



better lives BETTER FUTURES



A study of housing and support
needs of young people with
Autism Spectrum Disorder
in Dumfries and Galloway

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Foreword

About The Holywood Trust



The Holywood Trust
Scottish Charity No. SC009942

We welcome this important research which helps to give a voice to young people across the region with Autism Spectrum Disorder. We hope it will help to make a difference by highlighting the changes needed in providing suitable housing and support services.

The Holywood Trust is a charitable organisation which aims to help young people in Dumfries and Galloway by providing grants to individuals and to organisations supporting young people trying to move forward in their lives. We are delighted to work with Better Lives Partnership in funding this research project.

Karen Ward Boyd, CEO of The Holywood Trust

About Better Lives Partnership



Better Lives Partnership was established in 2016 with the explicit aim of supporting young people with Autism Spectrum Disorder in Dumfries and Galloway. As a registered Scottish charity, we have developed a number of innovative services and projects over our first two years that have made a real difference to the lives of the young people and their families who we support.

We were very pleased to be commissioned by The Holywood Trust to undertake this important work. We hope this Study of Housing and Support Needs of Young Adults with Autism Spectrum Disorder in Dumfries and Galloway will be another positive contribution towards our aim of supporting vulnerable young people in our community.

Dave Bleasdale, Chair of Better Lives Partnership



Acknowledgements

This study has been undertaken with the generous financial support of The Holywood Trust. Thanks must also go to the many families, carers and network of support agencies who contributed to this important work, in particular, our thanks go to:

Parent Inclusion Network, Dumfries and Galloway Carers Centre, Turning Point Scotland, The Usual Place, Potters Community Garden Centre, Dumfries and Galloway Autism Outreach Service, Housing Options Scotland, the Activity and Resource Centres and all of the families that have participated in the research. Special thanks to Kalpana Ratnam-Roarty of User and Carer Involvement.

Thanks also to the IJB Particular Needs Housing Strategy Group, Dumfries and Galloway Council Strategic Housing Service and Children and Families Social Work, NHS Strategic Commissioning team and partner Registered Social Landlords.

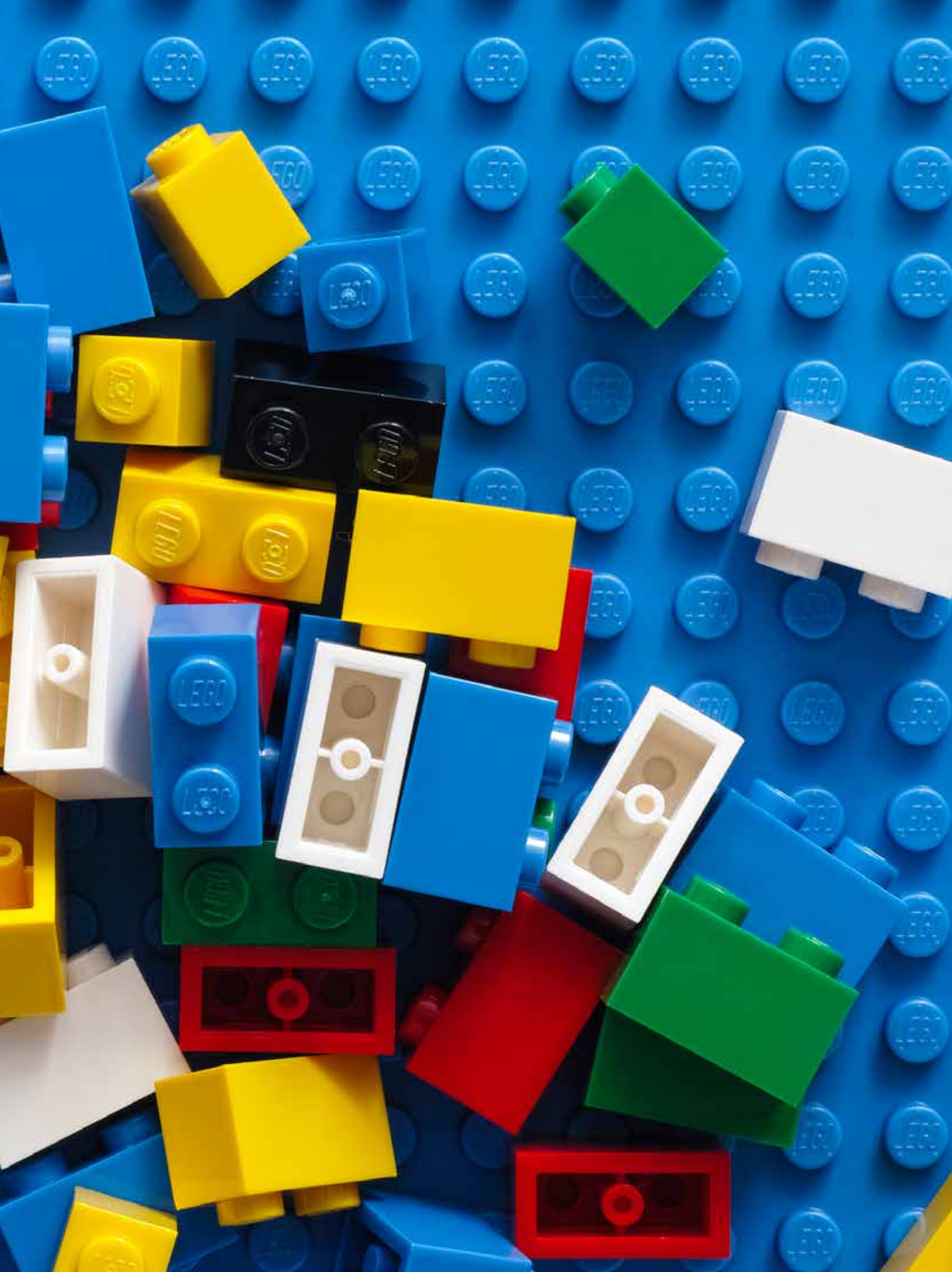


About The Researchers

The research has been undertaken by John Lynch and Dennis Cameron who between them have more than 50 years' experience in the sector.

John is a housing professional and former Head of Service with Dumfries and Galloway Council, who had responsibility for, amongst other matters, housing strategy, housing investment, homelessness and housing support.

Dennis has extensive experience in the third and voluntary sector working in community development, particular needs, addiction, mental health services and service development with a number of specialist organisations.



Introduction

About Better Lives Partnership - Our Aims and Objectives

Better Lives Partnership (BLP) became a registered Scottish charity on 1 June 2016 and our aims and objectives are:

- To develop opportunities for young people with Autism Spectrum Disorder (ASD) and other disabilities in Dumfries and Galloway so they are able to live as independent and fulfilled lives as possible within their communities
- To improve public awareness and understanding of autism and other disabilities
- To develop services and facilities for people affected by ASD and other disabilities, and to support their families, carers and practitioners
- To provide information and advice to anyone affected by ASD, including parents and carers
- To assist in the delivery of Dumfries and Galloway's Autism Strategy and related plans and working with other agencies and statutory bodies

In January 2018, and as a response to concerns raised by parents and carers with whom BLP worked, we applied to The Holywood Trust for funding to undertake research. The aim of the research was to establish the current provision and future need for specialist housing provision and support for young people with ASD and related disabilities. It is hoped that the evidence gathered and recommendations in the report will assist the key statutory and voluntary agencies when making investment and service development decisions. Parents of children and young adults with ASD were increasingly concerned about the lack of housing options as they looked to become more independent. This report aims to give voice to those concerns and provide a focus for future action and offer positive and sustainable solutions.

Methodology

The approach adopted for the research was to seek to place the young adults and their families at the centre of the study. To ensure this happened, the majority of the work has involved extensive meetings, group discussions and interviews along with the collection and analysis of primary research. The report, therefore, should be seen primarily as a reflection of the views and experiences of the families and young people themselves.

Consequently, the findings and recommendations have emerged from the information gathered from the families which it is hoped will provide a valuable insight to assist all of the key agencies to respond positively to the findings and recommendations.



The key stages of the research were:

- Review of all relevant national and regional strategies and plans to ensure 'strategic fit' for the study
- Intensive consultation and engagement programme
- Primary research through detailed housing and support needs survey
- Review of best practice and site visits
- Drafting the report and consultation process



Strategic Review

As part of the research project, we initially looked at the existing national and local strategies and plans that shape and direct current provision and potential future developments. It is, of course, critical to ensure any plans or strategies developed locally fit with the wider regional and national policy framework. This chapter provides a brief overview of the key strategies and plans which underpin the research.

National Strategy for Autism

The Scottish Government published its 10-year Scottish Strategy for Autism in 2011 containing its Vision and Goals over two, five and ten-year planning periods. The underpinning values of the Strategy are:

- **Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- **Privacy:** people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens; **Choice:** care and support should be personalised and based on the identified needs and wishes of the individual;
- **Choice:** care and support should be personalised and based on the identified needs and wishes of the individual;
- **Safety:** people should be supported to feel safe and secure without being over-protected;
- **Realising potential:** people should have the opportunity to achieve all they can;
- **Equality and diversity:** people should have equal access to information assessment and services; and, health and social care agencies should work to redress inequalities and challenge discrimination.

The National Strategy contains 13 goals, many of which align with the purpose of this research. In particular:

- Access to mainstream services where these are appropriate to meet individual needs
- Access to services which understand and are able to meet the needs of people specifically related to their autism
- Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism
- Access to appropriate transition planning across the lifespan

There have been a number of monitoring and review reports subsequently published by the Scottish Government (the Government) that assess the effectiveness of all partners in delivering the Autism Strategy.

Of particular interest and relevance is the **Outcomes and Priorities 2018-2021** document published in March 2018. It stated that a refreshed National Autism Strategy had been published in 2015 which had reframed it into an outcomes approach for the period 2015 to 2017. These new outcomes - **healthier life, choice and control, independence and active citizenship** - and their attendant priorities ensured the Scottish National Strategy for Autism was better placed to drive forward the realisation of the strategy's vision for autistic people and their families. One of the four Strategic Outcomes relates directly to this Research Project, **Outcome 3: Independence** which states: *Autistic people are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding.*

One of the key messages from the extensive engagement exercise undertaken by the Government as part of this refreshed Strategy was that autonomy and peer support are important to autistic people and that housing has a major role to play in delivering positive outcomes for autistic people.

In response to this, the Government stated that it wants everyone to have a home that is the right size, in the right location and able to meet their needs and to ensure people are able to live independently. Local authorities have a key role in planning for the housing needs of everyone within their local community including people on the autistic spectrum.

The Government made it clear that there is a need for full collaboration with the housing sector by setting out the Integration Authorities requirement to produce a Housing Contribution Statement as an integral part of their Strategic Commissioning Plans.

Furthermore, the Government confirmed it will ensure flexibility in the housing grant subsidy arrangements within the Affordable Housing Supply Programme (AHSP), so that social landlords are supported to build specialist housing in accordance with local need. Appropriate adaptations can also help disabled people stay in their own home. The Government has made a commitment that it will work with Integration Authorities, disabled people's organisations and the housing sector to improve access to these services for those who need them. To ensure strategic focus is maintained on this agenda, the Government has established an Autism Strategy Review Group and will publish a Progress Report in 2020.

