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What happens when I can no longer support my autistic relative? Worries about the future for family members of autistic adults.

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Conflicts of Interest

The authors declare that they have no conflict of interest.

Language

Based on the findings from the research conducted by UCL and the NAS, we have used preferred language as detailed from this report (i.e. autistic people/people on the autism spectrum).

Abstract

Very little is known about autism and adulthood. Family members are often the primary support for autistic adults and frequently express concerns about what the future will hold and what support will be available for their relative. 120 family members of autistic adults completed an online survey exploring concerns about the future for their relative. The most endorsed concerns were “their needs won’t be met” (77% worried weekly), “whether they will be happy” (72% worried weekly) and “who will care for them” (58% worried weekly). The results highlight the importance of implementing structured and timely support through collaboration with governmental policy, local commissioning and communication with charities to help prepare family members and their autistic relative for the future.

Keywords

Adults, Autism, Family Members, Future, Support, Worry.

Very little research to date has focused on adulthood for autistic individuals and even less is known about the lives of family members of autistic adults. Experiences of autistic adults and their parents/carers are only now beginning to receive research attention. Dell'Osso, Dalla Luche and Maj (2015) and Mandell (2013) both highlight that for some individuals, autism is not diagnosed until adulthood, and there are a growing number of individuals receiving a diagnosis in later life. Howlin, Goode, Hutton and Rutter (2004) report that the majority of autistic adults live with their parents or other family members, highlighting the significant ongoing role families play in supporting autistic adults. Hodapp and Urbano (2007) report 60% of adults with disabilities are cared for in the family home by ageing parents. It is therefore unsurprising that many family members worry about the future for their child, particularly in terms of where support will come from, once their capacity to provide it diminishes or they die (Eaves & Ho, 2008).

The support available to autistic children and their families typically reduces significantly into adulthood placing more responsibility on individual family members to provide support for their autistic relatives, when there is a lack of service provision (Graetz 2010; Gray, 2003; Howlin and Moss 2012; Blacher, Kraemer & Howell, 2010). Bianco, Garrison-Wade, Tobin and Lehmann (2009) found that parents of children with developmental disabilities expressed concern and felt apprehensive when attempting to access adult support services. In addition to this, 72% of caregivers of adults with disabilities, including autism, report that they have not made any long-term plans for the future (Dillenburger & McKerr 2011).

The impact of caring for an autistic relative on family members is potentially significant, often meaning adjustments must be made to carers' own lives in order to fulfil the responsibilities required (Glasberg, Martins & Harris, 2006; Mailick Seltzer, Greenberg, Floyd, Pettee & Hong, 2001). Hock, Timm and Ramisch (2012) and Saini and colleagues

(2015) explored the pressure and strains associated with caring for an autistic child or adolescent on marriage and family life and found divorce rates to be higher among couples caring for a child with a disability than those supporting a typically developing child. Indeed, high levels of stress and anxiety have been reported in a number of studies of family members of autistic individuals (Eisenhower, Baker & Blacher, 2005; Myers, Mackintosh & Goin-Kocel, 2009; Pisula, 2007). Little and Clark (2006) found that the most pressing concern for parents was for their child's adult life and future. Browning, Osborne and Reed (2009) also found that autistic adults themselves were concerned about their future and worried that they did not possess adequate coping skills to manage in stressful situations and were concerned about failure.

Concerns are reported to be more prevalent in parents of autistic adults compared with parents of adults with other development disabilities (Blacher et al., 2010). Recent enquiries into the quality of care in residential settings highlight the vulnerability of adults with higher support needs (Krauss, Seltzer & Jacobson 2005). Equally, autistic people living more independently in the community are at risk of becoming increasingly more isolated and vulnerable as the availability of familial support decreases (Perkins & Berkman, 2012). Therefore, concerns reported by family members about the future are apparent across the autism spectrum, irrespective of ability or presence of additional disabilities or level of independence (Glasberg et al., 2006).

A review of 'The Global Landscape of Autism Research' (Office of Autism Research Coordination (IACC/OARC), 2012) discusses seven critical questions for research, one of which highlights lifespan issues relating to what the future holds, for autistic adults. In addition, Autistica's Top 10 Research Priorities ("Autism: Top 10 Research Priorities", 2016) include; "#3 What are the most effective ways to support/provide social care for autistic

adults?” and “#6. How can parents/family members be supported to care for and better understand their autistic relative?” Thus far, there has been no systematic investigation of the specific nature of the concerns of family members of autistic adults or their suggestions as to what might help them to prepare their family for the future. This information is critical to inform appropriate, targeted service provision and guide future research.

