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ISL York Supported Living Service Evaluation

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Bringing Opportunities to Life

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ISL York Supported Living Service Evaluation

Executive Summary

Successful transition to adulthood is frequently associated with outcomes including access to employment, maintaining positive relationships, and independent living.

Introduction

Decisions about residential care are among the most important for predicting well-being and happiness. Studies have shown that housing arrangements can have a significant effect on individual capabilities and community engagement (Mandell 2017).

ISL York Supported Living is a supported living service for autistic adults without a learning disability. It consists of a mixture of shared and individual self-contained flats. There is access to 24/7 support. This service is commissioned by City of York Council, support is provided by ILS and the landlord is Blue Square Residential. It aims to prepare residents for the transition to further independence and equip them with the skills that they require for this.

This service evaluation of the service seeks to uncover the particular experiences of residents, parents/carers, and staff to better understand what has been successful in developing an independent living service and which elements might be improved for future service provision.

Methods

Quantitative measures of well-being and quality of life were conducted with 6 autistic adults with no comorbid diagnosis of learning disability aged between 21-35 residing at ISL York Supported Living Service. A quantitative measure of adaptive functioning was also completed with the 6 residents with the assistance of a staff member.

A semi-structured question schedule was comprised asking about experience with the service and interviews were conducted with the same 6 autistic adults, 5 of their family members and 7 members of staff working within or associated with the service. These were a mixture of face-to-face, phone call and via online survey software. Interviews were audio recorded, transcribed and analysed thematically.

Findings

Themes and sub-categories of these identified in the interviews are summarised below. Residents, family members and staff interviews were analysed separately.

Residents

- Positive experience of service
- Enhanced levels of wellbeing and/or independence for residents
- Challenges to independent living

Family members

- Improved family relations
- Recognition of staff input
- Scope for service development

"The staff and the team here are brilliant. They're a lot better to where I was living before, they just treat me with respect, they're very friendly, they're very supportive and I enjoy them working with me actually."

Staff members

- Dilemmas of in/dependence
- External barriers to successful transitions
- Success of person-centered approaches

Conclusions The findings of this report demonstrate that overall this service meets many of the needs of service users and fills an important gap in support towards independence. It demonstrates an emphasis on individualised supports; however, environmental modifications could be improved. It also demonstrates efforts made for a gradual transition to diverse supports, despite barriers to this such as the covid-19 pandemic. Lastly, there has been good information sharing and collaboration to a large extent within the service and between staff to residents and family members. However, there are some limitations to this evident, particularly with external services.

Recommendations

- More services of this kind should be established to increase the independence and wellbeing of autistic adults
- Build on the work already undertaken to support residents and families to understand the objectives of the Service and the development of skills for future move on.
- Enhance communication pathways prior to the move and maintain throughout
- Continue to build and expand links with other community and mental health supports locally
- Short preparation sessions or courses could be offered to residents prior to the move to help begin to facilitate the learning of independent living skills
- Continue to identify opportunities to enhance professional development opportunities for staff as part of the services commitment to continuous improvement and person-centred outcomes for residents.

Introduction

Successful transition to adulthood is frequently associated with outcomes including access to employment, maintaining positive relationships, and independent living (Fletcher-Watson et al. 2017; Henninger & Taylor, 2013; Test, Smith, & Carter, 2014). Mandell (2017) suggests that decisions about residential care are among the most important for predicting well-being and happiness and some studies have shown that particular housing arrangements can have a significant effect on individual capabilities and community engagement (Ticha et al., 2013). This is verified by data from a wide range of studies across the UK and beyond that indicate that independent living for adults with an autism diagnosis is a particular priority (Gotham et al, 2015; Pellicano et al 2014; Shattuck et al 2018).

However, evidence suggests that autistic adults are significantly less likely to be living outside of the family home. Demographic data across 25 states in the United States indicates only 8.4% of autistic adults live independently (Hewitt et al., 2012) with Billstedt et al.'s study (2005) putting this as low as 3.7%. The majority of autistic adults continue to live at home and report 44% lower odds of living in agency apartments, in their own home or 'other' living arrangement (Hewitt et al., 2012). These poor life outcomes are present even among autistic adults with average to above-average intellectual capacity (Howlin et al., 2004; Taylor, Henninger, & Mailick, 2015). In fact, Anderson et al (2014) indicate that diagnosis makes a difference. Compared to young adults with Learning Disabilities, those with an autism diagnosis (without learning disability) resided with a parent or guardian at higher rates and for longer periods of time after leaving high school. A study by Cederlund et al (2008) showed that 5 years after original diagnosis 64% of their sample with Asperger syndrome and only 8% with autism were living independently but all dependent upon parents for support.