In November 2018, the Government commissioned report, **Coming Home - A Report on Out of Area Placements and Delayed Discharges for People with Learning Disabilities and Complex Needs** (Dr Anne MacDonald), was published. Although its focus was not on ASD, and indeed the report looked to exclude cases where there was only an ASD diagnosis, the prevalence of adults with ASD in out-of-area placements from the data was such that the report flagged up the issue as a significant challenge. It stated that, when looking at the national numbers for those needing to return to their home local authority ('repatriation') nearly 50% of those who were priority to return were autistic which is higher than the main out-of-area group where 37% of the group was autistic.



Since this autistic subgroup is such a substantial element of the priority to return group, some additional analysis was done. The autistic sub-group were slightly younger and more likely to be male, have a mental health diagnosis and challenging behaviour, than the rest of the priority to return group. They were also more likely to be placed out-of-area in a crisis. This study points up the scale and urgency of the challenges facing every local authority and health board in Scotland in tackling these complex issues.

The study recorded 12 out-of-region placements from Dumfries and Galloway. The study notes that the impact of out-of-area placements for the individuals affected is often huge and life-changing. Breakdown of support has, for some, resulted in the loss of their home, sometimes moving far from their family or into hospital settings resulting in fractured family relationships and loss of community networks. This also has a significant impact on services.

The study also confirms that over-reliance on out-of-area placements to provide support to people with complex needs or challenging behaviours, can result in resources not being targeted at development within the local area. This can also result in an ongoing lack of local specialist provision and a vicious circle in the use of out-of-area placements.

Dumfries and Galloway Local Outcome Improvement Plan is an overview of what the Council and all its strategic partners will focus on over the planning period 2017 – 2027. Two of the seven Outcomes are of relevance to this research:

***Outcome 3** - Health and well-being inequalities are reduced*

***Outcome 4** - There is affordable and warm housing for those who need it*



Dumfries and Galloway Strategy for Autism

The Dumfries and Galloway Autism Strategy was published in 2014 and was produced through a multi-agency partnership. The Dumfries and Galloway Autism Strategy identified five priorities, including the need to provide care and support for people with autism as close to home as possible.

The Dumfries and Galloway Strategy identifies that most recent studies suggest that 1 in 100 is currently the best estimate of the prevalence of ASD in children. This suggests that there are over 50,000 affected young people in Scotland, and up to 40% of these may also be considered to have a diagnosed learning disability. Many will have difficulties in aspects of their learning and acquiring information even though they may have high levels of general ability. No studies have been carried out with the adult population. Information from services across Scotland suggests that an increasing number of adults are seeking and receiving a diagnosis of ASD.

The Strategy also identifies a number of challenges and barriers for people with ASD within Dumfries and Galloway. One such, and potentially the most significant, is that for many people reaching adulthood, services for 16- or 18-year olds are restricted to those assessed as having a complex learning disability as well as autism or where there is a known crisis. This often excludes young adults with ASD from accessing a range of support and care services and places the main responsibility for supporting them with their families.

This research fits most clearly with one of the five key priorities within the Dumfries and Galloway Strategy – *to provide care and support for people with autism as close to home as possible.*

Dumfries and Galloway Children's Services Plan

The Dumfries and Galloway Children's Services Plan is a multi-agency plan led by the three main statutory agencies – the Council, NHS and Police Scotland. The plan sets out their vision and commitment to improving the lives of children, young people and their families in Dumfries and Galloway. It contains six priorities which cover every aspect of supporting and protecting children and young people in Dumfries and Galloway. The two priorities that are of relevance to this research are:

Priority 3 - *We will improve the well-being and life chances of our most vulnerable children and young people*

Priority 4 - *We will work to reduce or remove barriers so that all children and young people have equity of opportunity*

The Priorities are supported by a number of Actions, with targets and performance measures.



Data from the National Schools Census indicates that there were 359 children in Dumfries and Galloway with Autism Spectrum Disorder in 2016, which equates to 1.7% of the school population (broadly in line with the national average). However, locally collected data would indicate that the incidence is slightly higher with 384 children and young people with ASD in schools in the region; this equates to 1.8% of the current school population compared to the national figure of 1.5%.

The overall percentage of children and young people with ASD in Dumfries and Galloway as a percentage of the ASD cohort (6.4%) is slightly below the national figure of 7.9%. The number of pupils with a diagnosis of ASD in schools in Dumfries and Galloway has been rising steadily over time, roughly at a rate of 10% per year.

Health and Social Care Integration Joint Board Strategic Plan 2016-2019

With the requirement for Health and Social Care Services to provide integrated planning and delivery of services, through the Public Bodies (Joint Working) (Scotland) Act 2014, there is also a requirement to produce a Housing Contribution Statement as part of the Integration Joint Board's Strategic Plan.

Dumfries and Galloway's Housing Contribution Statement confirms that the role of housing in the protection and promotion of individual well-being extends beyond bricks and mortar. The Council, and its partner Registered Social Landlords (RSLs), provide a wide range of other services designed to help people remain in their home as long as they can. These services include the provision of housing support based on an individual assessment of need. Whilst the Integration Joint Board (IJB) Strategic Plan has a much wider focus than this research, it provides important context for the way in which partners need to work together to deliver effective services and how it puts the individual's needs at the centre of its planning and delivery of services.

The IJB identifies nine national health and well-being outcomes set out by the Scottish Government, one of which is:

'for people, including those with disabilities or long-term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.'

The IJB Strategic Plan sets out several areas of focus that will change the way services are planned and delivered, many of which have relevance for this research:

- Enabling people to have more choice and control
- Supporting carers
- Developing and strengthening communities
- Making the most of well-being
- Maintaining safe, high quality care and protecting vulnerable adults
- Shifting the focus from institutional care to home and community-based care
- Integrated ways of working
- Reducing health inequalities

- Working efficiently and effectively
- Making the best use of technology

The IJB Strategic Plan sets out its vision for developing new models of care and support that should reflect and promote the shift towards greater choice and control for people and make a positive difference to their outcomes. As a result, it is crucial that people who use those services, their carers and families are involved in designing them.

Dumfries and Galloway Local Housing Strategy

The Dumfries and Galloway Local Housing Strategy (LHS) covers the period 2018 - 2023. The LHS is the key statutory document that sets out how the Council and its partners will improve the quality of housing and related services such as homelessness and housing support. As such it is a wide-ranging strategy that covers all tenure types and many issues and challenges.

Of particular relevance to this research is Outcome 7 in the LHS, which states that:

'People with particular needs will be able to live independently and fulfill their potential.'

The LHS confirms the establishment of the Particular Needs Housing Strategy Group whose role is defined as identifying and prioritising housing with care projects in partnership with RSLs. Its intention is to provide a co-ordinated and agreed approach to shaping service development and investment where there is an identified need for housing, health and care initiatives. Proposals for service development and investment, once agreed by this strategic group, will be presented to the IJB and submitted for inclusion within the Council's Strategic Housing Investment Plan.

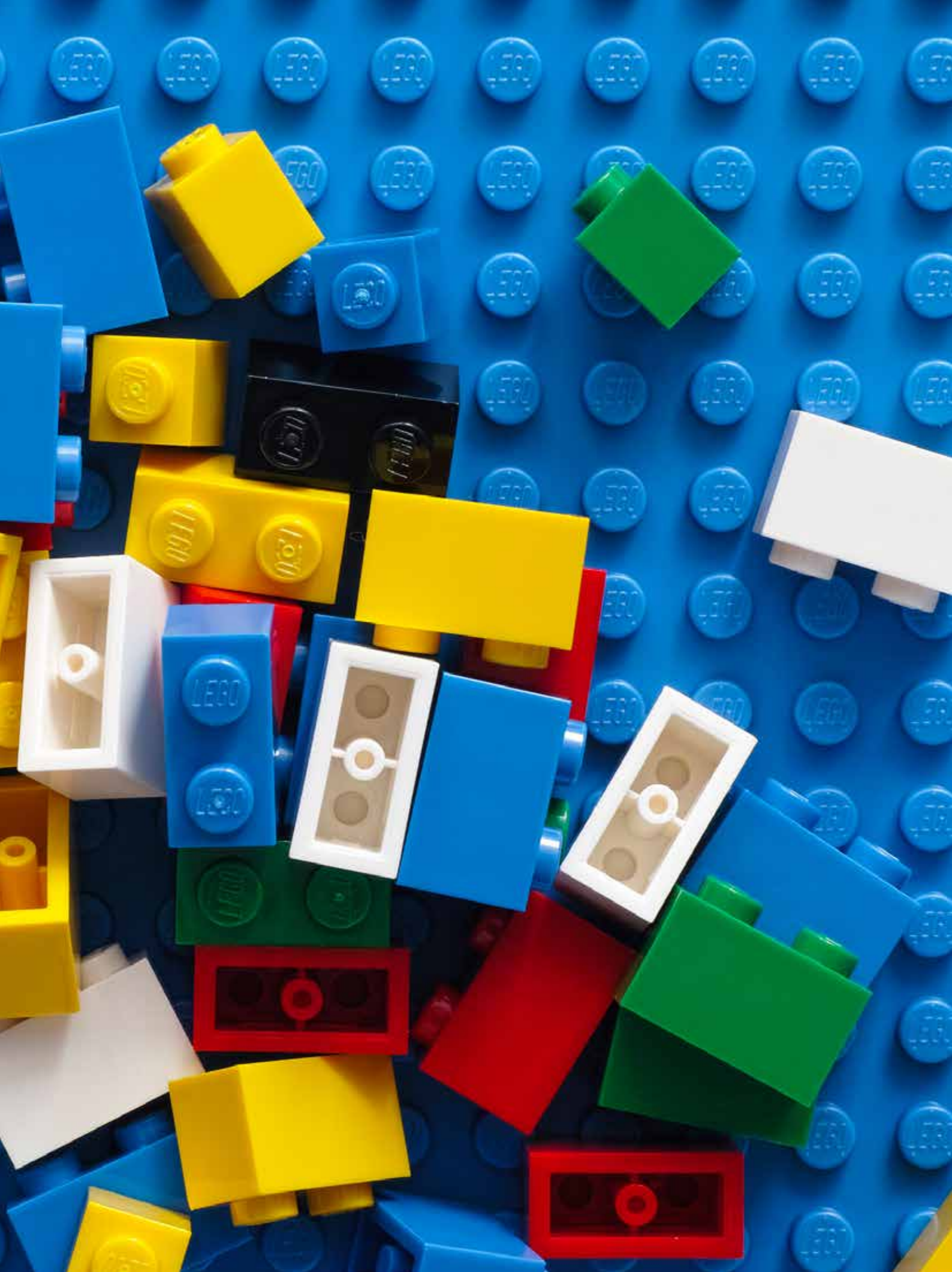
Summary of National and Regional Strategic Context

It is important to note that at every level, from the Scottish Government, Dumfries and Galloway Council, NHS Dumfries and Galloway, the IJB and all their key partners and stakeholders, the strategic focus and importance given to improving the lives, well-being and life chances of children, young people and adults with Autism Spectrum Disorder and related disabilities is consistently identified as a strategic priority.