The aims of this research are to assess the nature and scale of concerns regarding the future for family members of autistic adults. Specifically, whether family members have concerns, and if they do, which concerns are the most frequent. By increasing knowledge about the nature and impact of these concerns, a greater understanding of the specific and tailored support needed for family members of autistic adults can be developed, which in turn will inform policy and practice, to better support the autism community.

Methodology

Design and Analysis

The study is a single group, survey-based design. An online survey was created to facilitate nationwide participation. A mixed methods approach has been used (Cresswell & Clark, 2011). The majority of questions provided quantitative data, which yielded descriptive statistics of the frequency and intensity of concerns and worries expressed by family members for their autistic relative. For free text responses, thematic analysis guided by the method outlined by Braun and Clarke (2006) was used. Themes and sub-themes were derived from the free text analysis. The themes were then weighted and ordered in terms of their relevant frequency, to highlight the most common themes.

Participants

One hundred and twenty relatives of autistic adults completed the online survey 'Uncertain Futures' (n=120). Participants were recruited via National charities, including Research Autism, Scottish Autism, the National Autistic Society and The North East Autism Society. Participants were also recruited through the Adult Autism Spectrum Cohort (AASC-UK), a database hosted at Newcastle University. AASC-UK provides opportunities for autistic adults and their relatives to engage in research (<http://research.ncl.ac.uk/adultautismspectrum/>). These charities and services helped advertise the anonymous link to the survey for participants to access. Two hundred and one individuals initially accessed the online survey. Twenty-five individuals dropped out at the first question, which may suggest they wished to look at the survey but did not wish to complete it, a further 27 dropped out when asked the age of the relative they were supporting, suggesting that they may not have been a relative of an autistic adult or may have been the family member of an autistic child. A further 23 participants dropped out once reaching about a third of the way through the survey. Finally, 6 participants then dropped out when asked about the frequency of their worries. One hundred and twenty participants completed the survey, participants were considered to have 'completed' the survey if they had less than five incomplete questions.

Procedure

The content of the survey was guided by a recent literature review regarding concerns family members may have for their autistic relative (Herrema et al, in prep). The survey was presented on Qualtrics™ and the design, content and formatting were adapted based on feedback from members of the research team, including an adult with Asperger's syndrome and a parent of an autistic adult. Participants were directed to the survey through charities, service providers, websites, e-mails and social media advertising the web link and information about the study. In line with time constraints for the funded study, the survey was available for 10 weeks.

At the beginning of the survey, participants provided demographic information about themselves and their autistic relative. The next set of questions were derived from themes from the recent literature review (ibid). These questions addressed a range of concepts related to uncertainty about the future for autistic individuals; residence, day-to-day activities, support from other services, finance management, relationships with others and sense of fulfilment. Participants were asked to rate how frequently they experienced these concerns and rank a series of statements in order from most concerning to least concerning. In addition to this, participants were asked to identify, in their own words, five things they hoped for their relatives' future and five things which would enable them to achieve this.

Ethical approval

A favourable ethical opinion for the study was provided by the Faculty of Medical Sciences at Newcastle University. Participants were given detailed information regarding what the survey would involve and contact information regarding local support and how to contact the Primary Investigator of the research. Participants were requested to indicate their consent within the first question, prior to accessing the survey. Participants were made aware of the confidentiality procedure and that their contributions were completely anonymous. On exiting the survey, participants were presented with debriefing information and contact details for relevant support services.

Results

Respondent Demographic Information

Table 1 provides information about the age, gender, location, and marital status of respondents, as well as their relationship to the autistic adult they are supporting. As can be seen in Table 1, the majority of respondents were mothers of autistic adults (72%), and respondents were based across the UK. Table 1 shows demographic information for family members of autistic adults.