There is reason to believe that many autistic adults could live independently with success. A burgeoning body of literature reports that many autistic university students have developed skills and capacities including cooking, cleaning, and managing budgets etc. when given the chance to live away from home (Sarrett, 2018) and with appropriate support in place. These findings correlate with evidence that shows that higher IQ was the most consistent and strongest predictor of better adult outcomes and better skills in activities of daily living (Gillespie-Lynch et al., 2012; Bal et al, 2015).

Facilitating successful transitions

In their systematic review of the literature surrounding the successful transition to adulthood for autistic adults, Anderson et al (2018) identified three barriers and possible facilitators. Whilst these cover various aspects of the transition to adulthood generally, they have strong transferability to independent living specifically.

Barrier 1: Poor Person-Environment Fit	Facilitator 1: Individualized Supports and Environmental Modifications
Barrier 2: Uncertainty About Changing Parent Roles	Facilitator 2: Gradual Transition to Diverse Supports
Barrier 3: Lack of Comprehensive or Integrated Services	Facilitator 3: Information Sharing and Collaboration

The first barrier, poor person-environment fit, might include accommodation that is not appropriate (Cummins and Lau, 2004; Mandell 2017), where it creates high sensory demands (Flowers et al, 2020; Syu et al, 2020) or increases the chance of manipulation or 'risky' behaviours (Adhia et al, 2020). These challenges can be experienced both in the family home as well as in other accommodation options and can lead to poorer outcomes for both autistic adults and those who support them. Thus, putting in place supports and provision that suits the needs of the individual are a means of facilitating success. This might be by modifying the built environment or living accommodation to reduce sensory reactivity or social demands by having private rooms or spaces.

Anderson et al (2018) identify uncertainty around changing roles as a particular challenge. They position this in terms of parents and there is evidence that they typically play a central role in the lives of autistic individuals throughout adulthood (Cederlund et al 2008). It is clear, therefore, how unsettling the experience of moving out of the family home might be for some autistic adults as well as their parents (Vincent, 2019; Krauss et al, 2005). At the same time there is also evidence for increased tensions as children transition to adulthood but remain in the family home (Cheak-Zamora, Teti & First, 2015) particularly as needs and expectations diverge. To facilitate better transition to independence, changes ought to be a gradual and supplemented with a range of support to meet the individual needs of the autistic adult. This might look like; increased emotional support and an individual to support and/or co-ordinate the transitional process and clear information offered. It might also include help with developing social skills and daily living skills. Mitchell and Beresford (2014) write that such aspects have been reported by autistic young adults to support a positive transition.

The final barrier to successful transition to adulthood is a lack of comprehensive or integrated services. Given the fact that residential care is the single largest cost over the lifetime of individuals with autism (Buescher et al., 2014) it is not surprising that this has been under-funded in the UK (Slasberg & Beresford, 2020). Knapp et al (2011) calculate that for a 'high-functioning adult' living in supported accommodation or a care home, costs are between £84,703 and £87,299 respectively compared to the same individual living in a private household at £32,681 per annum. Studies have demonstrated that there is a great need for research that combines a focus on community- and systems-level factors that influence adult outcomes (Pellicano et al 2014; Shattuck et al 2018). This includes difficulties accessing mental health or allied health services (Crane et al, 2019; McMorris et al, 2019); disconnections between local authority services including employment or benefits (Hendricks 2010; Nicholas et al, 2018; Vincent and Fabri, 2020); and access to wider support in the community. Anderson et al (2018) also identify information sharing and collaboration as a key facilitator for enlarging the capacities of autistic adults and increasing the chances of success.

Scope of evaluation

ISL York Supported Living is a service for autistic adults without a learning disability. The service is commissioned by City of York Council and the support is provided by ISL. It aims to prepare residents for the transition to further independence and equip them with the skills that they require for this.

It consists of a mixture of shared and individual self-contained flats with access to 24/7 support which includes a core staffing model agreed to meet assessed eligibility and safety needs of the residents. The property was purchased and developed by a third-party property developer and is leased to a Registered Provider of Social Housing landlord, in this case Blue Square Residential. Thus, rectification of property issues is the responsibility of the landlord who issue tenancies and provide all housing management, maintenance and repair services.

This service evaluation of ISL York Supported Living seeks to uncover the particular experiences of residents, parents/carers, and staff to better understand what has been successful in developing an independent living service and which elements might be improved for future service provision.

Methods

Participants involved in evaluation

The evaluation took place between the months of July 2020 and April 2021. Ethical approval for the study was obtained from the York St John University Ethics Committee. Participants consisted of a group of autistic adults residing at the service, (n =6, Male =5, Female =1), residents family members (n=5, F=4, M=1) and staff members (n=7, M=2, F=5).