The key local strategies and plans for developing solutions to these issues are well-aligned and coherent, with clear evidence of improved partnership working across organisations and sectors. This research underpins the strategic context and as such provides a real opportunity to make a meaningful and lasting contribution.

Less developed are the operational plans, e.g. the IJB Locality Plans, to deliver the strategic aims and objectives in relation to autism. It is hoped that the publication of this report will assist in translating the strategies into specific actions.





Current Housing Provision & Demand Information

It is important to set out at this stage, the current provision and potential future demand for suitable housing to provide a baseline and proper context for the research.

In terms of overall provision, there is a slightly higher proportion of adapted housing in Dumfries and Galloway (22% of all stock) than nationally (21%). There is more adapted stock in the social rented sector (35%) than in the owner occupied (19%) and private rented sector (13%). However, these figures include all adaptations within the stock (ground floor bedrooms or bathrooms, level access showers, wet rooms, ramp access etc.) and does not identify specific accommodation suitable for young adults with ASD.

In terms of future provision, there are plans for 197 units of adapted accommodation to be provided through the Strategic Housing Investment Plan (SHIP) between 2016 and 2021. About 50% of this total is for sheltered or very sheltered housing for older people. The need for adapted housing and housing for particular needs is likely to increase as demand increases through the improved arrangements of the new IJB/DGC strategic planning structures.

Currently there is a total of 238 supported accommodation units for under 65s with a physical disability, learning disability or mental health problem. The proportion by locality is shown in the table below.

LOCALITY	UNITS	% OF STOCK
Annandale and Eskdale	17	8%
Nithsdale	149	62%
Stewartry	28	11 %
Wigtownshire	44	19%
D&G	238	100%

The estimated number of adults with ASD across Dumfries and Galloway is 1,345. The proportion by locality is shown in the table below.

LOCALITY	NUMBER WITH ASD	% OF TOTAL
Annandale and Eskdale	343	26%
Nithsdale	524	39%
Stewartry	217	16%
Wigtownshire	261	19%
D&G	1,345	100%



The estimated number of adults with learning and physical disabilities is 12,642. The proportion by locality is shown in the table below.

LOCALITY	NUMBER WITH LEARNING DISABILITY	NUMBER WITH PHYSICAL DISABILITY	TOTAL OF LEARNING AND PHYSICAL DISABILITY
Annandale & Eskdale	143	2,879	3,022
Nithsdale	327	4,511	4,838
Stewartry	108	1,845	1,953
Wigtownshire	140	2,689	2,829
Total D&G	718	11,924	12,642

Although the available data provides a useful snap-shot of the number of supported housing units, there is no correlation between the overall number of supported housing units, the number of adults with ASD or the level of particular housing need by locality.

The usual profile for supported housing for the under-65s is:

- Shared tenancies in large properties of 3 or 4 units
- They cater for a range of needs, predominantly complex physical and learning disabilities
- The turn-over in the units is low, meaning once someone has been allocated a supported unit, they tend to stay there for a long time even if their needs change over time
- A more systematic and regular review of the accommodation would assist in ensuring the changing needs of residents in supported accommodation are met
- None of the supported accommodation is designed specifically to meet the needs of adults with ASD

What is equally clear is that, when looking at the actual number of supported accommodation places, compared to the number of people with all disabilities in all localities there is a significant shortfall in provision of supported accommodation – a total of 238 units of supported accommodation compared to over 13,000 people with ASD, or learning and physical disabilities. Added to this, all available data shows that this demand will increase as the number of young people with additional support needs, and particularly those with ASD, increases at a rate of 10% per year.

There is a broad acknowledgement across all of the relevant statutory and voluntary agencies that more supported housing is needed. What is less clear is whether there is a detailed understanding of what type of accommodation is needed and where it should be located. An aim of this research is to provide the evidence to make informed investment decisions for future provision in relation to housing for people with ASD.

Consultation & Engagement

Introduction

As the need for this research originally emerged from concerns raised by parents and carers of young people with ASD about the availability of suitable housing options for their children, it was very important that a meaningful consultation and engagement programme was put in place. The aim was to give them a real voice in articulating what their main challenges and priorities are. This chapter sets out how the consultation and engagement programme was undertaken and the outcome of these extensive discussions.

The researchers' approach was to pro-actively engage with as many parents, carers and young adults with ASD as possible by connecting with existing facilities, groups and support networks. This approach proved highly effective and the assistance received from all of these groups was invaluable.

At the outset, meetings were held with key public and voluntary sector partners to raise awareness of the research and seek support for it. These meetings involved:

- Dumfries and Galloway Council - Strategic Housing Service
- Dumfries and Galloway Council - Children and Families Social Care
- NHS Commissioning team
- Integration Joint Board - Housing Lead
- Scottish Government - More Homes, Housing Investment Division
- Loreburn Housing Association
- Key Housing

The need for this research was well recognised by all the agencies and the proposed approach was well received.

After meeting all of the key statutory and voluntary agencies, an information campaign of posters, leaflets and radio adverts was completed to raise awareness of the research. Information was provided to dozens of local facilities including Activity and Resource Centres, GP's surgeries, health centres, hospitals, community centres, social enterprises, social work and housing offices.

Subsequently, meetings and drop-in sessions were held across Dumfries and Galloway in local community facilities, social work bases, youth support services and social enterprises where young adults with additional support needs, their parents and carers attended. It was very important to take this time to speak with people and provide an opportunity for them to talk about their concerns, needs and aspirations in a familiar setting where they felt comfortable. The insights gained from this extensive work have directly shaped the proposals in this report.



Consultation and Engagement Events

As stated, an extensive programme of consultation events were held across the region to maximise the level of engagement from parents, carers and young people. The following is a summary of the organisations and networks that engaged with the research:

- **Potters, Stair Park Community Garden Centre, Stranraer** is a social enterprise created to provide a place where people can volunteer to assist those with a range of disabilities to develop skills and improve self-confidence through gardening. A session was arranged to meet with staff and adults with additional support needs who volunteer at the garden centre and who welcomed the chance to share their stories of working and living independently with varied support.
- **Better Lives Partnership** - Three specific drop-in sessions were run from the project base in Castle Douglas with further engagement from staff and young adults on the BLP programme over the course of the engagement programme. The research was also promoted through Better Lives Partnership networks and contacts of over 1600 individuals and families.
- **Dumfries & Galloway Carers Centre** provide information, advice and support to anyone who cares for a relative or friend. They also aim to raise awareness of the needs of carers and the contribution they make to care in the community. The researchers attended several established carers' support groups throughout the region. There was a very positive response and level of engagement from carers throughout the region.
- **Usual Place, Dumfries - Inspired Community Enterprise Trust LTD (ICET)** was set up in November 2011 with the aim of providing employment and training opportunities and wider community relationships and citizenship opportunities for young people with additional support needs. There was enthusiastic engagement from the young adults with ASD through 7 different drop-in sessions, capturing real insight into what really matters to them.
- **Activity and Resource Centres (ARCs)** - Dumfries, Castle Douglas, Stranraer, Newton Stewart and Annan. The ARCs provide support, activities and personal development opportunities for people with learning disabilities, autism disorders and brain injuries. With support from the staff team, 10 tailored facilitated sessions with specialist materials were used to gather information from adults with profound support needs. This work was supported by User and Carer Involvement (UCI).
- **Dumfries and Galloway Autism Outreach Service** raises awareness of autism and organises events for families, carers and individuals affected by autism as well as professionals working in the field. Nine sessions were attended through the Autism Outreach Service network in Langholm, Dumfries, Dalbeattie, Castle Douglas, Stranraer and Newton Stewart. This saw valuable information gathered predominantly from parents and carers.
- **Turning Point Scotland** has been providing services in Dumfries and Galloway since 1999 and has grown to work across 19 separate locations in the region providing support to individuals living on their own and small groups of up to 3 to 4 people sharing accommodation. The researchers provided an information session to Aspiescope (run by Turning Point Scotland) to enable them to work with their clients.
- **Parents Inclusion Network (PIN)** is a SCIO and consists of a group of parents and carers who all have sons and daughters with a disability - children of all ages and adults with all types of disabilities. A number of positive engagement sessions were held through PIN.

- **Building Healthy Communities** – Presentations were given by Better Lives Partnership in Dumfries. There was representation from the NHS, Health and Social Care workers along with those from the third and independent sectors.
- **NHS at 70** celebrations at Easterbrook Hall – Better Lives Partnership were represented with young people, their parents and carers taking part in the housing research and sharing their stories.
- **Self Directed Support information and networking events** were attended in Stranraer, Newton Stewart and Dumfries. This helped raise awareness through other support providers of the housing research work being undertaken and allowed individuals to take part in our survey.
- **Registered Social Landlords (RSLs)** have provided information to their tenants of the work being carried out through meetings and the distribution of information through their tenant networks.
- **Housing Options Scotland** help disabled people, veterans and older people to find the right house in the right place. The researchers attended events in both Stranraer and Dumfries. There was good uptake and input from parents and carers through these events and further discussions took place at a later date with sons and daughters of those with additional support needs.
- **Radio coverage** - There was a media drive through local radio which started on the 4th September 2018 and was aired over a 3-week period with 82 individual commercials.

In total, **44** engagement events took place with over **80** young people with ASD and over **100** parents and carers directly engaged with the housing research. Of these, **120** were face-to-face interviews and just over **60** took part in group discussions with Better Lives Housing research officers.

The approach adopted was highly effective in engaging with the families in a meaningful way, providing the time and opportunity for them to give voice to the issues they face every day. The researchers gratefully acknowledge the help and support provided by all of these organisations, groups and individuals.



Housing & Support Needs Survey Analysis

Overview

A central part of the research work was to undertake a survey of the housing and support needs of young people with ASD in our region. No detailed data for this client group and at this level had been captured before, so it was clear that primary research was critical to providing an insight into their specific challenges, needs and aspirations. A housing and support needs survey was devised to capture all relevant information that would inform and shape the outcomes and recommendations of the research project.

