Glasgow City Council

Housing & Autism Spectrum Disorder (ASD) Survey 2009

Analysis & Findings



Housing Strategy, Housing Investment Development & Regeneration Services (DRS)

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Background to the Survey

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a developmental disorder that affects the way a person thinks, learns and communicates. It impairs the ability to form relationships and understand emotions. There are three main features associated with the condition:

- Difficulties in relating to or understanding other people or social situations.
- Difficulties in acquiring and oddities in the use of communication (approximately 50% of those with autism never develop spoken language, and those that do often have problems like immediate and/or delayed echolalia and pronominal reversal)
- A lack of imaginative ability, often substituted by obsessive, repetitive behaviour and a strong resistance to change.

For some people the condition may be severe and disruptive, undermining their capacity to live independently. Such people although responding to early intervention will require substantial and ongoing support. Others may only experience subtle effects in social behaviour. It will have a minimum impact on their capacity to live a normal life, require little by way of support and may remain undiagnosed.

Autism is a disability under the Disability Discrimination Act (DDA) 1995. As a public authority, Glasgow City Council is under a legislative requirement to act proactively on disability equality issues which complements the individual rights under the DDA.

Prevalence of ASD in the General Population

ASD cuts across all social and ethnic groups in equal measure although males are 4 times as likely to have ASD than females.

Estimating the number of people with ASD in Greater Glasgow is an important precursor to planning and delivering the right type and level of services. It is unclear the precise number of individuals with ASD there are in the Greater Glasgow area. Given current prevalence rates it is estimated that there may be as many as 8,000 individuals¹, but problems with diagnosis have meant that only around 15% have been identified.

The National Autistic Society (NAS) report 'Autism in schools: crisis or challenge?'² found that the rate of ASD reported by teachers is more than three times higher in primary than in secondary schools. Regardless of whether this represents a real increase in prevalence or reflects the availability of better diagnostic services, more people with autism spectrum disorders now require services than ever previously realised.

Glasgow City Council's Response to Arising Housing Issues

In response to families raising concerns and issues around Housing and ASD, Glasgow City Council's Executive Committee "instructed the Executive Director of Development and Regeneration Services to report back in 6 months on how the specific needs of families with children with Autism Spectrum Disorder would be met" (Executive Committee 15th August 2008).

The Autism Working Group was established to take forward the ASD agenda through joint working and is chaired by Councillor Christopher Mason. Work on Housing & ASD was remitted to a subgroup and is chaired by Councillor Graeme Hendry. The Sub-Group has representation from the Glasgow Autism Resource Centre, Scottish Federation of Housing Associations, Glasgow and West of Scotland Forum of Housing Associations, Glasgow Housing Association, the Scottish Society for Autism, The National Autistic Society, Development & Regeneration Services (Glasgow City Council), and parents of children with ASD.

¹ Figures calculated using a prevalence rate of 91 in 10,000. Source: Wing 1996 & National Autistic Society 1995.

^{1995.} ² Barnard, J. et al, Autism in schools: crisis or challenge?, NAS: London, 2002,

Objectives of the Survey

- To examine the current and future housing needs of families with children with ASD
- To assess the housing support needs of families with children with ASD
- To understand how best to target housing information and advice to families
- To form an evidence base to inform and further develop housing policy and practice in Glasgow in all tenures

Methodology

There is no comprehensive contact database for people with ASD in Glasgow and therefore, no easily accessible population on which to base a survey. Members of the Housing & ASD Sub-Group proposed that the housing needs of families with children with ASD could be examined through a survey questionnaire targeted at families with school-age children with a diagnosis of ASD (questionnaire is in Appendix 1).

Education Services, Glasgow City Council, provided a list of all educational establishments with an estimate of the number of children with a diagnosis of ASD and a letter was drafted from the Service Director of Education Services requesting that schools distribute these survey forms to households, highlighting the importance and status attached to this data collection.

In January 2009, Development & Regeneration Services (DRS) distributed the questionnaire forms to schools to be distributed to parents of children with ASD, with a deadline set for return by 27 February 2009. A reminder was sent out to all schools resulting in additional survey returns.

1274 survey forms were requested by schools and sent out to schools. 282 survey questionnaires were returned which is a response rate of 22.1% and is within expected response rate limits for a postal questionnaire.

Very useful quantitative data was gathered from the survey and the consistent messages which came through respondent's written comments provide rich and detailed accounts of the particularities of housing problems. Views and comments expressed by respondents are reflected in the Analysis and Findings section under grouped themes and have been condensed, but continue to mirror the relative volume of comments between these themes. More minority views are also represented.

240 respondents said the Council could contact them in the future if more in-depth research is required.

This report has been written by Jennifer Sheddan, DRS Housing Strategy Team

Summary Findings

The survey results underline the significance families give to appropriate housing in enabling the development of children with ASD, and improving the quality of life for these individuals and for the wider family.

"I don't think it is understood how unsatisfactory poor housing can affect autistic children in their development when they can't play out like other children and the sensory issues with noise and disruption"

"My accommodation supports my son at this present time, as it allows him his own bedroom. We have an enclosed back garden and most importantly we do not have neighbours below us who do not understand when my child has a 'melt-down'. Our accommodation also allows my child to be like his peers and go out to play in the cu de sac that is secure."