Table 1 - Respondents demographic information

| Question | Categories | Frequency and Percentage |
|--|---------------------------------|---------------------------------|
| Gender | Male | 14 (12%) |
| | Female | 106 (88%) |
| Age | Minimum | 25 |
| | Maximum | 71 |
| | Mean | 54 ± 9 (SD) |
| Marital Status | Single, never married | 11 (8%) |
| | Married or domestic partnership | 93 (78%) |
| | Widowed | 2 (2%) |
| | Divorced | 12 (10%) |
| | Separated | 2 (2%) |
| What is your relationship to the individual on the autism spectrum? | Mother | 86 (72%) |
| | Father | 11 (9%) |
| | Sibling | 11 (9%) |
| | Carer | 2 (2%) |
| | Spouse | 6 (5%) |
| | Other, please specify | 4 (3%) |
| Location | Northern England | 55 (46%) |
| | Midlands | 9 (7%) |
| | Southern England | 20 (17%) |
| | Scotland | 34 (28%) |
| | Wales | 2 (2%) |

Demographic Information about the autistic family member

Table 2 outlines the demographic information about the autistic adult the respondents were supporting. Of note, 60% of autistic adults lived in the family home and 67% were primarily supported by the family member responding to the survey. Respondents indicated that another family member, other than themselves, would care for their autistic relative in the future (29%), 33% would be cared for by a non-family member, whereas 36% of respondents were unsure who would support their relative in the future.

Table 2 – Demographic Information about the autistic adult receiving support

| Question | Categories | Frequency and Percentage |
|-----------------|-------------------|---------------------------------|
|-----------------|-------------------|---------------------------------|

| | | |
|---|--|--------------|
| Gender | Male | 85 (71%) |
| | Female | 35 (29%) |
| Age | Minimum | 18 |
| | Maximum | 67 |
| | Mean | 28 ± 11 (SD) |
| Age of Diagnosis | Minimum | 0 |
| | Maximum | 60 |
| | Mean | 16 ± 13 (SD) |
| Diagnosis | Autism | 27 (23%) |
| | Autism Spectrum Disorder (ASD) | 46 (38%) |
| | Asperger's Syndrome | 45 (37%) |
| | Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) | 2 (2%) |
| | | |
| Co-morbid Difficulties (tick all that apply) | Intellectual/Learning Disability (LD) | 49 (41%) |
| | Attention Deficit Hyperactivity Disorder (ADHD) | 19 (16%) |
| | Anxiety | 100 (83%) |
| | Depression | 56 (47%) |
| | Fragile X Syndrome | 0 (0%) |
| | Epilepsy | 13 (11%) |
| | Sleep disorders | 32 (27%) |
| | Challenging Behaviours | 52 (43%) |
| Other, please specify | 56 (47%) | |
| Marital Status | Single, never married | 107 (89%) |
| | Married or domestic partnership | 9 (7%) |
| | Divorced | 1 (1%) |
| | Separated | 3 (3%) |
| Living Arrangements | In the family home | 72 (60%) |
| | In supported accommodation | 9 (8%) |
| | In a residential care home | 6 (6%) |
| | Living Independently | 19 (15%) |
| | Other, please specify | 14 (11%) |
| Employment Status (tick all that apply) | Unemployed | 58 (48%) |
| | Studying at College | 21 (17%) |
| | Studying at University | 12 (10%) |
| | Working full-time | 13 (10%) |
| | Working part-time | 17 (14%) |
| | Doing Volunteer work | 20 (16%) |
| | Attending Day Centres | 10 (8%) |
| Other, please specify | 38 (31%) | |
| Main Source of Support | Respondent | 80 (67%) |
| | Other Family member | 19 (16%) |
| | Carer | 1 (1%) |
| | Support Worker | 9 (7.5%) |
| | Personal Assistant | 1 (1%) |
| | External Service | 9 (7.5%) |
| Future Source of Support | Other Family Member | 35 (29%) |
| | External Service | 24 (20%) |
| | Carer | 6 (5%) |

| | |
|----------------|----------|
| Other | 9 (8%) |
| Don't know | 43 (36%) |
| Not Applicable | 2 (2%) |

Main Worries or Concerns about the Future

Table 3 shows the most frequently endorsed worries or concerns family members have, when participants were asked to rank these statements in order of most concerning to least concerning. The median rank of each statement was calculated. These statements are presented in Table 3 from the highest median rank to the lowest median rank. The proportion of people who ranked each statement as the most concerning is also indicated. Participants also rated the frequency with which they worried about each concern, in order to be able to rank worries in order of which was the most frequently concerning to least frequently concerning. The most frequent concerns were “*whether they will be happy*” (72% worried weekly) and “*who will look after/care for them*” (58% worried weekly).