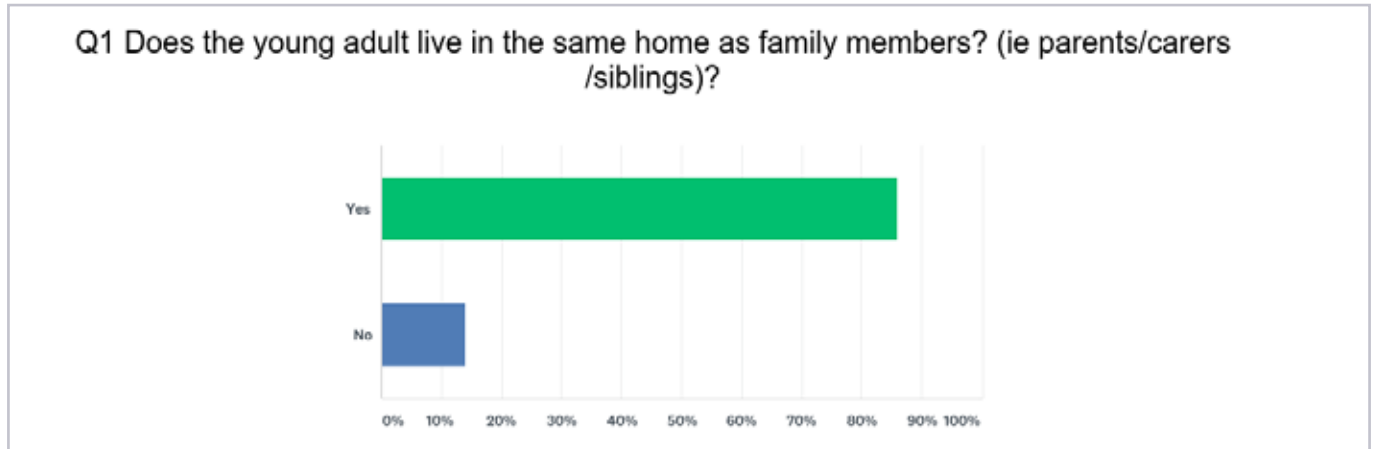
The survey ran from August to November 2018 to allow for maximum participation in the project. The survey was aimed at parents, carers and young people with ASD. It was undertaken through the extensive consultation and engagement exercise described in the previous chapter. It was not designed to be a representative sample of the general demographic. It was a focused and very detailed assessment of the issues, concerns and aspirations of young people with ASD and their families for whom current or future accommodation and support needs were significant issues.

The survey was available online, in hard copy and through face to face interviews with the researchers. This approach was taken to make it as accessible as possible to anyone who wanted to be involved.

In total 101 survey responses were recorded which, from an estimated total number of adults with ASD in our region of 1300, provides a very valuable data source. Given that a high proportion of the 1300 adults with ASD would fall out-with the scope of this report because they are either not within the age range of the research project or do not have an unmet housing or support need, this level of response is likely to represent a significant proportion of all of the affected households in the region. This chapter provides a summary of the responses, key trends and analysis of the information that was gathered.

Current Housing Circumstances

The majority of responses were from families where the young adult with ASD still lived in the family home, with a smaller number of responses from those who are living independently.



The survey provided various comments boxes to expand on a number of key questions. Through this, it was found that there are a wide range of circumstances that reflect the individual issues and challenges that families have to deal with. Alongside the consistent fact that the families feel they are providing a loving and supportive environment, there are acute challenges they have to face where there have been no obvious satisfactory solutions, both in relation to accommodation and support.

Some families explained their broad circumstances and some of the challenges they face. Examples of these are summarised below:

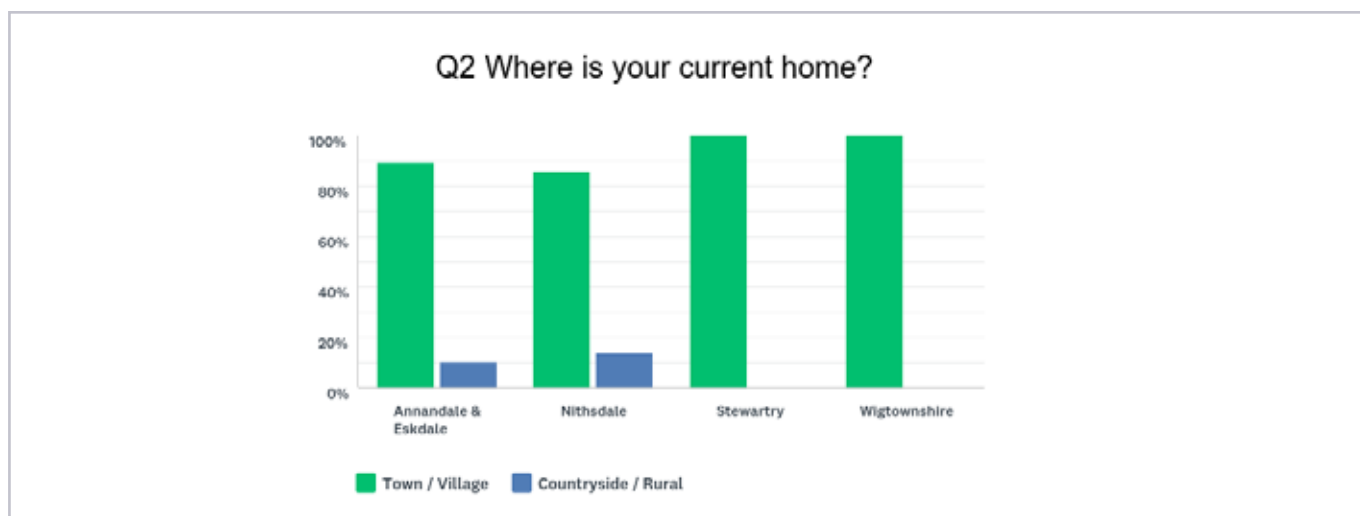
- A case where a household has three generations living together (grandmother, father and son) where both the father and son have ASD and the strains within the family unit were significant, having a negative and detrimental impact on the whole family
- A household with two sons both of whom had ASD but with very different needs which created challenges for the family
- A number of families said they felt they were forced to find accommodation out of the region due to their sons' challenging behaviour and what they saw as a lack of suitable and secure supported accommodation in Dumfries and Galloway
- A number of respondents who placed their child in short term foster care as they felt unable to cope with their sons' behaviour

Other examples of the challenges the families face have been highlighted in the 'Comments Wall' under the Quotes & Key Considerations section of this report to ensure their stories are told and their voices are heard.

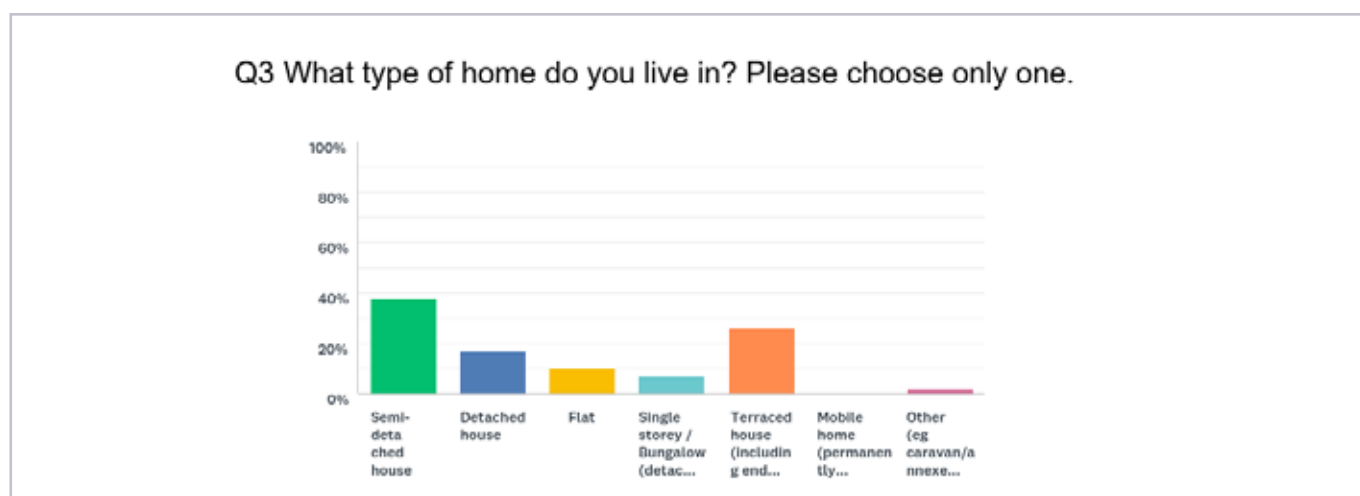


Current Location, Tenure and Size of Housing

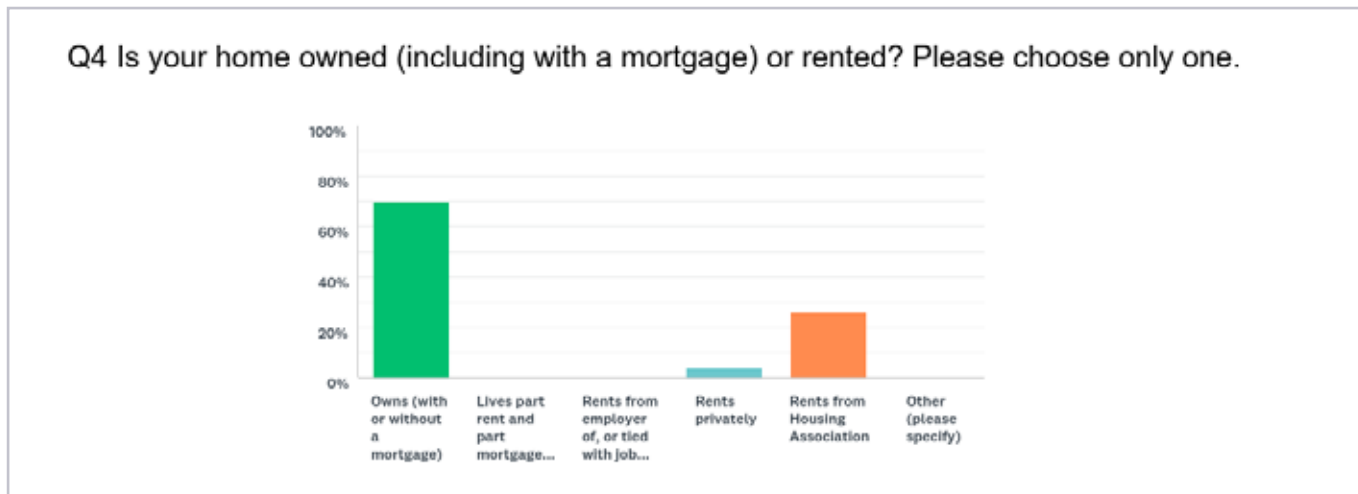
It was important to ensure a good geographic spread of responses, given the large rural nature of Dumfries and Galloway and this is reflected in the location of the families who participated in the research. Approximately 38% live in Annandale and Eskdale, 30% in Nithsdale, 22% in Wigtonshire and 10% in Stewartry.