The respondents and their families live in all tenures and in every type of property across the city.

There is a high incidence of single adult households with children with ASD which is significantly higher in the rented sectors.

The majority of households have only one child with ASD but almost 80% of households have more than 1 child.

The results underline the high priority given to friend and family networks in influencing the decision of where households locate due to the high levels of support provided by them with the most frequent reason given for families living in their current accommodation being the location and to be near friends, family and school.

Over a quarter of respondents indicate their current accommodation is the best of limited options, citing the lack of availability of larger houses and issues of housing affordability.

62% of respondents report their present home does not meet their needs with highest incidence in the rented sectors. The most frequently reported reasons for housing need are not enough bedrooms meaning siblings are sharing, rooms being too small, and lack of access to a safe and secure garden. Other reasons cited include housing affordability constraints coupled with caring/ working commitments creating a barrier to purchasing a more suitable property, access to funding for adaptations and in particular extensions, housing association allocation policies or housing staff not recognising housing need, and difficulties in living in proximity to neighbours with a particular focus on the need for improved soundproofing.

41% of respondents indicated their family's housing needs would change significantly in the next 5 years. Due to the age profile of the children with ASD (average age of 10), most of the change involved the need for more space for the family enabling the children to fully develop and to foster independence.

Half of all respondents receive support from their family and friends with a quarter receiving support from Social Work Services or the Health Service. A fifth of all respondents stated they received no support at all. The importance of benefit payments to families was highlighted by the frequency of being mentioned under 'other support'.

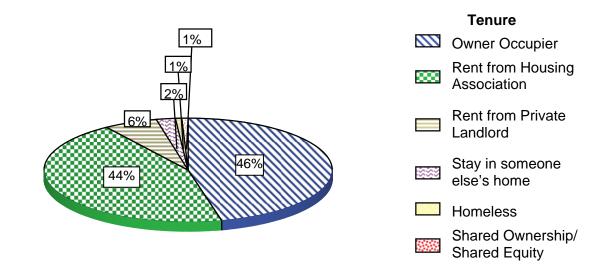
There were generally low levels of reported access to housing information and advice. Housing Associations were the most regularly quoted place where respondents get information and advice on housing, and this included households who currently rent socially and privately, and those who own.

Survey Analysis & Findings

Profile of Respondents and Housing

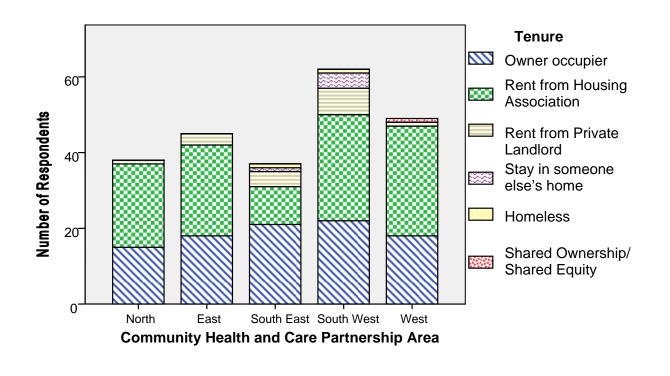
Housing Tenure

The respondents' tenure profile generally reflects that of the city, with slighter higher percentages in social rent and lower in the private sector (owner occupation & renting from a private landlord).

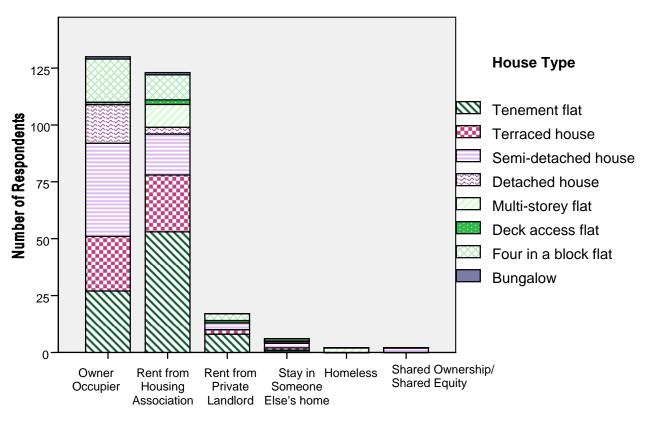


Area of Residence

The respondents to the survey are resident across the Glasgow city area.



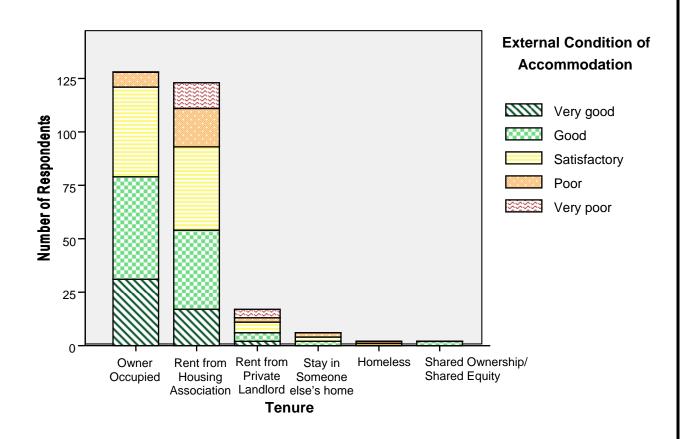
<u>Type of Property by Tenure</u> A higher proportion of renting households (both socially renting and privately renting) live in flatted house types with a greater proportion of owner occupiers in houses.