Recruitment of residents was conducted through ISL staff and easy-read advertisements in the service, with the manager acting as gatekeeper. Autistic adults were aged between 21-35, did not have comorbid diagnosis of learning disability, and were all residing at ISL supported living service at the time of recruitment.

Family members were recruited following consent obtained from the residents. This was also through ISL staff members, with the manager acting as gatekeeper. Following consent obtained by the manager to contact the family member, a researcher phoned them to arrange a suitable time for a phone interview.

All family members were a parent of the resident. Both internal and external staff members were recruited. Internal staff members (n=5) are those working at the supported living service. External staff are those associated with the service in some way but with no direct involvement e.g., social workers (n =2).

Ethical procedure for evaluation

Before completion of the study measures, participants were shown an accessible information sheet and a consent form to sign by the manager of the supported living service.

Participants were given a clear overview of the aims of the study, confidentiality and anonymity, their right to withdraw during or after the study before and provided with opportunity to ask any questions before signing the consent form. The consent form also included a question asking if a family member could be contacted for an interview.

Residents were asked to provide the name of whom they would prefer us to contact. This was optional.

All participants were made aware that the data provided may be used within this report. Confidentiality would be maintained by participants remaining anonymous. Therefore, any identifying details such as the use of names and places, were replaced or erased.

Procedure for evaluation: residents

Once participants had consented to take part, each resident was met with individually by the researcher to assist with completion of quantitative measures. Participants completed these within a timescale determined by themselves, with some choosing to meet twice.

The measures assessed self-esteem, identity, self-efficacy and quality of life. These were completed as close as possible to when residents moved into ISL Supported Living Service, in order to provide a baseline measure of these constructs, so that changes could be monitored over time in future studies. They were as follows; Rosenberg Self Esteem Scale, Autism Spectrum Identity Scale, General Self Efficacy Scale, World Health Organization Quality of Life Scale – Brief Version with the Autism Spectrum Quality of Life Scale. Participants also completed the ABAS-3 Adaptive Functioning measure with staff members to assess their ability to perform daily living tasks. (See Appendix 1 for further information on these measures.)

Residents met with the researcher in person a second time to complete a qualitative interview lasting between 30 to 60 minutes. They were asked questions about their experience at the Service so far including what they liked and disliked about the service and whether it met their needs. They were given the option to complete the interview over more than one meeting. Interviews were held in a confidential setting e.g. garden, and were recorded using a tablet device.

Procedure for evaluation: family / staff

After completion of the qualitative interviews with residents, 5 family members who had been nominated by residents were contacted by the service manager. This was to obtain consent for them to be contacted by a researcher for an interview. After consent was obtained, the nominated family member was contacted to arrange a suitable time for a phone interview. These were then conducted and ranged from 30 to 60 minutes in length.
Meanwhile, the n=7 recruited staff members completed an online interview using Qualtrics survey software. This was deemed as the most practical way for staff to engage with the study due to time constraints they faced within the service.

Analysis

Each interview was transcribed verbatim; participants names or any identifying factors were removed to preserve anonymity. The interviews were analysed using thematic analysis.

The questionnaire measures were inputted onto SPSS and descriptive statistics were obtained which offer information on participant characteristics at the time of completion.

Participant Characteristics

Self esteem

Self-esteem scores ranged from 20-26 out of a total possible score of 30. Higher scores indicate higher self-esteem. Scores between 15 and 25 are within normal range. Therefore, self-esteem for all participants fell within typical range indicating at least average self-esteem in all participants.

Self-efficacy

Self-efficacy scores ranged from 20-35 with a total possible score of 40 and lowest possible score of 10. Higher scores indicating higher self-efficacy. This indicates a range of moderate to high self-efficacy.

Adaptive Functioning

The ABAS-3 measures adaptive functioning across three domains: conceptual, social and practical. It also measures general adaptive functioning. Scores indicate adaptive skill level relative to typically developing peers of the same age range. Scores for conceptual functioning ranged from 57-108, social functioning 66-103, practical functioning 61-97 and general adaptive functioning, 63-100. These scores demonstrate a range of scores from extremely low to average functioning. The scores can be interpreted as follows: 70 or less = extremely low, 71-79 = low, 80-89 = below average, 90-109 = average, 110-119 = above average and 120+ = high.

