



Developing an exercise intervention for people with autism: A case study

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Lee Scrimshaw, Support Worker

Ashley Wilson, Head of Quality and Service Development

Toni Fyfe, Head of Complex Care

Dr Lisa Alcorn, Chief Operating Officer

Introduction

SJOG currently has three autism specific services. We consistently strive to develop our practice and explore where research can enhance the opportunities for the people supported in our services.

We aim to develop effective care and support that incorporates physical activity to help reduce the risk of short and long term physiological and/or mental illness becoming an influencing factor on a person's quality of life.

Physical activity is beneficial. It can help manage stress, improve sleep, mood, confidence and reduce the risk of developing some long-term health conditions, such as heart disease, through better physical health.

Exercise and autism

Individuals with autism are more likely to have chronic physical health conditions, particularly heart, lung, and diabetic conditions (Weir et al., 2020). This was corroborated in the Five-year NHS autism research strategy, (NHS 2022). The research strategy indicates that autistic people are more likely to be physically inactive, (MacDonald, M., Esposito, P., & Ulrich, D. 2011), or have restricted and under-nutritious diets, (Herndon, A. C., DiGuseppi, C., Johnson, S. L., Leiferman, J., & Reynolds, A. 2009). Being physical inactive can lead to obesity and disturbed sleeping patterns, as well as being linked to reduced mental wellbeing (NHS, 2022).

Where a person is physically inactive, they are more likely to be socially isolated through lack of participation in events that require a physical presence. This isolation can become a catalyst as to how they are feeling. For people with a diagnosis of autism, unmet sensory processing needs, social restrictions due to behavioural presentation and/or a lack of motivation can also be a factor. Through systematic reviews and meta-analysis, it has been shown physical activity has positive effects on social skills and behaviour for people with autism. (Sefen, J, Al-Salmi, S, Ebrahim Rajab, E, et al, 2020).

Exercise enhances mood and self-esteem while decreasing stress tendencies, a factor known to aggravate mental and physical diseases, (Agrawal, V, Pratil, P & Mahindru, A, 2023). When stress levels are high in services or the person is experiencing poor mental health, this can lead to increased challenges for the person and the people around them.

Challenging behaviour can become a maintaining process for social isolation and worsening the symptoms of low mood and depression. Ultimately this reduces quality of life. Studies have shown high rates of suicidal thoughts (10.9% – 66%), and suicidal behaviours (11% - 30%) in autistic adults and children, (Cassidy, S, 2015) and for a person in times of crisis, dependence on medical appointments or more restrictive approaches such as hospital admission also increases.

The Care Quality Commission published their 2023 work '*How you see me matters: perspectives of autistic people using primary care services*'. The report emphasised that physical health is a priority across the health and social care sector for ensuring quality of life for autistic people. It is also acknowledged that promotion of physical health outcomes will reduce the reliance on appointments or formal health interventions required for the person in the long term.

There is a growing need to support positive intervention which prevent hospital admission in times of crisis. 38% of autistic people were in long stay hospitals in 2015 due to challenging behaviour, but this has risen to 58% in 2022 (National Autistic Society, 2022).

There are currently 2035 people with a learning disability and/or autism being supported at an inpatient setting across the UK, (NHS England 2024). The average cost of support in an inpatient setting at £3,500 per week (Ince, R, Glasby, A, Glasby, J, Miller, R, 2022). 52% of people with learning disabilities and/or autism requiring a stay of over 2 years in a hospital setting (NHS England 2024).

By SJOG taking a focused approach in this area to promote physical activity helps to reduce risk of situation where hospitalisation may be required.

Aims and objectives

This project aimed to explore how increasing physical activity supported quality of life for an autistic person over a 10-week period in which walking exercises were increased. The project also aimed to improve our organisational knowledge and provide a case study of practice to learn from.

Methodology

The project used a single case study of a person with autism and associated learning disabilities who can present with challenging behaviours and who is supported at SJOG.

To maintain anonymity, detailed descriptions of demographic characteristics associated to the case study are not included. The focus was exploring and understanding the before and after-effects of the exercise.

Data

Datasets were captured through information routinely collected in daily support. A mix of quantitative and qualitative data was captured in the following categories.