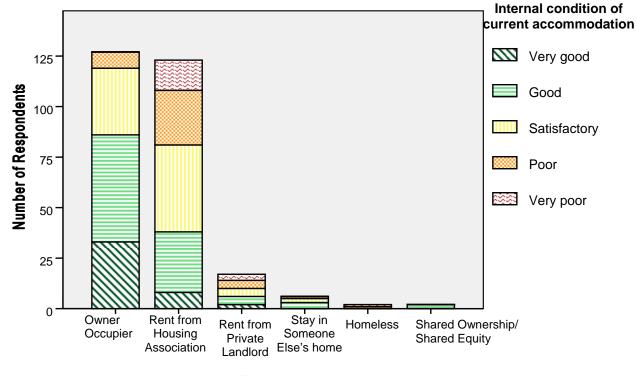
Tenure

External Condition of Housing by Tenure

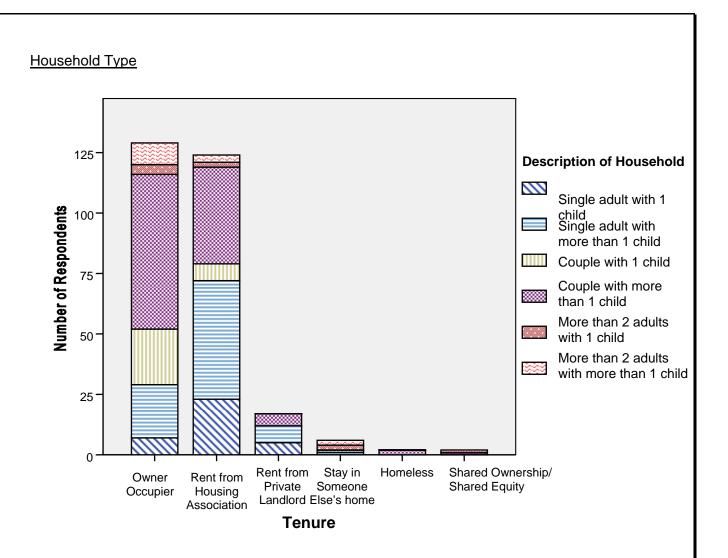
A higher proportion of respondents in the rented sector report poorer house condition both to the external and internal of the property.



Internal Condition of Housing by Tenure



Tenure



Single adult households

41% of all respondent households are single adult households with the remaining 59% being comprised of more than 1 adult. As can be seen from the bar chart above, there is a much higher incidence of single adult households with children with ASD in the rented sector (58% social renters, 71% private renters) than owner occupiers (22%).

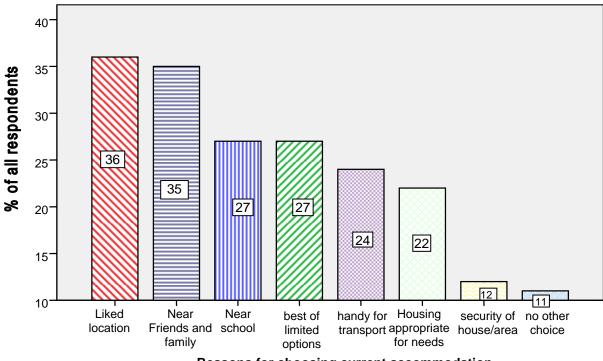
Children with ASD and siblings

92% (260) of households have 1 child with a diagnosis of ASD, 6% (18) households have 2 children with a diagnosis of ASD with 1% (3) households having 3 or 4 children with ASD.

Only 22% of households with a child with ASD are single child households with the remaining 78% having more than 1 child.

Current Accommodation

Reasons given by respondents for choosing current accommodation



Reasons for choosing current accommodation

- 36% liked location
 - o 53% owner occupiers
 - o 23% social renters
 - o 18% private renters (3)

• 35% near friends and family

- o 40% owner occupiers
- o 29% social renters
- o 41% private renters (7)

• 27% near school

- o 38% owner occupiers
- o 16% social renters
- o 41% private renters (7)

• 27% best of limited options

- o 22% owner occupiers
- 30% social renters
- 53% private renters (9)

• 24% handy for transport

- 33% owner occupiers
- o 16% social renters
- 12% private renters (2)

• 22% housing appropriate for needs

- 29% owner occupiers
- o 14% social renters
- o 12% private renters (2)

• 12% security of house/ area

- o 18% owner occupiers
- o 7% social renters
- 6% private renters (1)

• 11% no other choice

- 2% owner occupiers (3)
- o 19% social renters
- o 12% private renters (2)

Other Reasons

"Close to family for support and for sharing caring responsibilities."

"Separation from partner left few options."

"Importance of garden for stress reduction for all of the family and for helping children develop socialising skills."

"All that family could afford."

"Caring responsibilities reduce the ability to work, thereby reducing choice in housing."

"Near to work."

"Cul de sac location and so away from busy roads. One child has no sense of danger so unable to live near busy road, need cul-de-sac or similar."

"No other choice as previous property was being demolished."

"Overcrowding in previous accommodation."