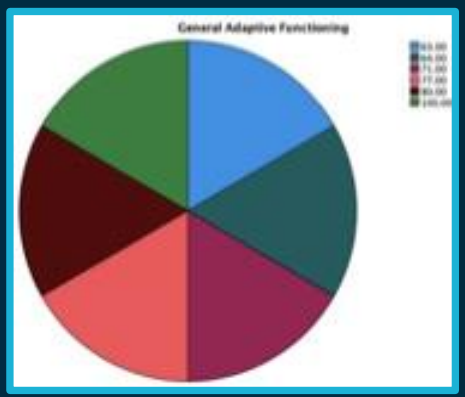

Figure 1: Pie Chart of General Adaptive Functioning scores

Figure 1 illustrates the range in adaptive functioning of the participants, and therefore, range of differences in abilities to perform daily living tasks.

Quality of Life

The WHOQoL-BREF scale measures quality of life in four domains: physical, psychological, social relationships and environmental. It also measures overall quality of life. Higher domain scores indicate higher quality of life. Scores for physical quality of life ranged from 38-75, psychological 38-63, social 31-81 and environmental 50-94. The maximum score for these domains is 100. This measure has been validated for use with autistic adults by McConachie et al. (2018). Below demonstrates a comparison of average Quality of Life domain scores for autistic adults (McConachie et al., 2018) with the current participants' average scores. This shows that overall for each domain quality of life scores were in line with or higher than average.

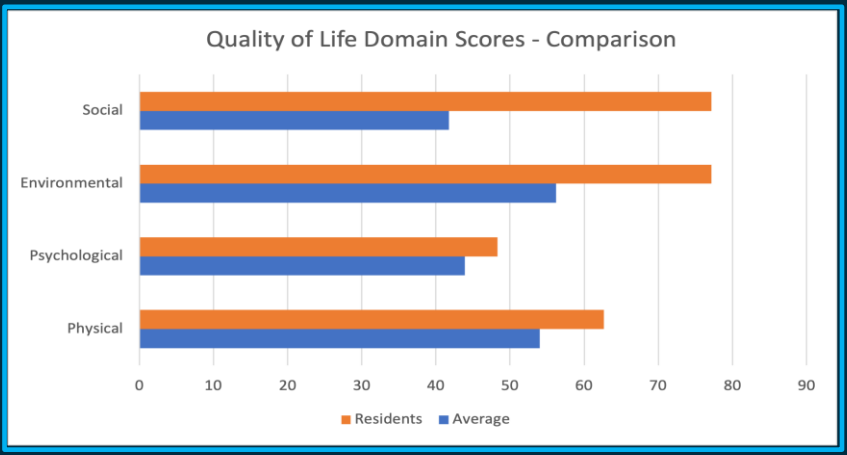

Figure 2: Comparison of Quality of Life domain scores

Figures 3 and 4 demonstrate the spread of the data for participants' quality of life. Half the participants scored 9/10 on overall Quality of Life. Scores for other participants ranged from 3-7. Independently participants have a range of below-average quality of life, average quality of life and some above-average quality of life for each domain. Scores for the ASQoL ranged from 2.75-4.38 with the maximum score being 5, indicating a range of satisfaction with autistic quality of life. Overall scores on this scale were more evenly spread.

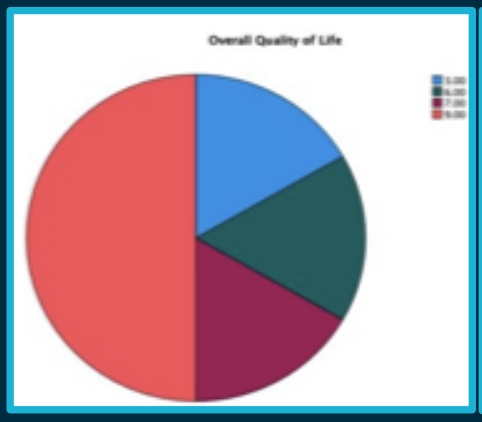

Figure 3: Pie chart showing range of overall WHO-BREF Quality of Life scores

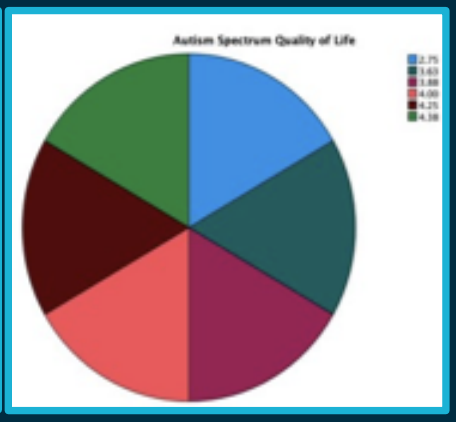

Figure 4: Pie Chart showing range of overall ASQoL Scale scores

Autistic identity

The ASIS scale measures variation in identity across four domains: positive difference, context dependent, spectrum abilities and changeability. Higher scores in positive difference, changeability and spectrum abilities represent a more positive autism identity. Positive difference scores ranged from 19-27 out of a total possible score of 35, changeability 7-14 out of a total possible score of 15, and spectrum abilities from 14-17 out of a total possible score of 25. Positive difference and spectrum abilities are thought to be associated with self-concept and optimism, and changeability is thought to be associated with perception of performance success e.g., vocational success (Macdonald, 2020).