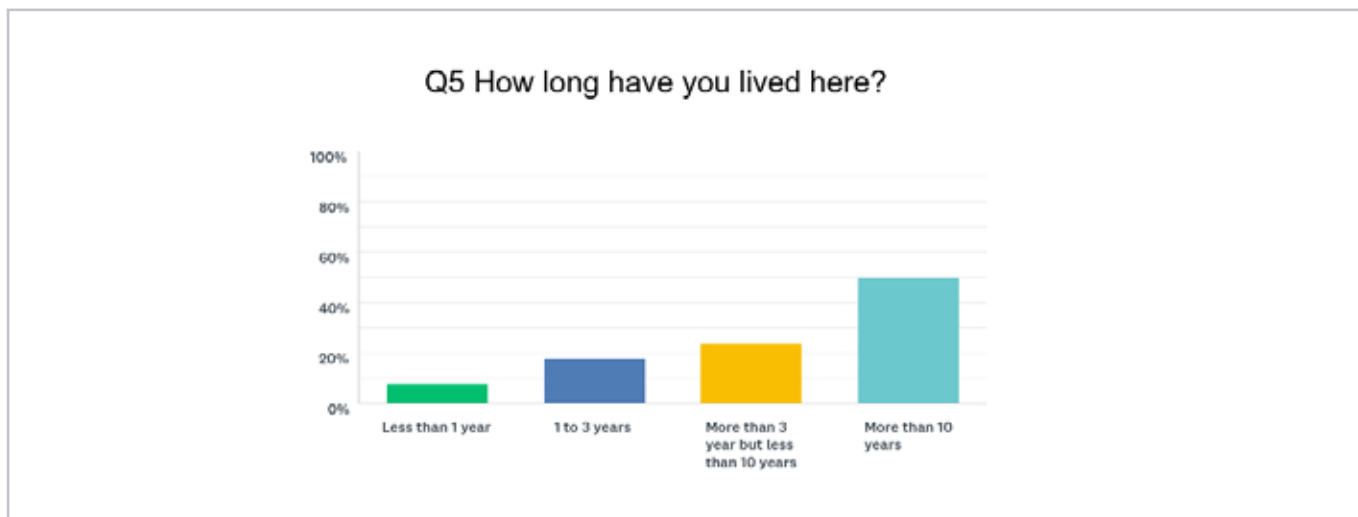
The vast majority (about 80%) said they lived in a town or village, rather than in very rural areas. The graph below shows the type of accommodation they currently live in. The majority (55%) live in semi-detached or detached houses; most are large family homes with 66% having three or four bedrooms.



In relation to tenure, most of the respondents (70%) are home owners, with 26% renting from a Registered Social Landlord and only 4% in the private rented sector. This profile differs slightly from the general demographic, where typically there is a slightly lower percentage in the owner occupier and RSL sectors and more in the private rented sector. However, this is unsurprising as generally fewer families with children tend to be housed in the private rented sector than single or couple households with no children.



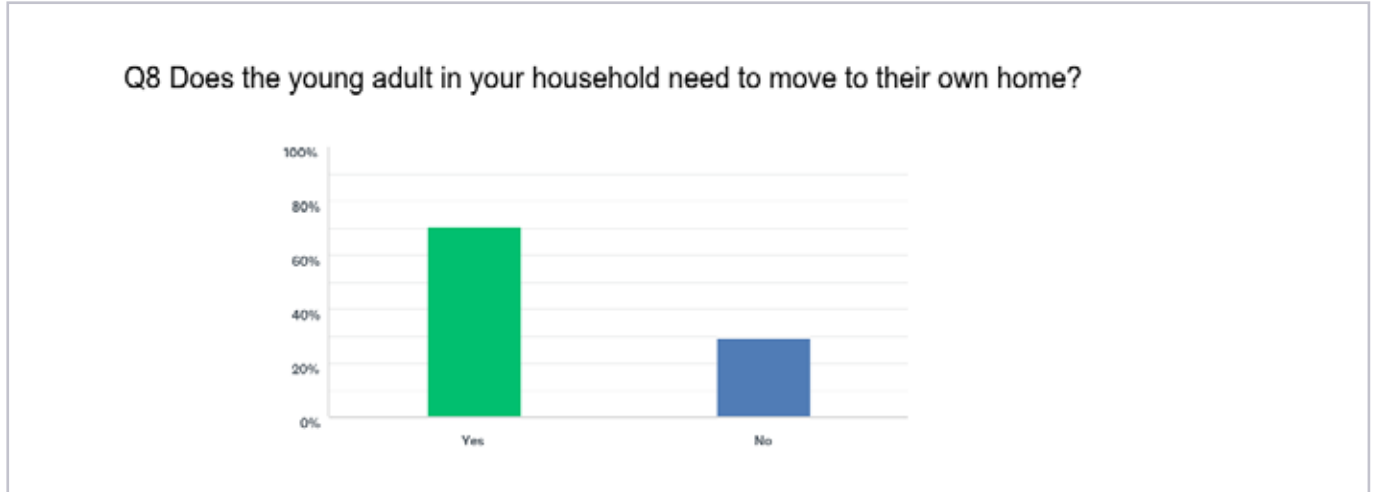
The families tend not to have moved recently, with 50% of respondents having lived in their home for more than 10 years. This reflects the broader trend of housing markets within the region being relatively static and self-contained. However, the distinct lack of movement within our research sample may also reflect the fact that families have limited choices to meet the needs of the young adult with ASD. If there is an increase in availability of suitable housing for these young people, it may be that some families would also then be in a position to move (for example to down-size) as their needs change.



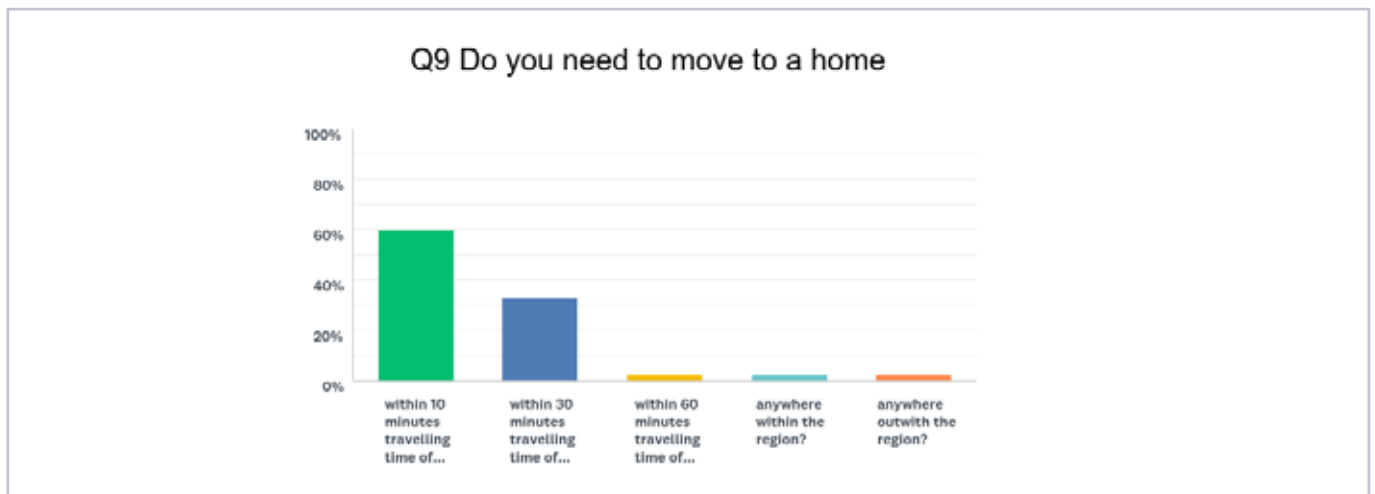
Household Composition and Future Need

In terms of household composition, given the focus of the research, it is unsurprising that the majority of respondents are older parents (45-64 years) with older teenage (16-19 years) or adult children (20-44 years).

The survey found that 70% of respondents stated that the young adult needs to move out of the family home and into their own home. Those responses that stated they did not need to move were from households with slightly younger children or where they had already moved out of the family home and were living independently.

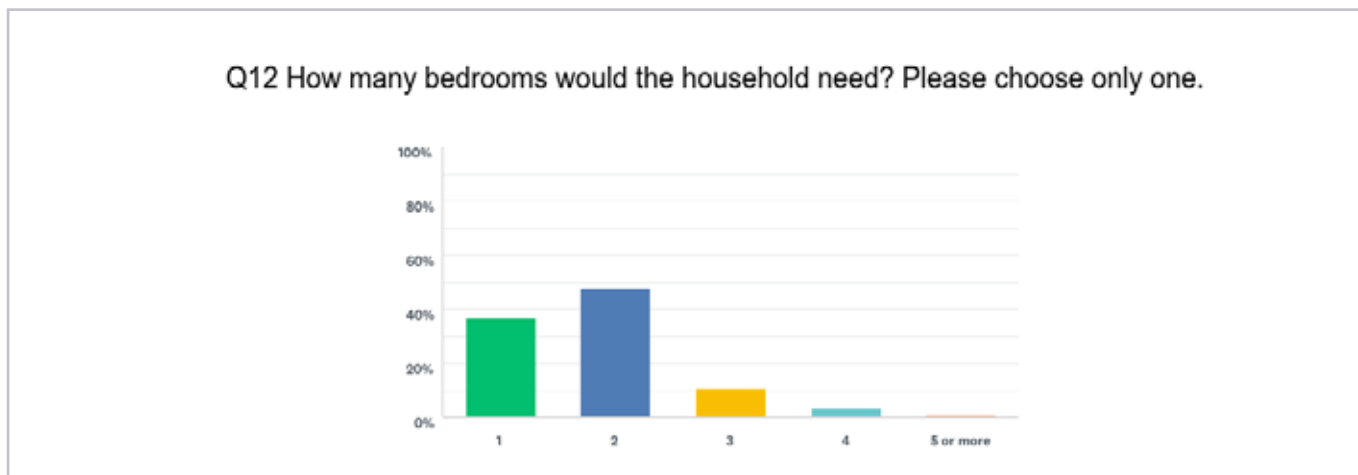


There is a clear preference from the vast majority of respondents for a new home to be within 30 minutes traveling time of the family home (by bus or car) with 91% stating this is a clear requirement. The overwhelming reasons for remaining close to the family home are to maintain support from family and friends, keep links with their community and sustain and develop social and educational support.

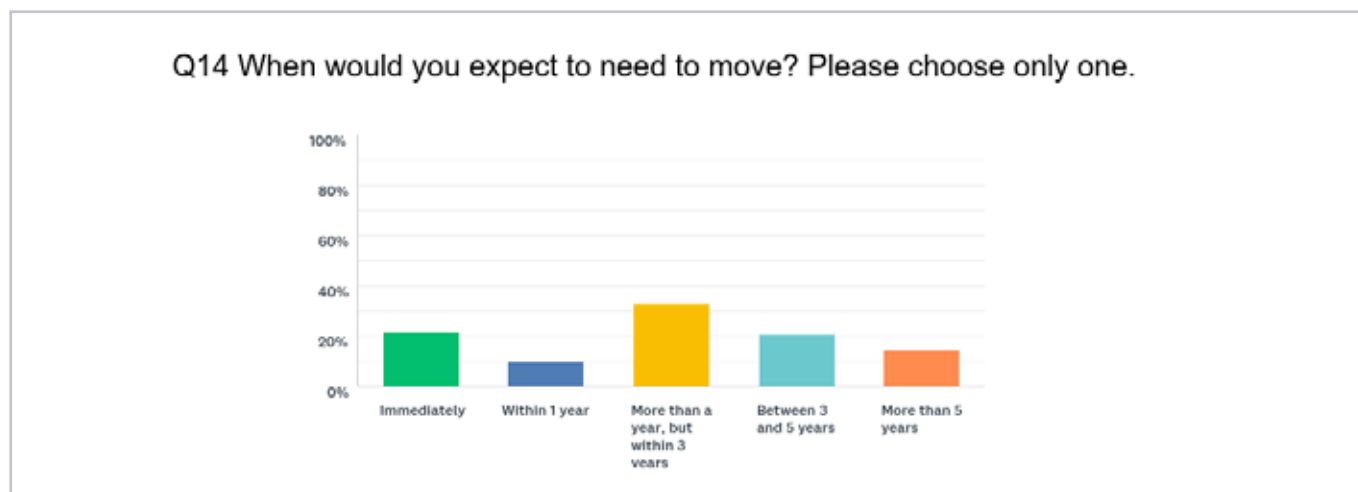


Of those needing to move, most of the respondents said the young person needed to move on their own, with only 6% stating the whole family needed to move to new accommodation, compared to 94% who do not.