"Living with family was creating a stressful situation for everyone."

"Two household indicated that they did not have any choice in their current home as they are asylum seekers."

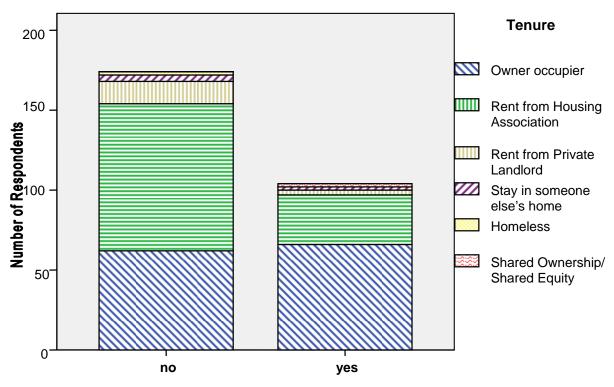
"We were the first family to move into the Cul de Sac this was also important for my son as he was comfortable and settled before other families moved in. We also watched the progress of the other houses. Moving house for a child with ASD is extremely stressful and can be a long process for them to adjust."

"I was re-housed due to the high flats I was living in are going to be demolished. I did receive medical points for my son which means I cannot be housed any more than 1 storey high".

Current Housing Needs

62% (174) of households report their present home does not meet their needs.

- The highest rates are in North, East then West, South East and South West.
 - This includes 82% private renters, 75% social renters, 48% owner occupiers.



Present home meet housing needs

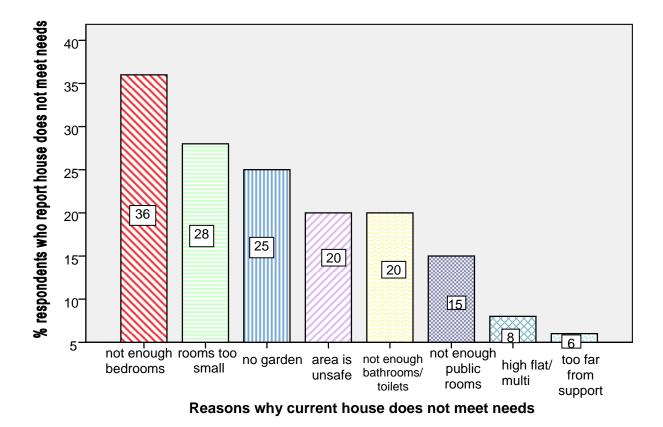
Attempts to Meet Housing Need

53% (90) of all households who reported their house did not meet their housing needs have tried to move to meet their needs and were unsuccessful.

- o 79% (11) private renters
- o 60% social renters
- o 38% owner occupiers

Reasons for Housing Needs

Of the respondents whose current house does not meet their needs, below are the reasons reported by respondents.



Not enough bedrooms

Of all survey respondents, 41% households have children with ASD who share bedrooms

- o 53% private renters (9)
- o 46% social renters
- o 33% owner occupiers
- o highest in South West and West

Of those respondents who reported that their current housing did not meet their needs, 36% respondents stated that there were not enough bedrooms

• bigger issue in Housing Association Stock and Private Rented

Respondents' Views

"Four bedroom houses are very difficult to acquire from the housing association we are with."

"Having an extension built onto the side of our house would benefit us greatly, it would give our son his own room and possibly a chill out area for him to relax in when needed."

"Need a better area and a house with 4 bedrooms. Haven't applied again as don't see the point, won't get anywhere with it."

"We would benefit from having a room specifically for his needs where we could have only his things because sharing, noise, light, behaviour, coordination are all problems." "More choice of 5/6 apt areas would help or help with some adaptations without feeling that you've just asked for a kidney."

"With only one public room our son has to use his bedroom for both playing and sleeping. He therefore has difficulty separating playtime and sleep time."

"The other child would like to sleep but he can't because the one with ASD is jumping and running constantly."

"Both of my sons have very different ASD needs, so can't share a bedroom. One is violent in his sleep, the other doesn't sleep, so is up 20-30 times a night. As a result I have to have one sharing my room which means no privacy for me and as they are getting older this is becoming more of a problem."

"As a family we need separate bedrooms for both kids. My other child without Autism has been falling asleep at school and his education is suffering because his sister is disruptive during the night."

Rooms are too small

Of those respondents who reported that their current housing did not meet their needs, 28% respondents stated that the rooms were too small

• bigger issue in Housing Association Stock and Private Rented

Respondents' Views

"We are very lucky to have been able to move into a larger more suitable flat 2 1/2 years ago. This improved our lives dramatically!"

"My son has a very small box room which distresses him as has difficulty with appropriate play and has no access to any safe play areas."

Access to a garden

Of all survey respondents, 25% have access to a shared garden and 13% do not have access to any garden. This is higher (47%) for social renters and private renters (37%) in comparison to owner occupiers (22%).

Of those households who do have access to a garden (private or shared), 23% report that the garden is not secure.

Of those respondents who reported that their current housing did not meet their needs, 25% respondents stated that there was no garden

• bigger issue in Housing Association Stock and Private Rented

Respondents' Views

"A garden would be a benefit but Maryhill doesn't have a lot of housing with gardens."

"Because of my son's difficulties, he is bullied regularly by other kids when he goes out, we would benefit greatly with a garden."