- Incidents
- PRN medication
- Daily notes to determine engagement in activity
- Sleeping pattern

Daily notes and sleeping patterns were used to provide a narrative of the impact on quality of life. Descriptive statistics were used to measure percentage change in incident and PRN medication.

Establishing a baseline

Baseline data was collected from the period August to December 2022. This was analysed to provide comparative data with 2023 for the same time to ensure seasonal variations were accounted for. Incidents during this period averaged 53.9 minutes with the most prolonged incident lasting over 4 hours.

From August to December 2022 there was a total of:

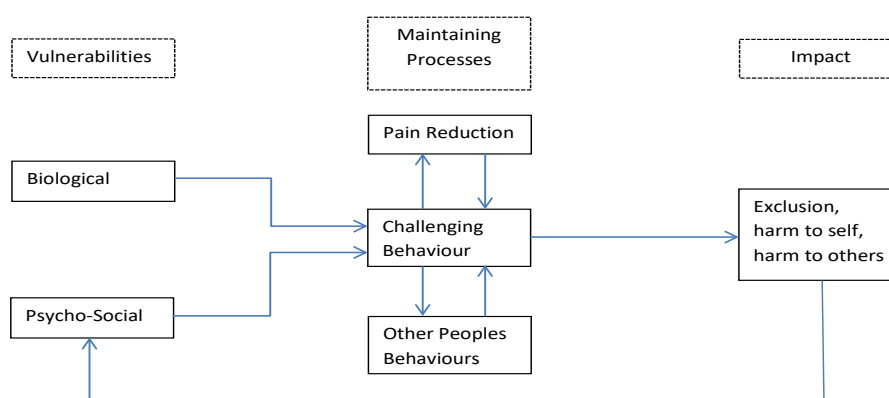
- 40 physical assaults
- 32 incidents of self-injurious behaviours
- 26 incidents of PRN medication
- 43 incidents of Restrictive Physical Intervention.

Proactive strategies were less effective in supporting the person at this time. November was a month where the service recorded most presentation of challenging behaviour.

Exercise activity intervention

When exploring the baseline results and applying this to the conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities, (Hastings et al, 2013), environmental factors became a maintaining process to the behaviour presented, (see figure 1). As a result, exercise activity intervention was specifically chosen to reduce challenging behaviour and improve quality of life.

Figure 1 – Processing behaviour schematic from Hastings et al. (2013).



Walking was chosen as the activity. The person enjoyed the activity and there was flexibility in locations and variation to keep the person interested. Activities also revolved around the persons sensory activities which they seek out behaviourally and this is used to improve his motivation (see Chevallier et al., 2012). Exercise took place between August and December 2023.

Exercise increased over a 10-week period as fitness improved, and routine was established (table 1). Walks were a mixture of road and off-road walks depending on the weather.

Table 1 – Exercise activity level over the 10-week period. Note, estimated step count captured using mobile phone pedometer.

Week number	Exercise level (estimated number of steps) per day	Estimated total number of steps per week based on 6 days of walking.
1	6,000	36,000
2	7,000	42,000
3	8,000	48,000
4	7,000	42,000
5	7,000	42,000
6, 7, 8, 9, 10	10,000 per day	60,000

Baseline data was collected between August and December 2022. Exercise was planned by SJOG support workers and data was provided detailing distance and number of hours of walking. Exercise intervention took place between August and December 2023.

Results

Exercise activity outcomes

Comparison of data between 2022 and 2023 is shown in figure 2. At the start of the project, we see that the number of Physical Assaults in August is higher than that of the previous year (11 in total) and this can be accounted for the change in routine.

As the exercise routine was established, the number of incidents fell. An increase was noted in November, matching patterns in baseline data, however, a 22% reduction from November 2022 suggested that although the person was presenting with behaviours of concern during the same time this was having less of an impact on wellbeing – as the exercise activity continued.

The average duration for incidents across the 5 months in 2023 dropped to 16.4 minutes. This represented a 73% reduction in the time taken to recover from challenging behaviours.

The most prominent outcome was reduction in the administration of PRN Medication. The context to this data is even more profound in that out of the 14 recorded incidents where PRN has been administered only two of these incidents included the administration of central nervous system depressants. It was also noted that milder pain relief, such as paracetamol, was required.