Table 3 - The most endorsed worries/concerns

| Rank | Statement/Worry | Percentage of respondents who rated as most concerning |
|--------------------|---|---|
| 1 Most Concerning | Whether they will be happy | 39% |
| 2 | Who will look after/care for them | 11.9% |
| 3 | Where they will live | 21% |
| 4 | How they will spend their days | 6.8% |
| 5 | Their own vulnerability from others/organisations | 8.5% |
| 6 | Their finances | 6.8% |
| 7 | Their relationships with others | 2.5% |
| 8 Least Concerning | “Other” | 3.4% |

Participants were asked to rate their frequency of worry for a series of concerns from *not at all to every day*. The information from these statements was collated and organised in terms

of which concerns about the future were worried about most frequently. The five most frequent worries are shown in Table 4. These were analysed by calculating which concerns were endorsed most frequently, as something that was worried about at least weekly. This table lists the top five of the most frequent worries from family members for their autistic relative. The most frequent concern in this table showed 77% of respondents worried at least weekly that *their relatives' needs won't be met in the future*.

Table 4 – Most Frequent Worries

| Worry | Frequency | Percentage |
|--|------------------|---------------------------|
| “I worry that their needs won't be met” | 92 | 77% worry at least weekly |
| “I worry that they won't have a good quality of life” | 91 | 76% worry at least weekly |
| “I worry that they will be lonely” | 88 | 73% worry at least weekly |
| “I worry that they won't be happy” | 86 | 72% worry at least weekly |
| “I worry that they won't be able to communicate their needs” | 85 | 72% worry at least weekly |

Table 5 reports how prepared respondents felt their relative was for the future and any steps taken in terms of future planning. Forty-four percent of respondents stated that they had begun to plan for their relative's future in some capacity, however, 28% of respondents had reflected that they would like to begin to plan for their relative's future but were unsure where to start. Sixty-four percent of respondents stated their autistic relative was “*not at all prepared*” for the future and 70% worried about this *at least weekly*.

Table 5 - Preparedness for future

| Question | Response | Frequency and Percentage | N |
|--|---------------------|---------------------------------|----------|
| How prepared do you feel X is for the future | Not at all prepared | 76 (64%) | 119 |
| | Slightly prepared | 24 (22%) | |

| | | | |
|---|--|----------|-----|
| if their current level of support diminishes? | Somewhat Prepared | 11 (9%) | |
| | Very Prepared | 2 (2%) | |
| | Completely Prepared | 1 (1%) | |
| | Prefer not to say | 2 (2%) | |
| Over the past month, how often have you worried about X's future if their current level of support diminishes? | Never | 7 (6%) | 119 |
| | Once/twice a month | 15 (12%) | |
| | Once/twice a fortnight | 12 (10%) | |
| | Once/twice a week | 30 (25%) | |
| | Every day | 54 (45%) | |
| | Prefer not to say | 1 (1%) | |
| Have you done anything to date to plan for X in the future? | No, I think it is too soon. | 20 (18%) | 113 |
| | No, I would like to but I don't know where to start. | 32 (28%) | |
| | No, I don't feel the need to (Not Applicable). | 11 (10%) | |
| | Yes, I have started to plan for X's future. | 50 (44%) | |
| When thinking about preparing for X's future, do you think feeling worried has stopped you from making progress with any future planning? | Definitely yes | 23 (20%) | 113 |
| | Probably yes | 18 (16%) | |
| | Unsure | 31 (27%) | |
| | Probably not | 21 (19%) | |
| | Definitely not | 20 (18%) | |

Table 6 and 7 show the themes derived from free text responses indicating five things hoped for their relatives' future and five things which would enable them to achieve these. Using a thematic analysis based approach (Braun & Clarke 2006), these responses have been categorised into themes and sub-themes. These themes were then organised by their relative weight from most frequently noted by family members, to show the prioritisation of these

hopes, as well as factors that would enable autistic adults to achieve these hopes in the future.