"He is susceptible to bullying (in our area NOT at school) and it would be a huge improvement in his/our quality of life if we were able to obtain a house with a garden of our own where he could get out and play when he wanted in a safe environment with his own friends."

"Safer environment outside would be better - i.e. away from traffic and wide, open, safe, grassy area within eye contact. Otherwise ASD kids don't go out much."

"Shared garden, won't go out to play. My son would benefit having his own back garden. Kids with ASD live in their own little world. When he's in the garden playing and the kids next door come out, he gets very upset and comes back in the house and won't go back out."

"My son cannot play outside in the community shared garden at the back by order of the Housing Association (no ball games, trampolines etc)."

"I would like a more secure garden to have outdoor space for my child. This would foster his independence and social skills."

"No driveway/fence at front. Our son is constantly running into the path of oncoming vehicles when we go out to the car and when we park to come back in. He likes the sensation of either drivers' faces or the oncoming headlights."

"He doesn't really go out to play and this is where a private garden would help, to stop him staying indoors when not at school."

"It is hard walking the streets every day or night of your life when a simple safe garden would be a god-send."

"I had to make the garden secure myself as the housing association wouldn't."

"Our son has Asperger's and is massively hyper-active. He would hugely benefit from having outdoor space and a family room. We re on the top floor of a tenement and find it virtually impossible to allow him to play outdoors."

Area is unsafe

Of those respondents who reported that their current housing did not meet their needs, 20% respondents stated that the area is unsafe

• bigger issue in Housing Association Stock and Private Rented

Respondents' Views

"We live in front of a railway track and behind a busy main road."

"The constant hanging about of teenagers outside my house is bad, the shouting and fighting upsets my son."

Not enough bathrooms/ toilets

Of those respondents who reported that their current housing did not meet their needs, 20% respondents stated there are not enough bathrooms or toilets

• bigger issue in Owner Occupation

Respondents' Views

"Large amount of time spent in toilet, preventing other family members access."

"Another bathroom or toilet is needed as my son is sick quite a lot as he doesn't digest his food properly due to a food phobia."

"Both my boys need their own space due to sleep patterns and toileting issues."

"Another toilet would be good as she doesn't like to be disturbed and takes a long time in the toilet."

Not enough public rooms

Of those who reported that their current housing did not meet their needs, 15% respondents stated that there were not enough public rooms

• bigger issue in Private Rented and Owner Occupation

75% of all respondents stated their child with ASD would benefit from having larger or more public rooms.

High flats do not meet needs

Of those respondents who reported that their current housing did not meet their needs, 8% respondents stated that the high flats did not meet their needs.

bigger issue in Private Rented and Housing Association Stock

Respondents' Views

"As I live in a high rise block of flat we have to use a lift which is always under maintenance, this distresses the boys who find any change to their routine very hard to cope with."

"Stairs - for an overactive autistic child a constant danger"

Location is too far from support which is needed

Of those respondents who reported that their current housing did not meet their needs, 6% respondents stated that the location is too far from support which is needed.

bigger issue in Housing Association Stock

<u>Respondents' Views</u>

"I need to be beside my family as they are the only ones (except my GP) who give me support."

"My child would benefit greatly if I was housed beside my parents and family who support and help me with my child."

"Although our home is fine for our needs, there is no local school with a provision for ASD children. We are currently awaiting a decision regarding a placement at Ruchill Autism Unit."

Other Identified Housing Issues

<u>Affordability</u> "The shortfall in rent means I have very little money to provide the things/activities. As a result I am looking for accommodation out with Glasgow resulting in a school change for my son."

"I had to find this accommodation myself. I have been in and out of Private rented Accommodation for the last 12 yrs. My house before then was a Housing Association and I got absolutely no help even though my children were in danger. Although this house is suitable for us. We get no extra help in meeting the costs of rent, even though on benefits. Housing Benefit does not cover full rent. I have very large payment to make myself every month."

"The rent shortfall on our property is so large it takes almost all of my son's DLA to cover it."

"I have had to reduce my working hours to care for him. Unfortunately I am not able to get a new mortgage on affordability. I am not wanting to sell my property as I am not wanting to be in a position of having to take on a rented house in an area which would not be convenient for school and work and that I may not be able to afford. This is why I have stayed in my current house, if I could get a house with my own garden this would be more beneficial for my son."

"His own bedroom would help. He shares a room with his sister as he is becoming a young man I feel he should have a room of his own, but because I own my flat and can't afford to move I feel we are stuck here."

"Losing home due to financial reasons will be looking to rent property."

"I have tried (unsuccessfully) to be rehoused via a Housing Association - we have found a new private let (stupidly expensive) with an extra room, but it is 3 miles from our current address, local schools etc."

"Family suffering stress through economic hardship. Is difficult to provide children with activities and stimulation necessary to support ASD."

Adaptations & Extensions

"We built an extension to our home 3 years ago to help meet our son's needs. It seems because our son is not in a wheelchair he falls through some kind of loophole. We asked our social worker for help, however, SWS were unable to help with a grant to build this adaptation. My son met all the criteria that they set out and we still received NO help. We then had to borrow over £60,000 to get our house to a standard that would help our son."

