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BRIEF REPORT

Brief Report: What Happens When I Can No Longer Support My Autistic Relative? Worries About the Future for Family Members of Autistic Adults

Renske Herrema[1] · Deborah Garland[2] · Malcolm Osborne[3] · Mark Freeston[4,5] · Emma Honey[4,5] · Jacqui Rodgers[1,6]

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

Introduction

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 et al. (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 et al. (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 and 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 et al. 2010). Bianco et al. (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,

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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).

✉ Jacqui Rodgers
jacqui.rodgers@ncl.ac.uk

[1] Faculty of Medical Sciences, Institute of Neuroscience, Newcastle University, Newcastle Upon Tyne, UK

[2] National Autistic Society, Newcastle Upon Tyne, UK

[3] The Kayaks Support Group, Tyne and Wear, UK

[4] Faculty of Medical Sciences, School of Psychology, Newcastle University, Newcastle Upon Tyne, UK

[5] Northumberland, Tyne and Wear NHS Foundation Trust, Newcastle Upon Tyne, UK

[6] Clinical Psychology, Institute of Neuroscience, Newcastle University, Ridley Building, Newcastle Upon Tyne NE1 7RU, UK

report that they have not made any long-term plans for the future (Dillenburger and 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 et al. 2006; Seltzer et al. 2001). Hock et al. (2012) and Saini et al. (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 et al. 2005; Myers et al. 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 et al. (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 et al. 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 and 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. 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 Twenty-seven 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, six 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. 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 blinded for review. 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

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%)

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.

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.

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).

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 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.

Tables 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 and 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.

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 and Singhal 2005; Hare et al. 2004; Renty and 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

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%)

Table 2 (continued)

Question	Categories	Frequency and percentage
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%)

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

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

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 et al. (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 et al. (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

Table 5 Preparedness for future

Question	Response	Frequency and percentage	N
How prepared do you feel X is for the future if their current level of support diminishes?	Not at all prepared	76 (64%)	119
	Slightly prepared	24 (22%)	
	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%)	

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 et al. 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

Table 6 Themes based on hopes of family members for "X" in the future

Themes	Sub-themes
1. Good quality of life	(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	(a) Good circle of friends (b) Good familial relationships (c) Romantic relationships—with someone understanding (d) Maintenance of current relationships (e) Relationships with others with autism (f) Not be alone/isolated
3. Housing/residence	(a) Appropriate—adapted to needs, independent where possible (b) Supported
4. Independence	(a) Sense of autonomy and fulfilment (b) Feeling valued
5. Support	(a) Consistent (b) Reliable (c) Accessible (d) Quality of Care
6. Employment	(a) Appropriate to needs—flexible, understanding, adaptable (b) Satisfying, enriching
7. Autism knowledge/awareness	(a) Increased knowledge by others—professionals, relatives, public (b) Understanding of additional difficulties, e.g. sensory
8. Financial	(a) Security (b) Stability (c) Consistent with current benefits
9. Safety	(a) Not vulnerable in relation to danger, abuse or manipulation (b) Ability to communicate needs or have an advocate (c) Be secure in terms of finance, employment and residence

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

Table 7 Themes based on what five 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

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.

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Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

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