Incidents of self-injury reduced by 29%. Severity of these incidents was dramatically reduced. No hospital or emergency services interventions were required throughout August – December 2023. It was the first time that self-harming reduced to a point where a consistent wound healed completely.

Figure 2 – Comparison of frequency of incidents and medication administration between August – December 2022 and 2023

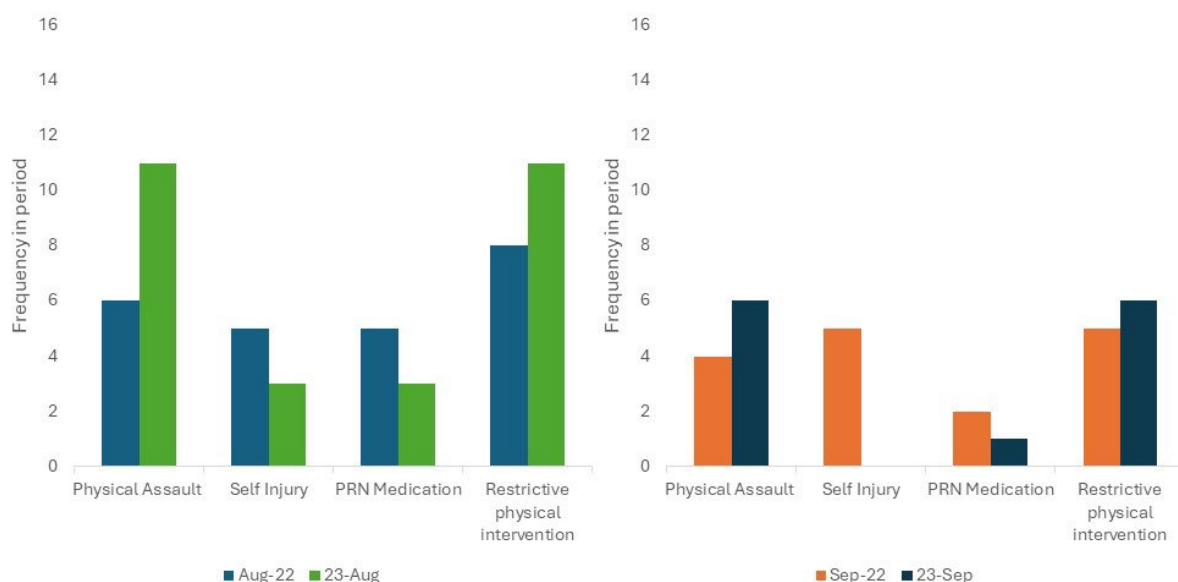
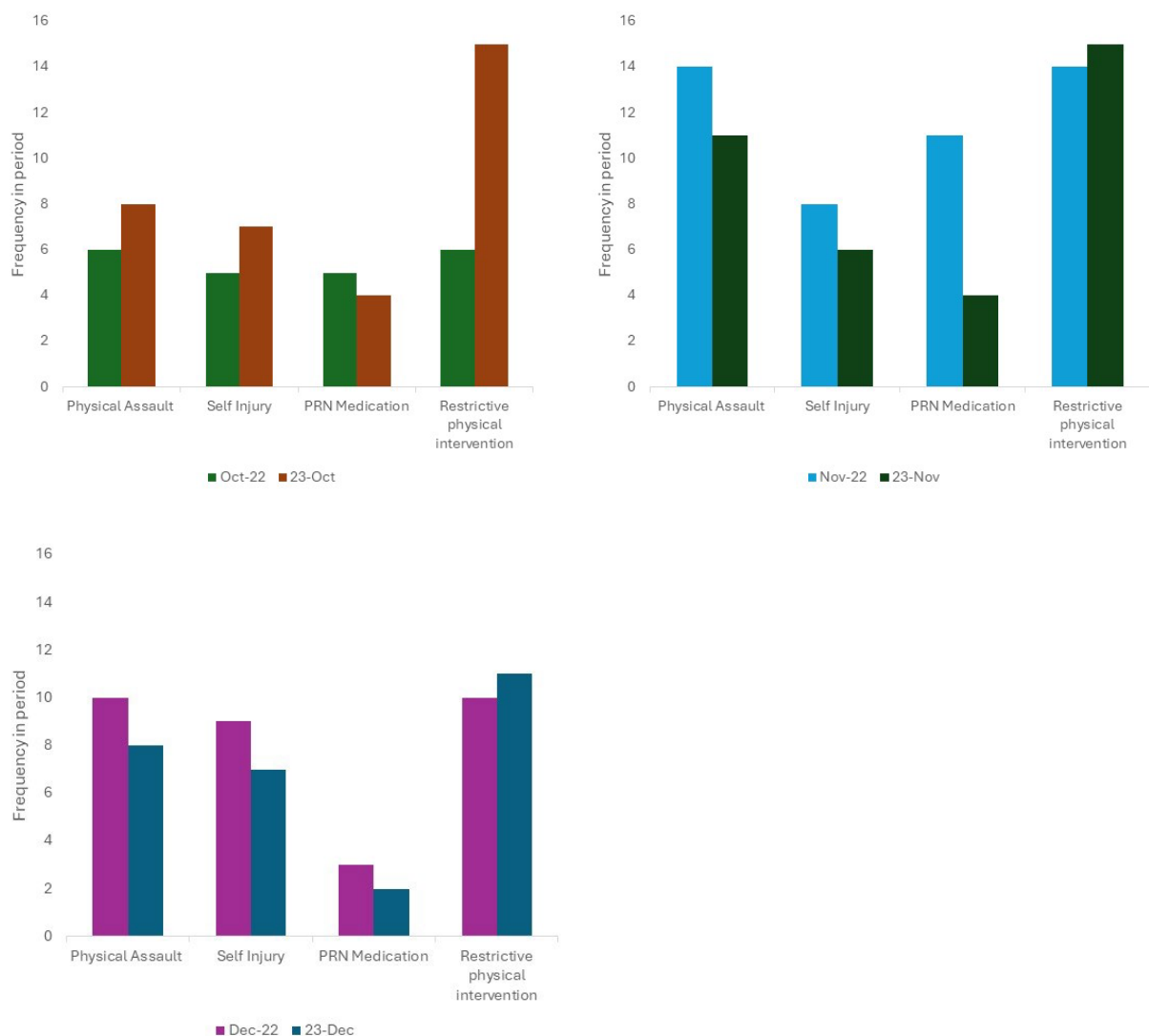