The new household composition is almost exclusively single people in the age ranges 16-19 years or 20-44 years, with about 30% more male than females needing to move across all age categories.



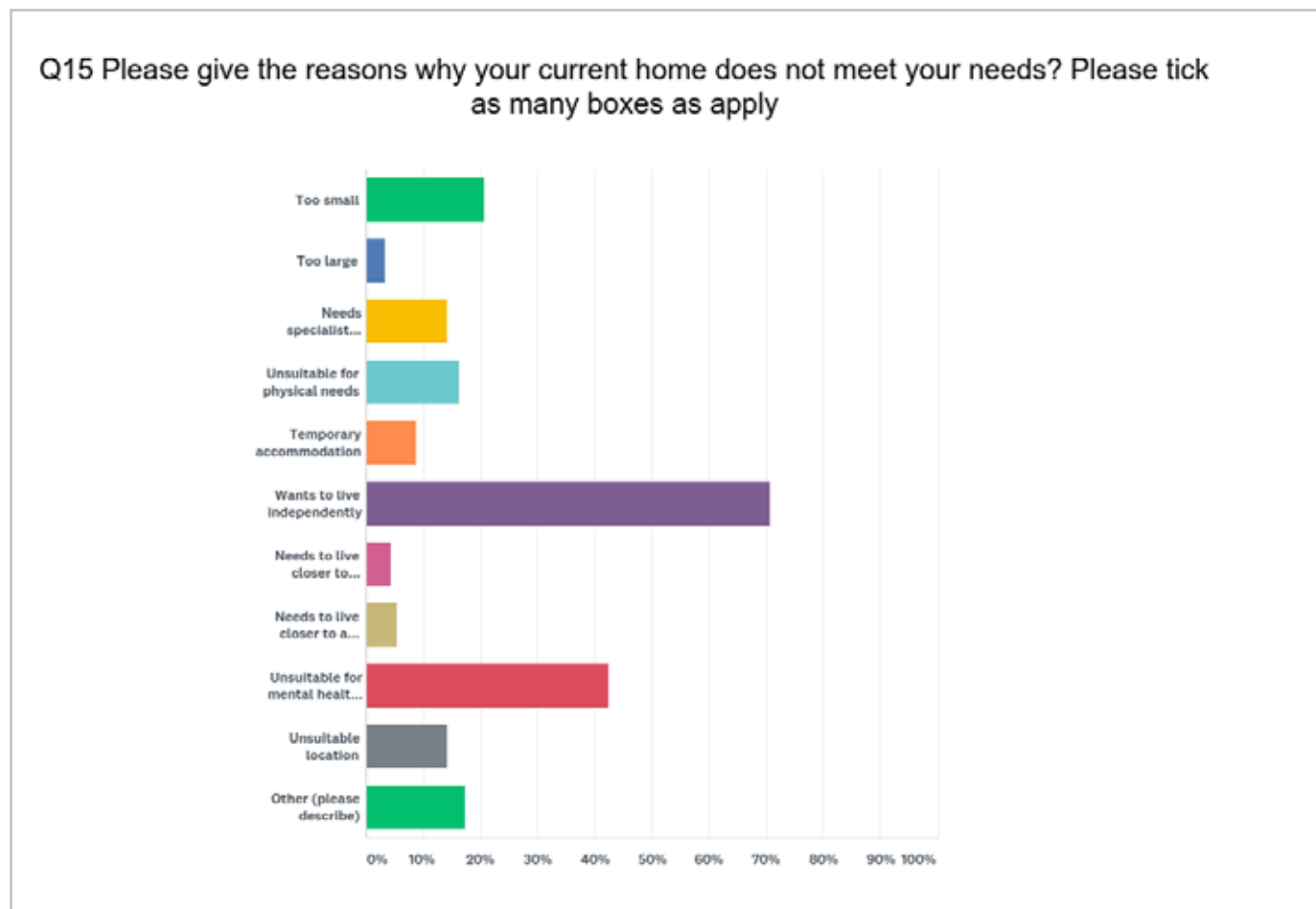
For these new households, most stated they need a two-bedroom home (48%) to provide overnight support or allow family and friends to stay over. Those needing one bedroom is 37%, with 14% needing three or more bedrooms.



Looking at timescales for moving home, almost 1 in 5 say they need to move immediately and overall 65% need to move within 3 years. This is an important finding as it shows the relative urgency of the need to move home for a large proportion of households. Given the likely lead-in time for any single move to take place (assessment, planning, developing or identifying properties, carrying out adaptations, arranging support packages etc.) it is clear that for many of these households there has been a lack of transitional planning to date. Often families felt powerless to change their circumstances as they could not see a pathway through to independence for their child. This was often exacerbated by the families feeling very protective and anxious for their child's future which is understandable given the uncertainties they feel they face in terms of future housing and support options.



There are a range of reasons for needing to move home, but the most common is 'the need for independence' (70%), followed by 'unsuitable for mental health and well-being' (42%), 'unsuitable for physical needs' (16%) or 'requires specialist support' (14%). **This question allowed multiple responses.*



Housing Support Needs

The range of care and support provided to young people with ASD varies greatly and reflects, to a large extent, the varying levels of need presented. Our survey found that a significant number of young people only receive support from family; about 1 in 3 attend Activity and Resource Centres on a regular and frequent basis; just under half receive outreach support from specialist providers or through their own support workers via Self-Directed Support; about 1 in 10 attend a social enterprise; and, a little more than that are still receiving their support through the education system.

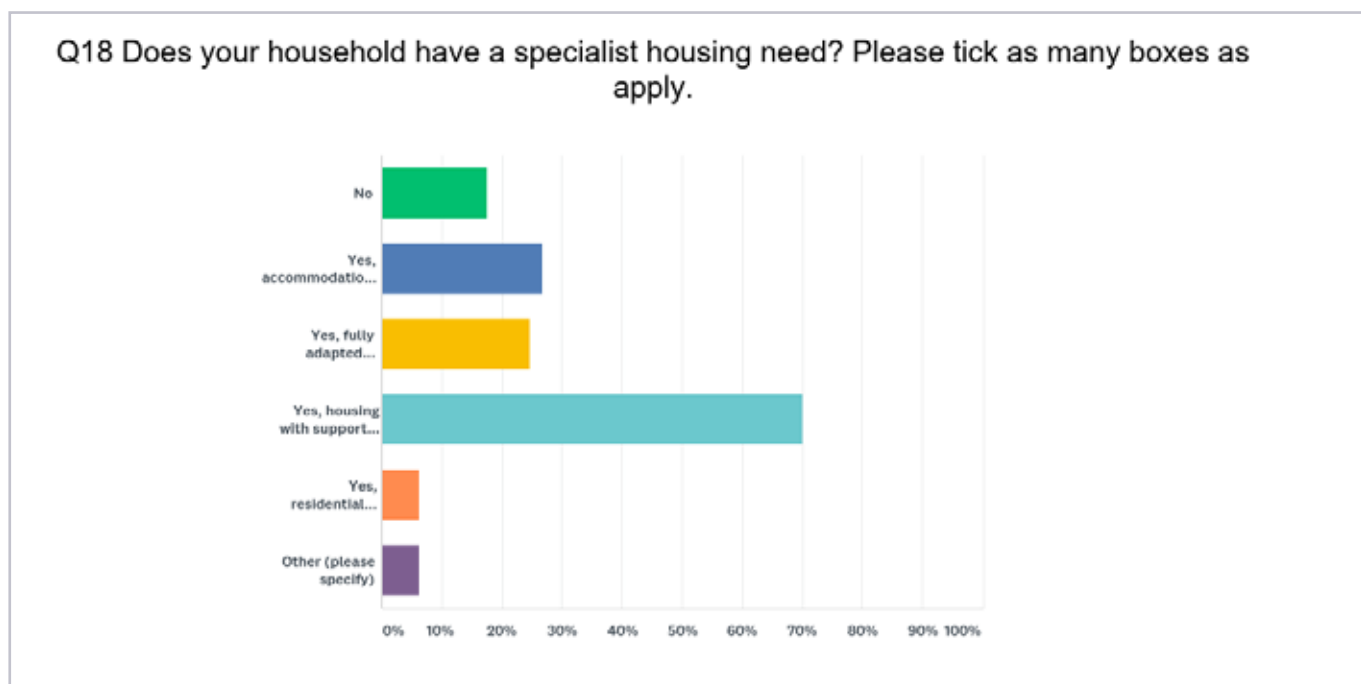
TYPE OF SUPPORT	% OF RESPONDENTS RECEIVING SUPPORT
Family support	100%
School service	15%
SDS	27%
Activity and resource centres	37%
Specialist outreach support	37%
Social enterprises/volunteering	11%

The families were very clear in articulating the issues and challenges they had to deal with, including:

- Distress caused by a lack of continuity with support staff, leaving the young person very anxious and confused about who will be supporting them on any given day
- Examples of support arrangements completely breaking down because of lack of continuity
- Problems for a large number of adults with ASD in accessing wider social work support because of the thresholds set by the Eligibility and Priority Assessment framework that requires a 'critical or substantial need' to ensure access to social work services which is perceived as a form of gate-keeping
- Many comments made about the lack of specialist support options available, particularly out-with the Dumfries area
- A common comment was that, apart from the ARCs, there were very few facilities that provided any kind of support, networking or social contact
- Restrictions on rates for SDS often limit choice and availability for suitably experienced and qualified support workers



The majority of respondents confirmed that, if they moved, they would need housing with support (70%), with further significant numbers requiring ground floor (27%) or adapted properties (25%). Overall, only 18% stated they did not have a specialist need of any kind.



Tenure Options, Design and Location

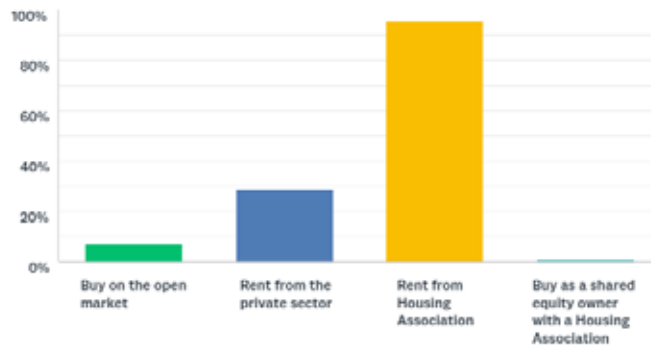
In planning for new housing provision for people with ASD, the research identifies a number of issues and design best principles that should be considered through the planning and implementation process. A subsequent chapter sets out both the issues raised by the families based on their experience of living with ASD, but also highlights useful guidance that can act as a checklist for any proposed project. Some key issues raised by many respondents include:

- The need for enhanced sound proofing, to mitigate both the behavioural challenges of some of the young people, who can at times be very noisy or disruptive, but also to assist if the young person is particularly sensitive to noise
- Additional security, especially if the young person is prone to 'flee'
- Enhanced lighting or mood lighting to respond to sensory changes
- Access to safe external spaces
- Large rooms
- Colour themed fixtures and fittings (kitchen/bathroom)
- Use of bespoke digital/assistive technology

These issues are considered in more detail in a later chapter.