"We live in a 3 bedroom semi-detached house that we bought before we had our kids. Unfortunately we cannot afford to buy a bigger house. The only affordable solution to us as home owners is to extend but we can't afford that at present either so we really just have to cope with what goes on."

"I have been in touch with the OT's and are awaiting funding for my garden to be secured, as it's not fair that my son cannot play without me."

"Cannot open windows as children try to climb out and cannot get window restrictions."

"Extended house for son to have the room he needed and own bathroom funded by ourselves. Sadly bathroom is not a wet room which he needs and has flooded bathroom many times causing damage."

"My son doesn't share a bedroom because we have put up a partition wall between him and his 8 year old sister - this means rooms are very small with no soundproofing."

"I have applied for a grant to convert my loft which was turned down flat, no funding in place for ASD, will not apply again, what's the point? Same answer 'No grants available'."

Housing Options and Information & Advice

"As it is a mortgaged house we are limited as a family by what we can afford. Both parents work so this excludes them from Housing Association property. More rooms is the main problem to give the children more space, more privacy."

"The house I am living in is my first and I am not really sure how to go about getting a new house. Some advice would be greatly appreciated."

Housing Association Allocation Policies and Priority

"I had no choice as was homeless, it was take it or leave it even though my children's needs were clearly stated."

"I am currently sharing a bedroom with my son. I need medical points for my son's medical application form. I have never received and medical points at all."

"I was very fortunate to have medical points awarded to help my housing needs ten years ago."

"Moved from a private let with 2 bedrooms to a house with a Housing Association. 3 bedrooms but boys can't share and daughter has a room, I have no bedroom and sleep on sofa in living room."

"The Housing Association judge no. of bedrooms on age of children which means my 3 girls share a small bedroom. My son's room is actually downstairs in what I would class a dinning

room but Housing Association call it a bedroom. I would like my bedrooms on the same floor so I can listen for the children at night."

"I moved to this house in Nov 2008. I was on waiting list for over 8 years. I think it's a disgrace that people with children who have ASD are made to wait for years for a house to become available. Before we moved we were living in a multi-storey flat with 2 bedrooms. I had to sleep in living room for over 4 years."

"I live in a private let and have been trying to get a house from the housing for 4 years. They told me I was not entitled to medical points. I have had to go to my MP and after 3 years I now have medical points but have been told I could wait over a year to get a house."

"We are on the waiting list to find out if we qualify for medical points. I have been struggling with our family's accommodation needs for years. Every organisation I have contacted to help us have no luck in doing so. It seems housing associations do not see the amount of challenged Autism beings to families."

"Two years ago we approached housing associations with a view to being put on a waiting list. We were told not to bother as our accommodation was adequate and as we were a couple with housing we would be so far down the waiting list that it wasn't an option."

"I was refused and was told I didn't qualify medical points as my housing association said he doesn't have a medical condition, that was their point of view even though he was diagnosed from a qualified medical doctor."

"We have recently moved from a flat to a house but it took years of fighting the housing every week to explain my son's needs. It was a relief to be offered a three bed house but now I am banging my head against a brick wall to have adaptations done to the inside and outside of the house for my son's safety and security."

"I feel anyone with ASD is not considered as much priority within housing organisations as individuals with a physical disability."

Neighbours & Soundproofing

"My child usually drops toys, plates and cups. He stamps his feet when he feels unhappy sometimes cries loud. The neighbours complain about the noise. We try to tell the children to be quiet but because of short space in the house it is very hard to please the neighbours and the children."

"The neighbours are all quite old and as my youngest son is up about 20-30 times a night, jumping, screaming etc. I find it very awkward facing them on a daily basis so living above and below other people just isn't fair on them or us."

"Child can be very noisy and active - better sound proofing. I get concerned neighbours will complain and/or I can't offer child freedom he needs."

"I constantly complain about the noise from the flat upstairs as my son gets upset about the noise, in saying this, it can't be pleasant from the downstairs flat."

"My son often does not feel safe in his own home due to the flats below us being rented out to different people all the time, this adds to his anxiety."

"My son needs a safe and secure environment. We also have a lot of trouble with noisy neighbours, which the housing association will not help us with."

"Our last home was a 4-in-a-block with very poor insulation and part of the reason we moved was the movement restrictions this brings (out of consideration for neighbours below). We have however moved to a relatively new house only to find the same noise difficulties." "Housing provider and house builders should consider the effects of poor sound insulation more. All children are active, however housing a child with a need to jump, roll, spin etc. increases the frustrations that go with poor sound insulation."

"Internally we are waiting to be required/new kitchens/bathrooms. This should all have been done before we moved in. It is going to cause upset for my son when this has to be done."

Changing Housing Needs

41% respondents report their housing needs will change significantly in the next 5 years

- o 63% private renters
- o 47% social renters
- o 33% owner occupiers

95% respondents envisage their children with ASD will be living with parents. This is unsurprising due to the age profile of the children – mean and median is 10 years old.

The reported changing needs focus on the need for more space for the family, to enable the children to develop and to foster independence.

7 households stating their child may be living independently with support.