Qualitative findings

Residents' accounts of ISL York Supported Living Service

Theme 1: Positive experience of the Service

Residents reported positive experiences of living in the Service and expressed feeling safe and satisfied that their needs were met by the Service.

For some, they felt that their living situation had improved, particularly following previous living arrangements which they felt created tension and breakdowns in relationships. Although the benefits and enjoyment of living with family members were acknowledged, some residents expressed that living in the family home had been difficult and there was a desire to move out to gain increased independence. Many residents valued having a space of their own that is both personal and private.

"I did want me independence though, so that's why I wanted to move here, really."

"It's my own space and I can do what I want."

"I enjoyed my home, but I prefer my flat more."

Residents expressed feeling safe at the Service, with many feeling reassured by the presence of CCTV and security measures on site. They were also reassured by the trust that they had established among other residents and staff that work with them. Residents described the staff team as approachable, accessible and friendly and reported a sense of enjoyment in connecting with them in the accommodation.
The only concerns that were raised related to the number of staff members working nights, which residents felt could be increased, in order to enhance their sense of safety. Despite this, levels of satisfaction regarding the support received were evident, and many felt that their needs were well-met.

Residents also expressed satisfaction with the service generally and specifically the facilities, which they described as "all there really when you need them on demand pretty much…everything is as it should be really…It's a good level of support, I'm quite happy with the support I'm receiving to do tasks like daily living tasks and all that." Thus, it is clear how the staff and facilities both lead to enhanced wellbeing and capacity to develop independence.

"The staff and the team here are brilliant. They're a lot better to where I was living before, they just treat me with respect. they're very friendly, they're very supportive and I enjoy them working with me actually."

Theme 2: Enhanced levels of wellbeing and/or independence for residents

Residents at the Service all reported some degree of positive change to their independence or well-being. However, there were differences in how these were manifested and the extent to which they were welcomed.

Many residents discussed newly acquired daily living skills and increased desire to live more independently beyond the Service. As part of this experience, they recognized how embracing change in their lives could lead to positive outcomes.

"My mental health's been a lot better so yeah. I've been keeping well."
"I've got more independent as time's gone on. Maybe before I'd ask for help every mealtime but now a day or two I won't ask for help."
"I used to struggle really badly with cooking but now I feel more confident with cooking."

Contrastingly, some of the residents, although experiencing a degree of positive change, expressed a need for continued dependence, rather than moving on. For some, developing the skills required to be independent in the long-term had been challenging and they expressed a reluctancy to move out of the Service. As one resident put it, "I want to stay here for the rest of my time", indicating the mindset of those less comfortable with the idea of independent living following their time at the Service.

Theme 3: Challenges to independent living

Some residents faced challenges during their time at ISL York Supported Living Service although not all of these were directly related to the Service itself. For example, one significant challenge expressed was the COVID-19 pandemic, which led to restrictions to social contact, access to community activities, and reduced employment opportunities. It is important in this context as the pandemic occurred at around the same time that many residents began to move-in and has lasted throughout their time at the Service so far. Thus, alongside adjusting to a new environment, residents were also having to self-isolate which "really upset me in some ways cause I've never done it before".

A further and more service-specific challenge was related to the building and facilities. Given that the building had recently been redesigned and updated with the needs of autistic adults in mind, there were still concerns regarding the physical spaces; for example, one resident suggested that "the communal space is not very good... it's not good enough for all of us to socialise in". Such a perspective shows the desire that residents have to meet and socialize together and how physical spaces can facilitate this to a greater or lesser extent.

Although residents expressed sensory needs were largely met, some drew attention to difficulties with the bright lighting and noise levels at the Service. Moreover, ongoing maintenance work as the new facility was in its initial stages of set-up led to a sense of frustration among some.

Family accounts of ISL York Supported Living Service

Theme 1: Improved family relations

The move into the service led to positive improvements to relationships between some residents and family members.

Some parents/carers expressed that life with their adult child living at home had been challenging at times, with increased demands on space, privacy, and the desire to be treated as an adult. One parent reported: "We were finding it increasingly difficult for us all to live together" which was indicative of this family arrangement.

As a result of their adult child living independently there were reports of increased parental wellbeing. This was in part due to their altered parental role, which had changed from being predominantly caring to more collaborative and supportive. It is likely that better familial relationships also precipitated increases in independence or wellbeing among residents too.