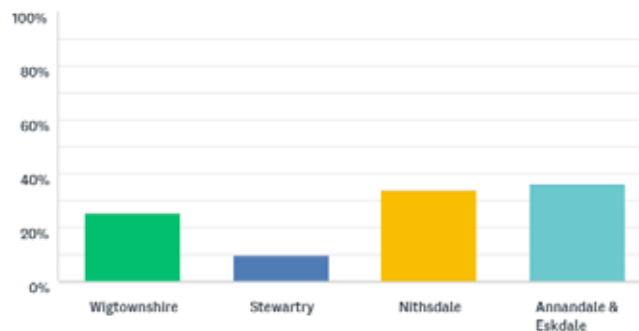
There is limited flexibility or choice about the type of tenure of any new accommodation, with over 95% stating they would need a social rented home through a Registered Social Landlord (RSL). This appears to be due to affordability issues, with most new households claiming benefits. None of the young adults interviewed were in paid employment but many expressed a desire to be. However, there is also clearly a significant lack of understanding of what housing options may be available and whether their needs could be met in other sectors.

Q20 How would this household consider paying for alternative accommodation that would meet their needs? Please tick as many boxes as apply.



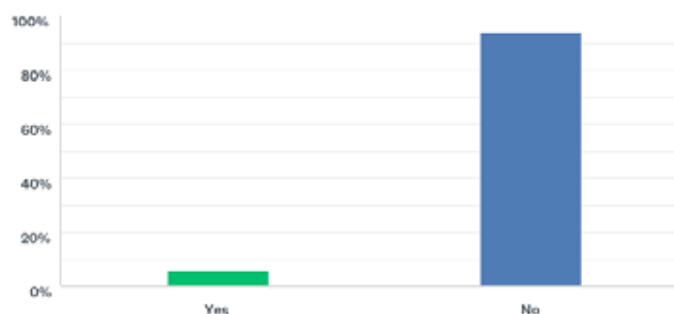
**This question allowed multiple responses*

Q22 In which area(s) would the household consider living? Please tick as many boxes as apply.



Most households would need to stay close to their current accommodation. However, there is some flexibility in the east with households in Annandale and Eskdale considering areas in Nithsdale, but little flexibility in the west, due to the relative distances involved.

Q24 Do you have a current application for housing with any housing association?



Only 6% of respondents stated they had a current application for housing with a RSL, even though 65% say they need to move within 3 years.



This clearly highlights that the current range of housing advice services are not reaching this client group. Many respondents stated they had very little or no information about housing options and felt there was a complete lack of specialist housing advice that could provide detailed relevant and comprehensive information and guidance that meets their needs.

Housing and Support Needs – A Summary of Findings

The response rate shows that the survey sample represents a significant proportion of the total number of young adults with ASD who feel they have unmet housing and support needs. On that basis, the findings provide a robust insight into the issues and challenges that need to be addressed.

As a general issue, a clear need was highlighted for Easy Read documents in relation to housing, care and support, welfare benefits and health services. By providing information in accessible formats, independence would be increased and, potentially, some support for everyday tasks be reduced.

There is a high level of housing need across the region and very little suitable accommodation that meets the needs of young adults with ASD, resulting in poor outcomes for the young people and their families. To avoid crises developing, early planning with well-established multi-agency processes and protocols is required to plan for and deliver new housing that is focused on the needs of the individual.

This new housing should be predominantly affordable social housing and provide for a variety of needs. It should be in locations that sustain close links to family and community and provide pathways to social, educational and employment opportunities. The new homes should have a minimum of 2 bedrooms and the design and lay-out should be innovative, flexible and responsive to the needs of individuals.

The issues highlighted through the survey about the support and care services for young people with ASD need to be addressed. There should be both a strategic and operational focus on improving the choice and availability of suitable support services. There needs to be a focus on ways to provide continuity of care and support by improving staff retention and promoting careers and opportunities within the care and support sector.

More work needs to be done around the roll-out of Self Directed Support (SDS) and the support families receive to sustain services. The financial framework and, particularly, hourly rates underpinning SDS need to be more responsive to the needs of the individual and to the market conditions in which it operates.

New Housing Solutions To Meet The Identified Need

Overview

As seen from the analysis of current provision, with a relatively small amount of supported accommodation for particular needs (238 units across the region) compared to the levels of need and demand, there has to be an increase in the availability of suitable accommodation to meet the varying requirements of all households with particular needs.

The evidence shows that not only is there insufficient supported accommodation, but the existing accommodation does not meet the specific needs of people with ASD. The current provision is more focused on the needs of people with physical disabilities. This has resulted in many families either having to accept that their housing situation will remain unchanged and that they have to 'make do' living in unsuitable accommodation, or they look at housing options out-with Dumfries and Galloway, usually out-of-region placements (the focus of 'Coming Home' - a study by Dr Anne MacDonald.) The message from the many families who engaged with this work is that this situation has to change and more and better housing options are needed to meet their needs.

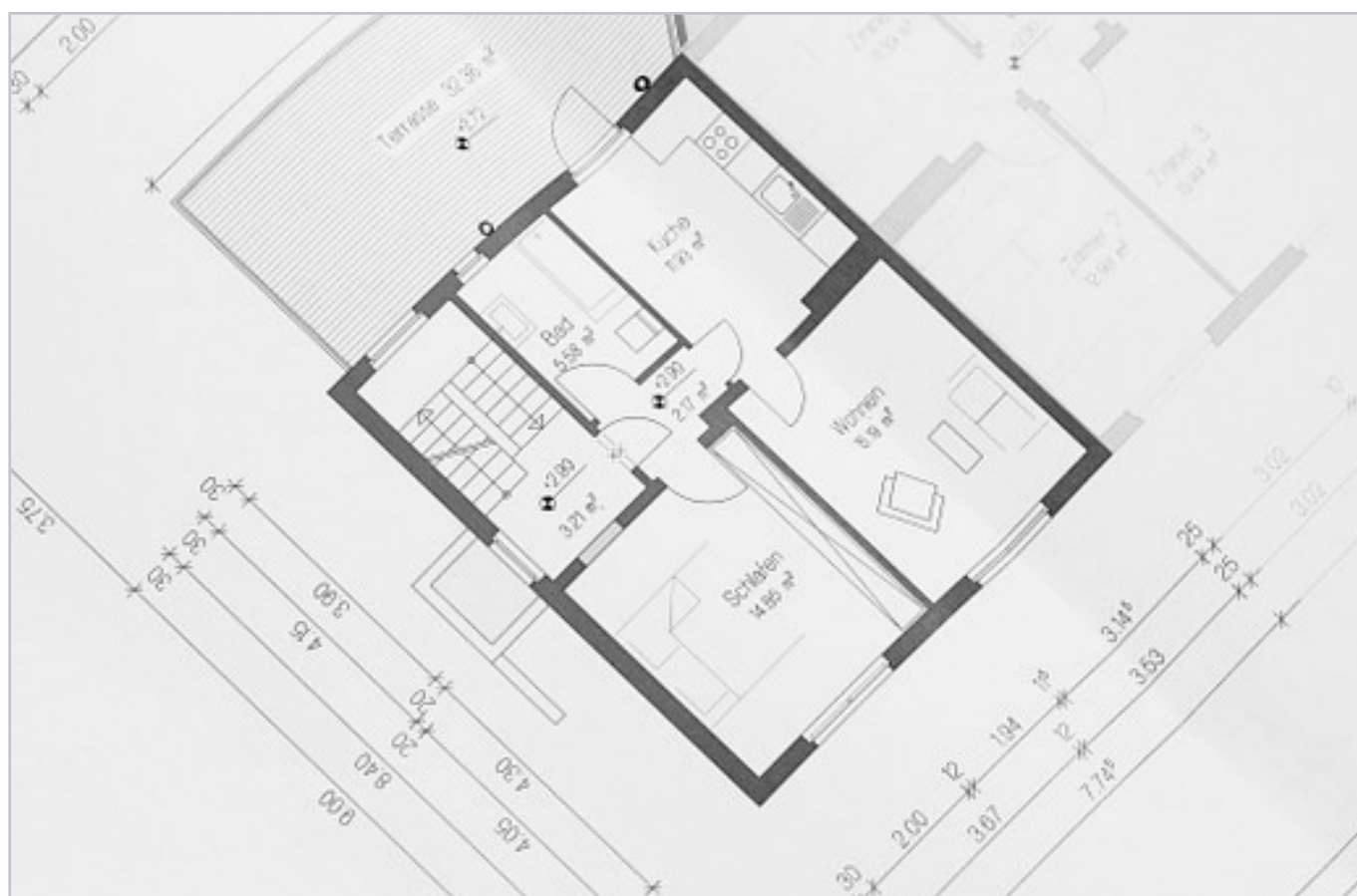
The data collected through the survey shows the vast majority of young people with ASD (91%) view social rented housing as the only realistic affordable option. Therefore, all agencies responsible for delivering affordable social housing in our region should prioritise the needs of these vulnerable households when jointly planning their housing investment programme. The social rented sector is best placed to meet these needs, to embrace innovation and has the capacity to deliver these new homes at a volume that is required.

A key issue to emerge from the research is that there must be a range of housing options to meet varying needs. At one end of the spectrum, a general needs property with minor but careful enhancements would be suitable, whilst at the other end, a unit with intensive specialist supported accommodation is needed. The delivery partners need to be open and flexible when planning their projects and adopt a person-centred approach. A specialist housing advice service would also assist in allowing households to review a range of options across sectors which best meets their needs. This could include, for example, owner/occupier housing, self-build and shared equity.

There is a buoyant development programme contained in the Council's Strategic Housing Investment Plan (SHIP) supported through a significant allocation of capital funding from the Scottish Government which amounts to over £61 million over the next three years. All indications are that this level of funding will be maintained in the medium and longer term to meet the Scottish Government's target of delivering 50,000 new affordable homes across Scotland. Therefore, the Council and its partners are ideally placed to focus more clearly on the development of housing for people with ASD alongside other key priorities for particular needs and general needs housing as part of its future core housing investment programme.



In addition to the capital investment that is required to build more suitable accommodation for people with ASD, there also needs to be priority given to the revenue costs of sustaining any new facilities. With the establishment of the Integration Joint Board overseeing all Adult Health and Social Care responsibilities, there is an expectation that there will be more flexibility within an annual revenue budget of over £370 million to ensure any new facilities have sufficient revenue to deliver the range of services, care and support that are key to successful projects. This is particularly relevant in relation to specialist supported housing where joint funding through the IJB arrangements, for both capital and revenue costs, would assist in over-coming the financial obstacles in developing these higher cost facilities. Given the on-going high cost of out-of-region placements, as detailed in Dr MacDonald's study, it also makes sound financial sense to adopt this flexible co-funding approach.