Respondents' Views

"As he gets older he becomes more unpredictable and harder to keep calm. I would not like to think he would stay at home causing discontent for the rest of my life but I don't think he could live independently"

"I need to foster independence by giving him his own room"

"He will become an adult and may need a home within a home until he is settled enough to move on"

"As youngest son now too old to be in out bedroom will have to move within next 1 - 2 years I cannot afford to move to a bigger house with 3 bedrooms"

"They need to be a lot more back and front houses"

"Our autistic child will move to supported housing"

"Expect our oldest to move out by then and give us more room to support him"

"I have been told I am not entitle to an extra bedroom until my children reach a certain age"

"With all the conditions our child has it is unlikely that he will leave the family home"

"I think now-a-days everyone should have a back and front door for their children with ASD at the moment there is no sign to any change"

"Hopefully eldest son gets his own house"

"We do not know what our child's needs may be in the future"

"Once my son is in his teenage years having his own space will become essential. It is difficult enough at the moment being so cramped and I feel his development will be seriously hindered if our living conditions continue as they are"

"The need for my child to have his own room and private space is growing. When he gets angry/excited he needs more space to calm down"

"My 3 yr old is displaying signs of ASD that would mean it is almost impossible to give them all their own space."

"Will need more space and my daughter (ASD) will be living with me into adulthood"

"Our child with ASD will soon be an adult sharing with a teenage brother. He needs his own room."

"Don't know - ever changing disorder - especially in teenage years."

Housing Support

50% respondents currently receive support from family and/or friends

- o 51% owner occupiers
- o 46% social renters
- o 59% private renters (10)

22% respondents currently receive support from Social Work

- o 18% owner occupiers
- o 28% social renters
- o 12% private renters (2)

22% respondents currently receive support from Health Services

- o 20% owner occupiers
- o 26% social renters
- 6% private renters (1)

19% respondents currently report receiving no support

- o 19% owner occupiers
- o 21% social renters
- o 17% private renters (1)

13% respondents currently receive support from voluntary organisations

- o 12% owner occupiers
- o 14% social renters
- o 12% private renters (2)

11% respondents report providing their own support

- o 10% owner occupiers
- o 13% social renters
- o 2% private renters (2)

Various other forms of support were mentioned by respondents: Disability Living Allowance (DLA); Carers Allowance; Income Support; Direct Payments for Childcare; respite for childcare in the summer; support at school including classroom assistances, auxiliary, speech/language support, nurture base; private provision including music therapy and exploring play therapy; parents carers group at the South East Carers Centre; Scottish Centre for Autism at Yorkhill; East End Carer; Autistic Societies.

Access to Information & Advice

26% respondents report receiving information and advice from housing associations

- o 9% owner occupiers
- o 43% social renters
- o 35% private renters (6)

21% respondents report receiving information and advice from family and friends

- o 18% owner occupiers
- o 19% social renters
- o 29% private renters (5)

12% respondents report receiving information and advice from Social Work

- o 10% owner occupiers
- o 15% social renters
- o 6% private renters (1)

4% respondents report receiving information and advice from Health Services

7% respondents report receiving information and advice from voluntary organisations

Other sources of information and advice were mentioned; other parents, school, South East Carers Centre, Scottish Centre for Autism, Councillor, newspapers, Glasgow Centre for Inclusive Living (GCIL), internet, NAAS or Scottish Refugee Council, health visitor, speech therapist, nursery and crèche.

Respondents' Views

"I receive no information or advice on this matter."

"Don't have any housing options as I own my house."

"Have made all enquiries on my own, still having no joy at present."

"Very little help on offer unless homeless."

"I had no idea that housing support was even available!"

Other Non- Housing related issues raised by respondents

Assessment Process

"Length of assessment process."

"We would also comment that the length of time it takes to wait for a diagnosis is problematic on many fronts - if we had to depend on social rented housing how would our provider assess us for a move in the absence of diagnosis? This must compound matters for such families. GCC needs to invest more as does CHCP in resources. 2 and a half years is too long."

Support

"More support for us parent, e.g. clubs after school care or different activities to stimulate the children."

"There is little support for families after diagnosis, I'm lucky that I am accepting of my daughter and have good family support, but there is a greater need for places to go, information and a social network for not only the children but parents and siblings."

"After Diagnosis support is very poor. Interventions are fragmented and poorly coordinated and depend on parental determination. Referral to C.A.T for diagnosis took a considerable amount of time, there was a process of constant opting in, I can only assume in an attempt to reduce the waiting list. Earlier diagnosis is a must. Case Management approach may improve coordination in intervention and support."

"Was awarded direct payments and never received money into account so lost two workers we were going to use. Not going to use this service. Too much to fight with Social Work."

Out of School Care

"Housing is not an issue, out of school care is the most difficult."

"I find it very difficult with childcare as most of children's places cannot accept him and as a result this is affecting me in terms of work/employment."

"How are parents meant to work and provide this care? If I use after school care, I end up with my wages going to this care. It's a vicious circle which does not let me work, also during holidays this care is provided in a specific way i.e. timing change, later opening hours, earlier closing hours, How am I supposed to work?"

"Having clubs or other places to go evenings and weekends that are not too costly would help him to mix with children more his age."

Local Amenities

"I can drive but most clubs tend to be well out of the area and too far to travel to by bus. My son does not have patience for sitting any length of time on public transport so this can be quite stressful to both of us. I think that sports clubs and amenities should be in every area for all children and not just children without disabilities. Also the price for a child to go to these clubs can be very expensive if they want to do more than one sport. So I think that children with disabilities should get it either for free or a discounted rate."