Table 6 – Themes based on hopes of family members for “X” in the future

| Themes | Sub-Themes |
|-----------------------------------|--|
| 1. Good Quality of Life | <ul style="list-style-type: none"> a) Happy b) Good health – physical and mental c) Active with interests d) Starting own family e) Acceptance of diagnosis f) To be part of the community/be involved in society |
| 2. Social Relationships | <ul style="list-style-type: none"> 1. Good circle of friends 2. Good familial relationships 3. Romantic relationships – with someone understanding 4. Maintenance of current relationships 5. Relationships with others with autism 6. Not be alone/isolated |
| 3. Housing/Residence | <ul style="list-style-type: none"> 1. Appropriate – adapted to needs, independent where possible 2. Supported |
| 4. Independence | <ul style="list-style-type: none"> 1. Sense of autonomy and fulfilment 2. Feeling valued |
| 5. Support | <ul style="list-style-type: none"> 1. Consistent 2. Reliable 3. Accessible 4. Quality of Care |
| 6. Employment | <ul style="list-style-type: none"> 1. Appropriate to needs – flexible, understanding, adaptable 2. Satisfying, enriching |
| 7. Autism Knowledge/ Awareness | <ul style="list-style-type: none"> 1. Increased knowledge by others – professionals, relatives, public 2. Understanding of additional difficulties, e.g. sensory |
| 8. Financial | <ul style="list-style-type: none"> 1. Security 2. Stability 3. Consistent with current benefits |
| 9. Safety | <ul style="list-style-type: none"> 1. Not vulnerable in relation to danger, abuse or manipulation 2. Ability to communicate needs or have an advocate 3. Be secure in terms of finance, employment and residence |

Table 7 – Themes based on what 5 things family members would need in place to achieve their hopes

| Themes | Sub-Themes |
|---|--|
| 1. “Appropriate” Support | a) Day-to-day b) Trustworthy/Reliable c) Personalised d) Mental Health Support e) Quality of Care – staff who genuinely care for their relative f) Accessible and Flexible g) Informed |
| 2. Opportunities for “X” | a) Be involved in the community b) Be able to pursue interests and hobbies c) Be able to achieve what they want to for employment, residence, future family/relationships |
| 3. Finances | a) Continuation of benefits/welfare payments b) Funding c) Lottery Win (!) |
| 4. Autism Knowledge/ Awareness | a) Well qualified experienced staff in support b) Public Awareness c) Professional Knowledge d) “Proper” training in autism |
| 5. Local Authorities/ Government Support | a) Recognition of current problems and willingness to adapt support b) Collaboration with parents and families c) Legal advice and support |
| 6. Residential Support | a) Appropriate amount of support b) Independence where possible c) Safe community |
| 7. “My” Support | a) Continued Familial Support b) Sibling Support in future |
| 8. Employment Support | a) Flexible b) Employer aware of autism and additional needs c) Fulfilment, value in work |
| 9. Safety | a) Security, not vulnerable from abuse |
| 10. Engagement from “X” | a) Enthusiasm and willingness from “X” to plan for future b) Understanding from “X” of where to seek support |
| 11. “I don’t know” | a) Uncertainty |

Discussion

To our knowledge this is the largest online survey to date to be conducted with family members of autistic adults. Forty-one percent of respondents stated their relative also had an

intellectual disability indicating that the sample was representative of the autistic population (Shattuck, 2006).

It is imperative that we find out more about the lives of autistic adults and their family members and carers, because at present so little is known. The results here illustrate that family members of autistic adults do frequently experience significant concerns and worries about the future for the autistic adults that they support. The data illustrate the range of concerns experienced and highlight the importance of implementing structured and timely support plans to help prepare all members of the family for the future. This finding has been emphasised by previous research which demonstrates the importance of effective support services (Gupta & Singhal, 2005; Hare et al., 2004; Renty & Roeyers, 2006). Our findings highlight the importance of listening to family members, in order to incorporate their needs and wishes in to the development of appropriate support for their relatives and the wider autism community. Robertson (2009) stressed the importance of a collaborative approach with family members and professionals working together, to provide the best possible support and of course, this should also include autistic adults themselves.

Our findings demonstrate the importance of support for families and autistic adults, on a practical level, for example, to help to organise finances, find appropriate housing and obtain and maintain suitable employment. This is further highlighted by the themes from the free text comments provided by family members, relating to their views of what would be needed in order to achieve what they hoped for their relative in the future. Practical support to address their autistic relatives' basic needs, such as obtaining secure finances, employment and safe residence, were expressed as a frequent concerns alongside the belief that achievement of these needs would promote independence for the autistic adult and greater feelings of confidence and mastery in relation to their future security and quality of life. Our

findings are in line with Bennett, Wood and Hare (2005) who highlighted the importance of targeting the specific needs of autistic adults to ensure efficient service provision. In addition, Powell (2002) specify services required for autistic adults including health, housing and employment.