Figure 2 (continued) – Comparison of frequency of incidents and medication administration between August – December 2022 and 2023



Outcomes related to quality of life

When triangulating data from formal reporting and the service the intervention has a significant positive impact on quality of life. Physical health and fitness have improved, evidenced by the increase in and sustained step counts. Increased structure through exercise has supported the person's ability to tolerate a seasonal change which previously presented difficulties. Although there was no reduction in frequency, a reduction in severity and impact of challenging behaviours was noted.

The project had indirect benefits and is supported by the social motivation theory of Chevallier et al., (2012). Skill development was noted in completing tasks such as personal shopping. This has enhanced social opportunities and a low stimulus environment in the service is no longer required. The person has also re-engaged with peers in the home by accessing the communal areas for times of leisure.

Overnight reports evidenced better sleep and processing of routines in a more positive manner - previously on a morning meaning the person was in the past not starting his day until around 11:30am. When putting this into the context of the 'norms' of the daily routine the person was previously finding it difficult to complete all points of their routine during the day. This was resulting in extreme anxiety before bed. This stopped during the exercise activity.

Reflections

This research aimed to explore how increasing physical activity supported quality of life for an autistic person over a 10-week period in which walking exercises were increased. The evaluation detailed the effect of the exercise routine across quality-of-life indicators.

Positive impact of the intervention was seen through a reduction in medication usage and intensity of incidents, and improved fitness and sleep. This builds on the academic research and literature which supports the use of exercise to improve physical and mental health for people with autism. Capturing this effect for the person has informed support planning and embedded the new routine to sustain the positive effects.

More widely, the results inform practice at SJOG. The methodological approach of identifying patterns of behaviour, capturing baseline evidence, and developing a person-centred exercise intervention can be replicated.

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