"We have a much … better relationship than we've ever had in years…even now, my partner, he's got a much better relationship with him now. Even with me, in a way it has done them really good actually, just to have that independence".

Family members noticed changes in the independence, confidence, and wellbeing of the residents, remarking for example, "I think he's becoming more independent and he's learning to have confidence in his skills because he's supported to shop and cook and meal plan". They recognized how having "that freedom to think about how to organize [their] own space" was an important dimension of the transition to adulthood and how it made a positive difference for all involved.

Parents / carers spoke very positively about the service and the particular gap that it fills for families. They acknowledged previous difficulties in accessing appropriate services for their children in the home when relational and practical difficulties arose.

"I think there needs to be more like them [ISL York Supported Living Service] because the opportunities for people, especially for parents who've got children with Asperger's and they're struggling, and they've got to that stage where they don't really wanna be at home, but you need the places there"

"I don't know what I would have done without I think, I think our situation would be far worse without it really, I can't imagine what it would be like."

Such remarks demonstrate the positive impact that funded independent living can have for both the residents but also those around them in terms of their wellbeing. It also signals the importance of the transition to independence and adulthood for sustaining relationships and family support in the long-term.

Theme 2: Recognition of staff input

Family members praised the efforts made by the staff to work collaboratively and the meaningful relationships they developed in supporting the residents. In particular, they were acknowledged for their effective communication with families, each other as a staff team, and with the residents. As one parent remarked, "It works. Anything, any issues, we just speak to each other." This approach was particularly relevant as they addressed problems and led to a perceived increase in trust and satisfaction with the service.

"The staff are absolutely amazing… they've all been amazing with him, absolutely amazing. And when there's a problem or whatever, pop into the office they're always so welcoming."

Theme 3: Scope for service development

Although most family members praised staff members for their communication and engaged efforts in aiding the transition and development of independence among the residents, there was some scope for development identified. In a small number of cases parents reported breakdowns in communication, noting that "communication with parents about news, what's happening to our loved ones in terms of activities and social, is non-existent" and some parents / carers suggested that certain approaches could be improved to better suit the needs of the residents.

"I think that sometimes the way they explain things to [resident], is still too complex for him to fully understand."

"Perhaps I think some of the staff are a bit free with their opinions about things and I think that seems, I just wouldn't think should be talked about in front of [resident]."

These two quotations indicate the expertise that parents have with respect to their children and their needs, even into adulthood. They are authoritative on what can enable success and ought to be recognised as a vital resource in the transition to independence. However, it was also clear that parents themselves are going through a process of transition as their child leaves their care and learns to cope and interact independent of them as an adult in their own right.

Happily, there was acknowledgement that staff were often willing to listen to feedback and adapt their approach to better suit the individual's needs where necessary. Evidence of this is clear from one family member who noted, "it's good that they've decided to be a bit more involved and to break tasks down for her". This collaborative approach is acknowledged as one of the core strengths of the Service.

Staff reflections

Theme 1: Dilemmas of in/dependence

Staff reported various positive transitions to independent living. Many spoke of how rewarding it was to notice "positive change, no matter how small" in all residents with respect to increases in confidence, practical skills, wellbeing, and socialisation.

However, there was also concern around the slow progress made by some of the residents and the need for staff input in order to affect positive outcomes. As one team member put it,

"Some residents have very little motivation and some days it is extremely hard to keep finding the time or resources to motivate them."

Some staff reported the need to "prompt and encourage a lot" in order for residents to perform daily living tasks and signaled that they did not consider some residents ready for the transition to independence. They identified functional challenges, for example "for a few it is very hard to manage their money" and noted for others the difficulties they experience to "maintain their flats".

Moreover, given the levels of support currently in place there were concerns about the capacity that some residents would have if and when they were required to leave. For these residents it was recognised that "moving on may be a challenge" and staff were genuinely worried about the implications that this might have as "if staff didn't do this then the quality of life would dramatically decline".

Theme 2: Barriers to successful transitions

Staff identified various barriers to the residents' transition to independent living. These included the implications of the COVID-19 pandemic, mental health difficulties of the residents, and building problems.

Like the residents, staff also recognised how the COVID-19 pandemic and the subsequent restrictions had negative implications for effective transitions. As a result, residents were unable to engage in activities that would have helped to promote socialisation, practical skills, "access other support networks", and develop independence. This might, therefore, explain delays identified among certain residents in the previous section.

As noted by parents, staff were often only learning about the residents as they moved in and as a result were not always aware of their complex needs or mental health difficulties.

"Information needed about the person moving in was insufficient and could have been improved."