As well as practical support, the need for individual professionals and services to have a thorough understanding of autism and provide good quality of care and be 'trustworthy' were highlighted. Powell (2002) also stated the importance of increased professional knowledge of autism, in order to provide efficient support. This finding was emphasised further by the respondents most frequently expressed worries, which were associated with their relatives being able to communicate their needs to professionals who would understand and meet those needs. Seventy-seven percent of family members reported worrying at least weekly that their family members' needs won't be met in the future. It was suggested by family members that communication with professionals may be improved if those working with the family had a thorough understanding of autism and an awareness of the specific difficulties autistic individuals may experience.

In line with Hodapp and Urbano (2007) and Howlin and colleagues (2004), in our sample 60% of autistic adults lived in the family home, whilst 16% were supported by another family member and only 7.5% were receiving support from an external service. These results highlight the significant, long-term involvement of family members in the lives of autistic adults and authenticates concerns regarding future care, beyond the time at which those providing current levels of support are able to support their autistic relative. Twenty-nine percent of respondents indicated that another family member would provide support in the future, whereas 36% "didn't know" who would care for their relative in the future.

Dillenburger and McKerr (2011) reported that 72% of carers in their sample had not made any long-term plans for the future.

Concerns were also expressed relating to the quality of care that autistic adults may receive in the future and whether support in the future could *match up* to the care that families had been able to provide over a lifetime of understanding their relatives' specific needs and capabilities (Krauss, Seltzer & Jacobson 2005). Respondents in our survey expressed concern that "*no one will be able to care for them as well as I have*" (58% worried at least weekly) and "*I worry about their care not being appropriate*" (56% worried at least weekly). This was further highlighted within the free text responses where family members emphasised that "*appropriate*" support was imperative in order to sufficiently assist their relative to achieve their full potential. These concerns demonstrate the high levels of uncertainty and worry experienced by family members related to the suitability about their relative's future care and support. This further emphasises the need to capitalise on and tap into the expertise and unparalleled knowledge that family members have, in relation to the care of their autistic relatives, as well as consulting directly with the autistic person themselves. These data point clearly towards the need for effective person-centred planning with the whole system around the autistic adult.

Research from Gray (2002) highlights the increased stress levels experienced by parents of autistic individuals and a dearth in support and services for this. In addition Graetz (2010) discussed the lack of support for caregivers of autistic adults. Respondents in our sample indicated that 83% of the autistic adults they were supporting experienced anxiety and 47% experienced depression, highlighting the prevalence of co-morbid mental health difficulties within this population. These co-occurring difficulties may contribute to specific concerns that family members have regarding future care and support for mental health difficulties

over and above the care and support needs conferred by an autism diagnosis. This may be particularly apposite given the already documented difficulties experienced by autistic individuals accessing services for problems with physical health problems (Mandell, 2013). In addition Rao and Beidel (2009) state that treatment programs need to address parental stress as well, in order to optimize familial outcomes.

Our research has some limitations. Our survey only included family members of autistic adults and of course it is critical to hear from the autistic people themselves about their concerns and worries about their future. We need to be mindful of the representativeness of our sample given the heterogeneity within the autism community. In addition, those accessing the survey may be a biased sample, who particularly related to the focus of the study on worries regarding the future, especially as participants were recruited mostly through their involvement in services or charities. Another potential limitation is that the majority of family members who completed the survey were mothers (n=86, 72%), which may bias the data obtained towards their views. Future research should endeavour to gain the views of a wider range of family members. Finally, we have no data regarding diversity, socio-economic status and cultural background of the participants and these factors may impact in important ways on the nature of worries and concerns.

Recommendations

The findings from this research highlight the significant, pervasive and frequent worries that relatives of autistic adults experience in relation to future care for the adult they are supporting (Hare et al., 2004). Future research could explore whether some of these worries are specific to autism spectrum disorder or whether family members of adults with other developmental disabilities have similar concerns. Family members have emphasised the importance of future support being delivered by services with a good knowledge of autism

and which are flexible and person-centred, which is also emphasised in research from Renty and Roeyers (2006). Current support for autistic adults and their family members is extremely limited and thus, it is not surprising that family members feel concerned about what might happen to their relative when they are no longer able to care for them (Graetz, 2010; Hare et al., 2004).