Autism-friendly Design

When looking at developing housing to meet the needs of people with ASD, it must first be acknowledged that there is no generic particular needs model of housing that can meet the needs of all households with learning and physical disabilities or ASD. Nor is there a single design concept that will be right for every person with ASD. Everyone is different and their needs are different. However, there are key design principles that must always be considered when developing particular needs housing.

Clinical and behavioral studies have shown that autistic people suffer from a high degree of stress, which in turn can have an effect on their behaviour. They may display obsessional behaviour, be hyperactive, or have severe and unpredictable mood-swings, all of which can have implications for the environment in which they live and work. This can also represent a risk factor for carers and support workers and, where possible, the design and lay-out of homes should look to mitigate such risks. A high proportion of autistic adults also have associated learning disabilities. This combination of factors can give rise to:

- Inappropriate use of domestic fittings
- Poor co-ordination and balance
- A need for assistance with basic self-care functions
- A need to control access to areas of risk
- A need for an increased surface area and reduction in surface temperature for heating systems

Most autistic people experience difficulty in adjusting to changes in their environment. Fixtures and fittings that already exist when the person moves into a building are less likely to be tampered with than fittings which appear after they have become familiar with their environment. The planning and design process should be as painstaking as possible in order to minimise the need for change during the first year of occupancy and minimise risk for the vulnerable individual.

The specific issues that were raised during the extensive engagement work for this study include:

- Enhanced sound proofing - both to reduce extraneous noise for the person with ASD but also to minimise any impact their own behaviour may have on neighbouring properties
- Additional security features, especially if there is a risk of fleeing
- Bespoke lighting, including 'mood-lighting' to respond to different behaviours
- Sensory zoning – defining separate spaces as 'high stimulus' or 'low stimulus' and ensuring there are transitional spaces as the person moves between the spaces
- Good digital connectivity
- Technology-enabled 'smart' homes to promote health and well-being
- Access to safe external spaces, either communal or private
- Avoidance of multi-function rooms (e.g. kitchen-diners)
- Avoidance of food preparation smells penetrating other areas



Autistic people can be socially isolated and have difficulty in making and maintaining relationships with others. Building design can assist in avoiding unnecessary stress in social settings by providing:

- Wide corridors
- Large communal rooms with high ceilings
- A choice of exits from communal rooms
- One or two single-person alcove areas in communal rooms
- A choice of recreational rooms or areas*

*Guidance - National Autism Society

Through the consultation and engagement work, a number of ideas emerged about the kind of housing that is needed. The following section sets out the type of innovative projects that should be developed based on the aspirations of the families involved in the study and by reviewing best practice and national guidance.

Specialist Supported Housing Facility

Currently, there is no specialist supported housing facility specifically for adults with ASD in Dumfries and Galloway. Many parents and carers who support someone with profound and complex needs have said without this facility there will be no opportunity for them to move out of the family home. In some cases, they would have to consider, or continue with, out-of-region placements. The prospect of having to be the primary carer for someone with challenging behaviour and complex needs as the parents/carers themselves become older and less able to cope is a real and constant anxiety for many of them. Equally, having to cope with their son or daughter in a long-term out-of-region placement, is often distressing and isolating. A locally-based facility that can provide specialist care and support is, for them, the answer.

A specialist supported housing facility should provide:

- Independent homes (sole occupancy) with security of tenure. These units would be self-contained houses or flats. They could be in a core and cluster model or more potentially dispersed within the community
- 24/7 support. The support would utilise assistive technology as well as on-site presence from key support workers
- Individual support workers to provide continuity of care and support
- Communal facilities (sensory rooms/gardens/activity rooms etc.)
- Access to specialist therapists (OT/speech and language/clinical psychologist/music/art/well-being)
- Training/IT facilities
- Regular social activities
- Outreach services for non-residential clients and links to local community groups and activities
- Located in or close to amenities of a larger town with good transport links

There are some projects across Scotland that provide these facilities and services, but they are insufficient to meet demand. There is a real need to look at developing at least two specialist ASD supported housing facilities in Dumfries and Galloway. Apart from the capital costs, which would be determined by site availability, scale and specifications, such a project would need significant revenue funding. Based on projects elsewhere, the average cost per client would be approximately £100k - £150k per year, depending on the range of services provided. This compares favourably to the costs of out-of region placements in specialist units where a recent study indicated about half of such placements cost more than £200k - and are often well in excess of this figure (*Coming Home, Dr Anne MacDonald, 2018*).

Semi-permanent Adaptations / Extensions

Another proposal that emerged from the research is the concept of a pre-fabricated 'assisted living pod' that provides fully adapted additional living space for someone on a semi-permanent or transitional basis where it is anticipated their needs will change over time. The pod can be attached to the existing family home to provide additional space and bespoke adaptations (bedroom/bathroom/living space) or alternatively located within the curtilage of the property as an independent unit. The pods can then be relocated/reused as needs change.

This type of innovation would provide a positive additional and affordable choice for some families where neither a permanent extension nor a house move would be suitable. Flexible funding arrangements would be required for this model as it would typically involve installing a 'pod' on to a family home that is owner/occupied. However, discretionary grants through a Scheme of Assistance could be available if this type of project became a strategic priority and was seen as a viable and suitable solution.

There are a number of specialist companies that promote this model and highlight that they are flexible enough to provide low carbon, highly bespoke units that can also provide a range of assistive technologies.

SMART HOME



Autism-friendly Housing

There is also a need to routinely develop designated autism-friendly housing as part of wider general needs schemes where relatively 'light touch' design features will make a significant difference to the living environment for those with high functioning ASD. This approach would also meet other care and support needs for vulnerable adults.

Some of these design features are highlighted earlier in the report. The key is to adopt a personalised approach to ensure individual needs are met. These clients can then be further supported through appropriate outreach services.

A programme of providing autism-friendly housing in 10% of the core general needs housing development programme could see 60 - 100 new units developed across the region over a three-year period based on current anticipated completions within the Strategic Housing Investment Plan. Over time, this could provide real choice and opportunity for the many young adults with ASD who, with relatively minor design interventions, could live full and independent lives.

Potential Location of New Housing

The research found a consistent view that travel time of no more than 30 minutes from their existing family home (by car or public transport) would be necessary to allow for independent living whilst also maintaining critical family support and sustaining social networks. Due to the geographic spread of settlements across Dumfries and Galloway, it is sensible to look at providing suitable new autism-friendly designed social rented homes for people with ASD in or around the following locations:

- Annan or Lockerbie
- Dumfries
- Sanquhar or Kirkconnel
- Castle Douglas or Dalbeattie
- Newton Stewart
- Stranraer

Given the specialist nature of the proposed supported housing facilities, it would be appropriate to look for suitable locations for these facilities in Dumfries and Newton Stewart. These locations would allow the specialist units to be accessible for households in both the east and west of the region, bearing in mind the 30 minute radius that most families would look for.

- 4 A dedicated specialist housing advice service is needed to develop an expertise in understanding the needs of people with disabilities and complex needs. This service should be supported by all the key statutory and voluntary agencies. The group responsible for the emerging Particular Needs Housing Strategy is best placed to consider how this Specialist Housing Advice Service can be realised.
- 5 There should be priority given within the Strategic Housing Investment Plan for new social housing to provide for the needs of people with ASD. The new homes should have a minimum of 2 bedrooms and the design and lay-out of the properties should be innovative, flexible and responsive to the needs of individuals. The three models of housing summarised earlier in this report should be templates for future developments. These models are:
 - Specialist residential care and support facilities
 - Assisted living pods
 - Autism-friendly units within general needs schemes
- 6 Based on the evidence of need within our primary research, a target of 80 – 120 additional social rented homes suitable to meet the needs of adults with ASD is a reasonable target over the medium term (3 – 5 years).
- 7 The new homes should be in locations that sustain close links to family and community and provide pathways to social, educational and employment opportunities. This approach would also minimise on-going care and support costs. The precise locations for the new homes will depend on site availability but should be in the towns identified on page 39. The proposal for 2 specialist residential care and support facilities should be located in Dumfries and Newton Stewart to maximise accessibility for households across the region.
- 8 The issues highlighted through the survey about the support and care services for young people with ASD need to be addressed. There should be both a strategic and operational focus on improving the choice and availability of suitable support services. There needs to be a focus on ways to provide better continuity of care and support by improving staff retention and promoting careers and opportunities within the care and support sector to tackle the emerging recruitment crisis facing many support providers.
- 9 A systematic and regular review of existing supported accommodation is needed to ensure the changing needs of residents are met and, where appropriate, alternative suitable accommodation provided. This will also ensure best use is being made of the supported accommodation stock.
- 10 There should be more specialist support services that are designed to meet the needs of people with ASD across the region through a strategic commissioning process that sets out service standards and best practice.
- 11 More work needs to be done around the roll-out of SDS and the support families receive to sustain services. The financial framework and hourly rates underpinning SDS need to be more responsive to the needs of the individual and to the market conditions in which it operates.
- 12 The role of community-based facilities (ARCs, social enterprises etc.) in supporting, training and developing vulnerable young people should be supported and, if possible, broadened to provide better access and more choices, particularly in more rural parts of the region.

Quotes & Key Considerations

<i>Own home</i>	<i>Friends & Family</i>	<i>"Being in my own community"</i>	<i>"Being close to work, family and friends"</i>	<i>Being able to go to college / university / further training</i>	<i>Easy Read documents & language used</i>
<i>Garden - no garden - shared garden - growing space - greenhouse</i>	<i>Early planning with identified young people and families</i>	<i>"Be more independent"</i>	<i>Wifi – internet – gaming</i>	<i>Shared care & shared homes</i>	<i>Making friends</i>
<i>"Be me!"</i>	<i>"What matters to me"</i>	<i>Transport</i>	<i>Knowledge sharing and being kept involved</i>	<i>Feeling of safety at home and outside</i>	<i>Being part of a community – a sense of belonging</i>
<i>Spare room for friends and family</i>	<i>"To stay together with my partner where we want"</i>	<i>"A peaceful area"</i>	<i>Textures – Space – Layout – Visual – Sound proof</i>	<i>"No one will love our children like us"</i>	<i>Pets</i>
<i>Games room</i>	<i>Easily maintained home</i>	<i>"The right support from the right people when it suits me"</i>	<i>"Not being bullied by my family"</i>	<i>"To live with my friends and family"</i>	<i>"A bigger home for me and my family"</i>
<i>Single storey home</i>	<i>"A nice wee flat for me and my dog"</i>	<i>Lighting to define rooms, spaces, worktops & doorways</i>	<i>Purpose built community for my son and his friends with similar needs</i>	<i>Safety features</i>	<i>Self build options</i>



Better Lives Partnership

relaxing

SPECIAL DAY

happy memories

YOU IN MIND

Special moments