"The mental health of my resident means that he is quite disorganised and unmotivated"

Consequently, staff were unable to put in place effective plans to support these individuals particularly at times of high stress, for example simultaneously leaving their family home and experiencing Covid-19 lockdowns.

Finally, staff reported how practical issues at the outset had created barriers to effective transitions for residents. One member of the team noted that “the building wasn't really ready and now a lot of time is spent trying to sort out structural problems…almost every flat has had issues with doors windows and plumbing causing leaks” and another cited difficulties controlling “noise due to poor soundproofing”. Like residents, staff also acknowledged the lack of communal space leading to fewer opportunities for residents to socialise and for staff to build relationships with them. Overall, there was a sense that more time in the initial stages would have allowed greater capacity to foresee and plan for challenges that may arise.

Theme 3: Success of person-centred approaches

Meeting the unique needs of each resident is something staff viewed as being core to the service and their approach as professionals. This sense of getting “to know the whole person, not just the condition” was a central value reported by staff and was also acknowledged by external members of the wider team, where “staff always appear to know the people they support well”. This was characterised by understanding the particular needs of particular residents in their particular context of ISL York Supported Living.

“It is a friendly place and all the staff are great to work with and we support each other and having a good manager makes a big difference.”

Moreover, strong leadership and a sense of team identity both helped to sustain this person-centred approach. Members of staff reported a culture where communication, teamwork, and understanding are present and reported the positive difference that this makes to them individually as members of staff but also for the service they can then provide as a result.

Conclusions

The participants in this study described their experience of this supported living service. It can be concluded that overall experience of the service was positive. Residents reported that the living environment was an improvement for them, as well as family dynamics improving because of the change in environment. The service appeared to have filled a gap in supports for family members and residents. The importance of not generalising the needs of one individual to another was recognised by the staff's person-centred approach. One main limitation noted by all participant groups was related to building issues. This impacted upon the sensory needs of the residents, and a lack of communal space meant less opportunity for socialising. Linked to Anderson et al., (2018) facilitator 1: 'individualized supports and environmental modifications', this service places emphasis on the unique qualities of each individual and thus the individualised support they require. However, modifications to the environment would lead to improvement. This may be something for future services to consider. Residents did however report feeling as though they had a private space to go to, which was their own flat or room.

Anderson et al., (2018) identified another facilitator of 'gradual transition to diverse supports'. This is evidenced in the data, family members and residents both discussed being satisfied with new familial roles and support residents received through ISL York Supported Living. This perhaps demonstrates that the transition was managed at a pace that suited both family and resident. It also shows that staff members were able to handle the moving process well. This is despite the COVID-19 pandemic, which presented challenges to the transitional process and meant that residents were not able to access all types of support they might usually.

The positive experience of the service can also be linked to the relations between staff, family members and residents. A collaborative approach was reported overall. However, there had been some challenges to communication. For example, staff members were not aware of some of the complex needs e.g., mental health difficulties experienced by some of the residents. Sometimes the approach of staff in the service differed from that which the family members believe to be the most effective for their adult child, and so, increased communication in relation to reasoning for such differences could be useful. Despite the challenges, staff were able to problem-solve and continue to provide individualized support upon receipt of new information that has surfaced about those they provide care to. Therefore, linking to Anderson et al (2018) facilitator 3: 'information sharing and collaboration', it appears this is generally good; but improvements could be made by, for example, holding regular meetings between family members, residents and involved staff. This would provide opportunity to communicate openly and discuss any concerns about differences in approaches. A systems level approach has been found to assist with transitions that autistic individuals may go through (Pellicano et al., 2014). Therefore, involving higher management in ISL, social workers, etc., in such meetings may also be of value.

In relation to meeting the aims of the service, to aid the transition to further independence by providing residents with skills necessary, there seemed to be varying amounts of progress. There were also differences in residents' desire for independence. Some residents appeared ready for further independence, whilst others want to stay in the Service. There had, however, been positive change for all residents, ranging from small to large changes, with an increase in ability to perform skills or in well-being apparent for all. This supports research in a university sample demonstrating that, with support, autistic individuals can learn new independent living skills (Sarrett, 2018). The participants' characteristics help to contextualise the differences in progress and show that they are to be expected for this sample. Though only a small group of autistic adults were involved in this evaluation (n=6), they were wide ranging in relation to their well-being and adaptive functioning. Linking this to Anderson et al's (2018) facilitator 2 'gradual transition to diverse supports', it supports the practice of progress happening at a pace that suits the individual. It is also important to again consider barriers to progress, particularly the covid-19 pandemic. This has meant that other community supports have not been available which may help to facilitate further changes to independence and increase a systems level approach (Pellicano et al., 2014).

