



better lives BETTER FUTURES



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

REPORT SUMMARY

Introduction

This report was commissioned by The Holywood Trust to establish the current provision and future need for specialist housing provision and support for young people with Autism Spectrum Disorder (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.

The report has been produced by Better Lives Partnership, a registered Scottish Charity, established in 2016 with the primary aim of supporting young people with autism in Dumfries and Galloway.

The Research

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 of the report and consultation process

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. In total, 44 engagement events took place with over 80 young people with ASD and over 100 parents and carers directly engaging in 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.

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. 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. 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.

Key Findings

Some key findings from the survey are:

- 70% need to move to a new home
- Over 90% need to move on their own
- Over 60% are male
- Over 60% need at least 2 bedrooms
- 65% need to move home within 3 years
- Most need to move to be independent (70%); some find their current home unsuitable for mental health or well-being (42%); unsuitable for physical needs (16%), or require specialist support (14%)

Many issues and concerns were raised about the care and support received, 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 with the thresholds set by the Eligibility and Priority Assessment framework which is perceived as a form of gate-keeping
- Many comments made about the lack of specialist support options available, particularly outwith the Dumfries area
- Very few facilities that provide any kind of support, networking or social contact
- Restrictions on rates for Self Directed Support (SDS) often limit choice and availability for suitably experienced and qualified support workers

Over 90% say they need a social rented home (RSL property) with only 5% being able to buy a home. However, only 6% said they have registered with a Registered Social Landlord (RSL) with many having very little knowledge of how to access social housing.

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 inadequate provision is more focussed 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 outwith Dumfries and Galloway, usually a high-cost specialist out-of-region placement. The use of out-of-region placements should be addressed through additional specialist provision within the region. This will not only improve the lives of the young adults and their families but also offer more affordable options for the statutory agencies that have to fund the placements.

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. There is an expectation that there will be more flexibility within the IJB 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. A co-funding model through the IJB structures to deal with the capital and revenue costs should be developed as an innovative way to deliver these facilities.

Recommendations

The report proposes three broad models for delivering new homes. These are:

- Specialist Supported Housing facilities
- Semi-permanent assisted-living pods
- Autism-friendly homes integrated within general needs projects

The new homes should be located in or around the main settlements of:

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

The two specialist facilities should be located in Newton Stewart and Dumfries, to maximise accessibility and be sufficiently connected to other key services and infrastructure to ensure they are sustainable.

All agencies involved in providing services and planning for new affordable homes for young adults with ASD must ensure they are listening and responding to their needs. Better arrangements for early and meaningful consultation need to be put in place to ensure communication is encouraged with a person-centred approach.

To avoid crises developing, early planning with well-established multi-agency protocols, policies and processes is required to plan for and deliver new housing that is focussed on the needs of the individual. The new strategic structures through the IJB and other statutory and voluntary agencies should have within their remit a clear requirement to review and improve joint planning and delivery mechanisms to address these needs.

It is clear that for many families there are significant gaps in understanding around housing options and where to go for specialist housing advice that fully understands and is responsive to their needs. 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 of the key statutory and voluntary agencies.



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 layout of the properties should be innovative, flexible and responsive to the needs of individuals. 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).

The new homes should be in locations that sustain close links to family and community and provide pathways to social, educational and employment opportunities.

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.

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.

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.

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 hourly rates underpinning SDS need to be more responsive to the needs of the individual and to the market conditions in which it operates.

The role of community-based facilities (Activity and Resources Centres, 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.