Appendix 1

Questionnaire: Housing Needs and Autism Spectrum Disorder

<u> PART 1</u>

Current Accommodation

1. Please tick the box that applies to you:

You own your home	
You rent from a Housing Association	
You rent from a private landlord	
You stay in someone else's home	
You are homeless	

2. How many children do you have?

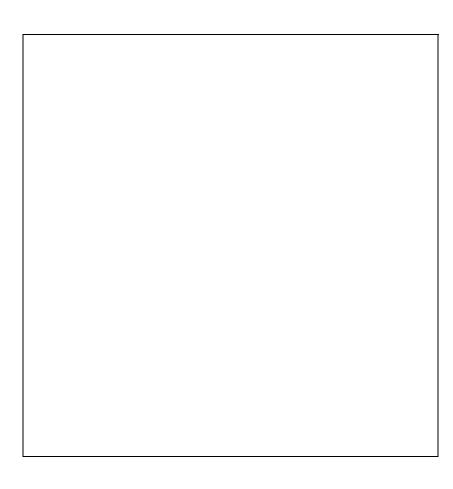
3.	How many of your children have a diagnosis of Autism Spectrum Disord	er (ASD)?
		, ,

4. In your opinion, does your present home meet your needs as a family with a child or children with ASD?

|--|

If your answer is No, please look at the boxes below and tick any of them that describe your housing situation. Please tick each box that applies to you.

Not enough bedrooms	
Not enough public rooms	
Not enough bathrooms/toilets	
Rooms too small	
No garden	
Multi-storey/High Flat	
The area is not safe for my children	
The location is too far from the support we need	
Other reason (please describe it below)	



5. Have you tried to move to better accommodation that would meet your needs?

Yes	No	

6. Were you successful?

Yes		No	
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<u>PART 2</u>

<u>Household</u>

7. What type of house do you live in? (Please tick)?

Tenement Flat	Terraced House	Semi- detached House	Detached House
Multi-storey Flat	Deck Access Flat	Four in a Block Flat	Bungalow
Other (please sp	ecify)		

- 8. How many people (including you) currently live in your household?
- 9. How would you describe your household? (Please tick)

Single adult with 1 childSingle adult with more than 1 child	Couple with 1 child	Couple with more than 1 child	
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More than 2	More than 2	
adults with 1	adults with more	
child	than 1 child	

10. How many children (18 years or under) are in your household?

11. Number of children with autism, Asperger's syndrome or other ASD?

12. How old are the children with ASD?

Current Accommodation

- 13. How many public rooms does your accommodation have (excluding bathrooms, kitchen, bedrooms)?
- 14. How many bedrooms does your accommodation have?
- 15. How would you describe the external condition of your current accommodation? (Please tick)

/ good	Good	Satisfactory	Poor	Very Poor
16. How v (Please		be the internal con	dition of your cur	rent accommodation?
/ good	Good	Satisfactory	Poor	Very Poor
17. Do you	u currently have a	ccess to your own ga	arden? (Please tick	x)
Yes	No			
lf yes,	go to question ²	19.		
18. Do you	u currently have a	ccess to a shared ga	rden? (Please tick)
Yes	No			
lf yes,	go to question '	19.		
lf no, g	go to question 2	0.		
19. Is the g	garden secure (e.	g. fenced, walled etc)? (Please tick)	
Yes	No			
20. Why di		ur current accommod	·	all that apply)
Liked location	n Handy transpo		e near	family and/or friends
Security of house/area	House approp for nee	riate limite	ed d	Not given any choice
Other (please	e specify)]
Other (piedse				
other (please				

21. How long have you lived at this address? (Please tick)

Less than a year1-2 years2-5 years5-10 years

Over 10 years	Other (please
over to years	specify)

22. Do you or your child/children with ASD currently receive support from any of the following? (Please tick all that apply)

Family/friends	Social Work	Health Service	Voluntary Organisation
Given funding to provide own support e.g. Direct Payments	No other support	Other (please specify)	

Housing and ASD

23. Do any of your children with ASD share bedrooms?

Yes		No	
-----	--	----	--

24. Would your child/children with ASD benefit from having more or larger public rooms?

	Yes	No	
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25. Please add any other comments about your accommodation (either internally or externally), including anything else that would help you or your child/children with ASD?

Changing needs – Transitions

26. In relation to your child/children with ASD, do you think your household's housing needs will significantly change in the next 5 years?

Yes No

Please give details

27. In the next 5 years where do you see your child/children with ASD living? (Please tick)

Living with Parents/Carers	Living in supported accommodation	
Living independently	Living independently with support	

Information & Advice

28. Where do you get information and advice on housing options and housing support?

Family/friends	Social Work	Health Service	Voluntary Organisation	
Housing Association	Other (please specify			

Future Contact

29. In the future we may wish to contact you to discuss some of the issues highlighted by this questionnaire. Would you be willing to be contacted?

Yes No

If yes, please provide your name, phone number and/or email address:

Name:

Address:

Phone Number:

Email address:

Thank you for your assistance in completing this questionnaire.

Please return the questionnaire in the prepaid envelope provided by Friday 27th February 2009 to Housing Investment, Development & Regeneration Services, Glasgow City Council, 229 George Street, Glasgow G1 1QU.