This unmet need could be directly addressed in two ways; firstly service providers should increase knowledge of autism amongst their personnel and adapt services to ensure that they are accessible to this population. Secondly, policy makers need to place the needs of autistic adults and their families on the agenda, to ensure a top down approach to the development of provision and influence local commissioning. In order to achieve this, it is imperative that the voices of autistic adults and their families are heard, and charities and advocacy groups continue to have a key role to play in facilitating this process, to work towards a time when autistic adults are supported across the lifespan, alongside their family members and carers.

Conclusion

The findings from this research support and build on existing literature regarding the prevalence of worries for family members of autistic adults. In particular, the lack of support and services available for autistic adults and their family members is a primary concern, and in order to sufficiently enable autistic adults and their family members to not only meet basic needs and requirements but also to thrive, autism specific and tailored services are essential.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Attwood, T. (2004). Cognitive behaviour therapy for children and adults with Asperger's syndrome. *Behaviour Change*, 21(03), 147-161.
- Autism: Top 10 Research Priorities. (2016, October 08). Retrieved from <https://www.autistica.org.uk/research/top10/>
- Autistica's Research Strategy 2015-20 (2016, October 08). Retrieved from <https://www.autistica.org.uk/wp-content/uploads/2014/11/Autistica-Research-Strategy-2015-2020.pdf>
- Baine, D., McDonald, L., Wilgosh, L., & Mellon, S. (1993). Stress experienced by families of older adolescents or young adults with severe disability. *Australia and New Zealand Journal of Developmental Disabilities*, 18(3), 177-188.
doi:10.1080/07263869300034941
- Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). *Ignored or ineligible?: the reality for adults with Autism Spectrum disorders*. London: National Autistic Society.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of intellectual disability Research*, 51(9), 702-714.
- Bennett, H. E., Wood, C. L., & Hare, D. J. (2005). Providing Care for adults with Autistic Spectrum Disorders in Learning Disability Services: Needs-based or Diagnosis-driven? *Journal of Applied Research in Intellectual Disabilities*, 18(1), 57-64.

- Bianco, M., Garrison-Wade, D. F., Tobin, R., & Lehmann, J. P. (2009). Parents' perceptions of postschool years for young adults with developmental disabilities. *Intellectual and developmental disabilities, 47*(3), 186-196.
- Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: population-based 13-to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of autism and developmental disorders, 35*(3), 351-360.
- Blacher, J., Kraemer, B., & Howell, E. (2010). Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter?. *Advances in Mental Health and Learning Disabilities, 4*(1), 3-16.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.
- Bristol, M. M., & Schopler, E. (1983). Stress and coping in families of autistic adolescents. In *Autism in adolescents and adults* (pp. 251-278). Springer US.
- Browning, J., Osborne, L. A., & Reed, P. (2009). RESEARCH SECTION: A qualitative comparison of perceived stress and coping in adolescents with and without autistic spectrum disorders as they approach leaving school. *British Journal of Special Education, 36*(1), 36-43.
- Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research, 20*(8), 1279-1294.
- Creswell, J. W., & Clark, V. L. P. (2007). Designing and conducting mixed methods research.

- Daniels, J. L., Forssen, U., Hultman, C. M., Cnattingius, S., Savitz, D. A., Feychting, M., et al. (2008). Parental psychiatric disorders associated with autism spectrum disorders in the offspring. *Pediatrics*, *121*(5), e1357-e1362.
- Dell'Osso, L., Dalle Luche, R., & Maj, M. (2015). Adult autism spectrum as a transnosographic dimension. *CNS Spectr*, *9*(September), 1-3.
- Dillenburger, K., & McKerr, L. (2011). 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities*, *39*(1), 29-38. doi:10.1111/j.1468-3156.2010.00613.x
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of autism and developmental disorders*, *38*(4), 739-747.
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, *49*(9), 657-671.
- Farley, M., & McMahon, B. (2014). Range of Outcomes and Challenges in Middle and Later Life. In *Adolescents and Adults with Autism Spectrum Disorders* (pp. 211-238). Springer New York.
- Gehardt, P. F. (2009). *The current state of services for adults with autism*. New York: Organization for Autism Research.
- Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy*, *41*(1), 37-45.
- Glasberg, B. A., Martins, M., & Harris, S. L. (2006). Stress and coping among family members of individuals with autism. *Stress and coping in autism*, 277-301.

