above recommendation, Centre 404 is well positioned to work actively in the local community to raise awareness around learning disability and the role of carers. Centre 404 is often focused on the important detailed work it carries out with individuals and families. But by developing a successful local campaign the organisation would raise its profile whilst developing awareness, which would support carers in their day-to-day encounters with the public by reducing the need for individual carers to be taking on this responsibility themselves.
- vi. **Advocacy during safeguarding enquiries.** Working closely with family carers, caseworkers come to know and understand a family's needs and dynamics very well. This can be particularly useful and applied in supporting a family carer through advocacy work if a carer is going through any safeguarding enquiry in relation to the person they care for. This should alleviate some of the pressure and scrutiny felt by carers within these circumstances, by helping them to communicate about their situation and role as a carer.
- vii. **The need for bespoke groups.** The carers we spoke to explained they find it much easier to discuss caring issues with other parents/carers who have similar experiences and insights to them and therefore a better level of understanding. More specifically, a male carers group could provide a place to "*listen to others stories*" as part of the process of "*putting things in perspective*" that male carers discussed (see page 7). As well as providing a space for carers to implement this coping mechanism, this would be balanced by allowing Centre 404 and other male carers to respond with recognition and acknowledgement of the difficulties that individual carers experience in their caring role, and consequently to address the impact of these on the carer within a group setting.

This emphasises the need for carers groups to exist for these means, and the potential benefit for bespoke groups such as our proposal for male carers. Centre 404 should consider this need when developing new groups and services in future.
- viii. **Personal care advice and support.** Delivering personal care workshops would help carers access information about personal care without having to approach services for support around this issue

themselves. In addition, holding a workshop specifically for male carers would be hugely beneficial to provide advice and guidance around supporting a female loved one with menstruation, and provide a confidential space for male carers to ask questions and share experiences about a sensitive issue.

- ix. The need for quality, reliable support for the cared for person and its consequential impact on the carer.** If support for the cared for person is of low quality, this increases the stress and anxiety experienced by carers and makes them less likely to accept external help in future to receive the respite they need themselves. The need for support services to recruit in a values-based way, provide quality training and supervision to frontline support staff and managers, as well as ensure lines of communication and feedback are constantly open for carers to discuss the support they receive, are all crucial to ensuring that quality standards of care and support are met and maintained. This will subsequently reduce the likelihood of stress upon the carer and enable them to communicate any concerns before reaching this point.
- x. Innovative involvement & engagement.** A male carers group requires innovative involvement and engagement methods in order to include and therefore benefit as many carers as possible. For example:
- Hold regular, varied and flexible groups
 - Hold inclusive sessions whereby carers are able to bring their cared for person with them and take part in an activity together. However, it is important to note that participants may also need additional support with inclusive group activities (in the form of extra Support Workers for example), to help avoid any potentially stressful situations that could take the carer and their loved one away from the group.
 - Hold online group sessions to allow participation from home for those who struggle to step away from caring and to create an easier transition out of social isolation.
 - A secure, confidential space for sharing experiences in a non-judgemental and facilitated setting.
- xi. Support with identifying as a carer and communicating their needs.** Male carers in particular often need support to fully identify as a carer and recognise their rights and needs in relation to this role. In line with this, support around how to effectively communicate their individual needs with others within certain circumstances (specifically within the context of employment) is also crucial. Providing information about carers' rights is essential to ensure they receive services and benefits in line with these needs and feel comfortable and confident to ask for them.
- xii. Support to recognise, understand and manage guilt.** The depth and recurrence of feelings of guilt identified by carers indicates a potential need for practical and emotional support to manage this. Centre 404 should consider delivering a workshop to benefit carers who experience/or may experience this guilt in order to improve wellbeing. A safe space where carers can openly discuss and share these experiences, and learn ways to understand and manage them could be useful. This may also go some way in raising awareness about and challenging the taboo of carers' guilt.

5. *The Male Carer Experience: Insights from a Carer*

I was really eager to take part in this research when Lottie contacted me. So much so that I went to both of the focus group meetings and on to the group that has met a few times after. The reason is that I know very well just how hard it can be to care for someone as a man. It is probably one of the rare times when our privilege is inversed. We often have been less able to embrace a role which demands patience and compassion and a general un-celebratedness that is usually and often left for women. But then it turns out that almost half of carers are men and along the line we have found ourselves out of the opportunity to help each other and embrace the mind-set! I have had to give up a lot of the opportunities that have been laid out for me simply because of the sleepless nights, exhaustion and being roughed up that caring, often alone, for a full-on son entailed. Even now that he has gone into care, it is difficult to adjust back into a more traditional male role.

As a male carer, my social experience has been of a kind othering. People generally respond so well and supportively when they find out about your circumstances, but from a distance. Also, I have had an estrangement from the friends and circles I was part of before. It is simply not possible to keep up with or maintain an interest in things which become quite fickle. Who wants to talk about some political intrigue when your child has had you up at 4am having a seizure? And really, if you are having a nice day, who wants someone offloading that information onto you? We are often estranged and deprived of the space to share and relate to others in a genuine way. I barely have had the tools to do this, again, something a male carers group can hopefully provide space for.

I know this report emphasises guilt, and indeed that is so important. I have come to learn that I feel less guilty as I allow my vulnerability to take light and as others do the same, together we learn that we all are 'only human' and simply need to 'try again'. Caring can mean that we are faced with situations we will never really be able to cope with, which will mean we make mistakes every day, and that we doubt and want to escape our situation. In a way this is made worse by being told you are so great and wonderful maybe. Even writing this bit about guilt, I have had two or three memories emerge that have made me feel guilt and it really hurts. These are things we live with and having a male carers group provides an opportunity to keep these feelings in perspective.

The other part of the puzzle is that it is the same situation of caring that makes me hide my vulnerability, which makes me feel guilt that I then have to take to the authorities to seek help with. It is a catch 22 in some ways. Almost all carers need help from the authorities to cope (e.g. with benefits, respite or advice) and the way you get that help is by being honest about your challenges and circumstances - the very things we find hardest to tell. And then you find that in fact it is a bit more confrontational with the authorities than you realised, and that you have to deal with someone not really believing the troublesome truth that you need a break and are having trouble coping. And then shifting the gear, often alone, from asking for help from a very vulnerable emotional place to fighting to get help, and then finding that the help you have sought is not really helpful enough or gets taken away before you know it. It is all a real strain and again I think made more challenging for me by the particular 'male' conditioning that I have had - if I could be vulnerable without being ashamed then that would be easier.

This is where organisations like Centre 404 are so valuable. It is where we can get together and get on each other's side. I really celebrate the work of Lottie (the Research and Development Coordinator) and the organisations' initiative to do this work, it has benefited me and the other men I have met so far. Thank you.

-Paul Formosa. Primary carer, research contributor and valued volunteer.