This report highlights the importance of involving service users when evaluating what works well and what could be improved. The involvement of service users in this evaluation has allowed us to gain first-hand accounts of different individuals' experience and perspectives of ISL Supported Living Service.

Recommendations

More services of this kind should be established to increase the independence and wellbeing of autistic adults. These might include single occupancy flats with adjustable lighting and sound-proofing, private spaces as well as communal areas big enough for socialisation opportunities.

Build on the work already undertaken to support residents and families to understand the objectives of the Service and the development of skills for future move on

Establish meaningful communication from the outset which is maintained throughout. This should include external services for example social workers as well as the management team at ISL and the staff team.

Create opportunities to raise concerns through regular review meetings to include internal and external staff representatives, family members, and residents.

Continue to build and expand links with other community and mental health supports locally

Establish preparation sessions or courses to residents prior to the move to help facilitate the learning of independent living skills e.g. cooking, cleaning, managing finances.

Continue to identify opportunities to enhance professional development opportunities for staff as part of the services commitment to continuous improvement and person-centred outcomes for residents.

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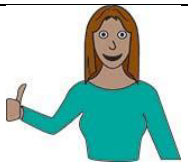
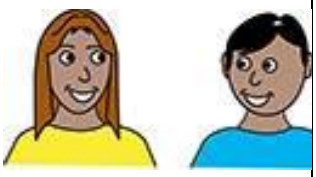
thank you

Appendix 1:

Easy Read version of Executive Summary

York ISL Supported Living Evaluation - Easy Read Summary	
Background York ISL Supported Living is a new service for adults with Autism. The research team at York St John University were asked by City of York Council to find out what the service is like and write a report.	
What we did We interviewed 7 people (residents) who live in the service. They also filled out some questionnaires about their independent living skills and wellbeing. We also interviewed 5 family members and 7 staff members.	
What we found from the questionnaires Residents overall had good wellbeing and self-confidence. Levels of independence of residents is varied.	
What we found from the interviews **Residents said:** The service and support provided is good. Their wellbeing and independent living skills have improved. They feel safe.	

They like having more independence. Some would like to be able to stay at the service in the long term. They would like there to be more staff at night-time. The building could be improved in terms of having more communal space, less bright lights, and noise.	
Families said: They could see improvements in their child's independence, and wellbeing since moving in and their family relationships were better. The service filled a gap in service provision that had not been there before, and this was positive. The staff are very good and have made good relationships with families. Families still want to be involved to offer their expertise on ways to work with their child.	 
Staff said: They could see positive changes in residents in relation to social and independent living skills and wellbeing.	

Some residents needed a lot of support and encouragement, and might not want to or be able to move on to their own accommodation. Staff sometimes needed more information about the person for their care plan. There were initially some problems with the building, and they would benefit from more communal spaces. The staff have worked together as a team to get to know the residents well.	
What will happen now? The information in this report can be used by York City Council and ILS staff to further improve the service.	

Appendix 2.

Measures and Psychometric Properties

Measure	Description	Psychometric Properties
Rosenberg Self-Esteem Scale	A 10-item measure with items being scored from 1 (strongly disagree) to 4 (strongly agree). It measures an individual's view of themselves.	It has been found to have good reliability (Schmitt & Allik, 2005) and validity (Sinclair et al., 2010).
Autism Spectrum Identity Scale	A 22-item measure scored on a five-point Likert scale. It measures four domains: positive difference, context dependent, spectrum abilities, and changeability.	Good construct validity and internal consistency (McDonald, 2020).
General Efficacy Scale	A 10-item measure with items scored from 1 to 4. Assesses self-beliefs about being able to cope with a variety of different demands in life.	Good reliability and good construct validity (Leganger, Kraft & R∅ysamb 2000).
World Health Organization Quality of Life Scale – Brief Version (WHO-BREF)	A 26-item measure. It comprises four domains of Quality of Life: physical, psychological, social and environment.	Good internal consistency for each domain (Skevington et al., 2004). Structural validity has been found to be acceptable for use with autistic individuals (McConachie et al., 2018)
Autism Spectrum Quality of Life Scale	This is a 9-item add on to be used alongside the WHO-BREF. Created following consultation with autistic people about what might be missing from existing quality of life measures.	Good construct validity and test-retest reliability. (McConachie et al., 2018). Validated for use with autistic population.
ABAS-3 Adaptive Functioning Measure	Covers three adaptive domains: conceptual, social and practical. Assesses 11 adaptive skill areas within these. It is scored on a four-point response scale with rater's indicating whether they can perform each skill and how often.	Good internal reliability across each adaptive domain, adaptive skill areas and for the general adaptive composite score and good test-retest reliability.