- Graetz, J. E. (2010). Autism grows up: Opportunities for adults with autism. *Disability & Society, 25*(1), 33-47.
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3), 215-222. doi: 10.1080/1366825021000008639
- Gray, D. E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine, 56*(3), 631-642.
- Gupta, A., & Singhal, N. (2005). Psychosocial support for families of children with autism. *Asia Pacific Disability Rehabilitation Journal, 16*(2), 62-83.
- Hare, D. J., Pratt, C., Burton, M., Bromley, J., & Emerson, E. (2004). The health and social care needs of family carers supporting adults with autistic spectrum disorders. *Autism, 8*(4), 425-444.
- Hastings, R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4-5), 231-237.
- Herrema, R., Robson, R., & Rodgers, J. (2016) *Anxiety about the Future for Autistic Adults and their families: A Literature Review*. Manuscript in preparation.
- Hock, R. M., Timm, T. M., & Ramisch, J. L. (2012). Parenting children with autism spectrum disorders: A crucible for couple relationships. *Child & Family Social Work, 17*(4), 406-415.
- Hodapp, R. M., Glidden, L. M., & Kaiser, A. P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental retardation, 43*(5), 334-338.

- Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: findings from a large-scale US survey. *Journal of Intellectual Disability Research, 51*(12), 1018-1029.
- Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229.
- Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry, 57*(5), 275-283.
- Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *Journal of intellectual disability research, 49*(2), 111-124.
- Little, L., & Clark, R. R. (2006). Wonders and worries of parenting a child with Asperger syndrome & nonverbal learning disorder. *MCN: The American Journal of Maternal/Child Nursing, 31*(1), 39-44.
- Mailick Seltzer, M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American journal on mental retardation, 106*(3), 265-286.
- Mandell, D. S. (2013). Adults with autism—A new minority. *Journal of general internal medicine, 28*(6), 751-752.
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heartache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders, 3*(3), 670-684.

- Mukaetova-Ladinska, E. B., Perry, E., Baron, M., & Povey, C. (2012). Ageing in people with autistic spectrum disorder. *International journal of geriatric psychiatry*, 27(2), 109-118.
- Office of Autism Research Coordination (OARC), National Institute of Mental Health and Thomson Reuters, Inc. on behalf of the Interagency Autism Coordinating Committee (IACC) (2012). IACC/OARC autism spectrum disorder research publications analysis report: The global landscape of autism research. (2017, February 15) Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/publications-analysis/july2012/index.shtml>.
- Orsmond, G. I., Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (2006). Mother-child relationship quality among adolescents and adults with autism. *American Journal on Mental Retardation*, 111(2), 121-137.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research*, 51(9), 682-696.
- Perkins, E. A., & Berkman, K. A. (2012). Into the unknown: Aging with autism spectrum disorders. *American journal on intellectual and developmental disabilities*, 117(6), 478-496.
- Pisula, E. (2007). A comparative study of stress profiles in mothers of children with autism and those of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 20(3), 274-278.
- Powell, A. (2002). *Taking Responsibility: Good practice guidelines for services-adults with Asperger Syndrome*. National Autistic Society.

- Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior modification*, 33(4), 437-451.
- Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10(5), 511-524.
- Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Studies Quarterly*, 30(1).
- Saini, M., Stoddart, K. P., Gibson, M., Morris, R., Barrett, D., Muskat, B., et al. (2015). Couple relationships among parents of children and adolescents with autism spectrum disorder: Findings from a scoping review of the literature. *Research in Autism Spectrum Disorders*, 17, 142-157.
- Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 10(4), 234-247.
- Shattuck, P. T. (2006). The contribution of diagnostic substitution to the growing administrative prevalence of autism in US special education. *Pediatrics*, 117(4), 1028-1037.
- Shu, B. C., & Lung, F. W. (2005). The effect of support group on the mental health and quality of life for mothers with autistic children. *Journal of Intellectual Disability Research*, 49(1), 47-53.

- Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current psychiatry reports, 14*(6), 732-738.
- Weiss, J. A., & Lunskey, Y. (2011). The brief family distress scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of child and family studies, 20*(4), 521-528.
- Wolf, L. C., Noh, S., Fisman, S. N., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of autism and developmental disorders, 19*(1), 157-166.