

Providing Effective Respiratory Care in Patients with a Learning Disability or Autism



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The Project

Respiratory disease is one of the leading causes of avoidable death of people with a learning disability in England (Trusedale, 2021). The UK Equality Act 2010 requires providers of health services to make changes or 'reasonable adjustments' to their practices to protect disabled people from discrimination or disadvantage when accessing care. Patients with a learning disability and/or autism were identified as high usage of emergency and out of hours services. A specialist clinic and patient pathway was developed to empower the patients, encourage compliance, eliminate diagnostic overshadowing, ensure reasonable adjustments were applied to personalized care.

Aim/Objective

- To empower the patient to manage or be involved in managing their own respiratory disease.
- Embed personalized care planning and shared decision making.
- To improve compliance and improve quality of life.
- To reduce admissions and use of emergency services, in turn reducing the carbon footprint

Method

The clinic is run by the Respiratory Clinical Nurse Lead and supported by an HCA. Each appointment is 30 minutes long (extended from normal appointments). Adjustments are made to address any sensory issues with patients having their appointments at the end of the day when the department is quieter. An accessible room is always used and sensory lighting available. The first appointment is a 'fact finding' appointment, using the patient passport, establishing the patient's preferences and understanding. The second appointment, (2 weeks later) involves developing an individualized management plan, which includes materials that are personalized, such as easy read patient information leaflets, self-management plans, incentive peak flow, visual trigger aids, videos, and messaging services.

Results

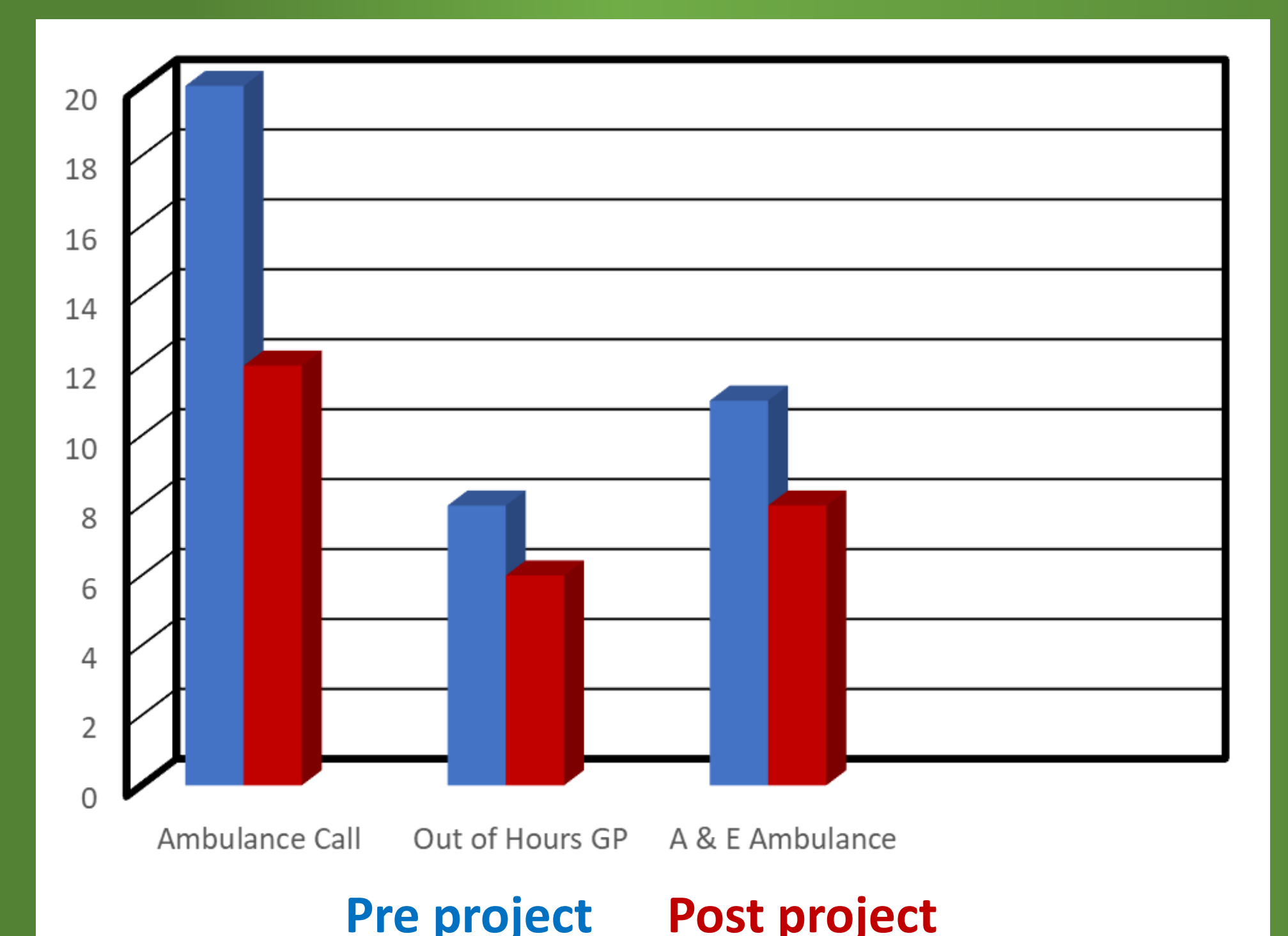
There was found to be a 25% reduction in ED or out of hour's services usage by the patients. 68% reduction in short acting beta agonist (SABA) use and 70% reduction in oral corticosteroid use

It is difficult to understand whether this is due to improved engagement and concordance, greater understanding of their self-management plan, knowing there was support available or the reasonable adjustments being made.

Patient feedback via asthma control questionnaire and Asthma Quality of Life questionnaires supported improved asthma control and quality of life for patients.

Money savings were identified as over £2000 during the 6 months of the project.

Carbon footprint was reduced with less hospital attendances and admissions and a significant reduction in SABA use.



Conclusion

The development of the service has made a significant impact on the quality of care given to this group of underserved patients. It has empowered and enabled them to manage their respiratory disease. They have been issued with information at level's which are personally adapted to their literacy and comprehension.

There has been the development of personalized shared care, with improvements in medicine and treatment concordance.

"Before I met Sharon I was in A&E a lot, I was anxious and no one listened to me about my asthma, I am now much happier, I understand what to do and how to use my inhalers properly, the Chest Clinic always gives me extra time and have not been back to ED. I can manage my asthma myself" - Dawn (37 years old - allergic asthma, learning disability)

Next Steps and Future Developments

The reasonable adjustment respiratory clinic has now been rolled out across all respiratory diseases, and we now have the only Sleep related breathing disorder reasonable adjustment clinic in the UK.

A patient pathway has been developed for the diagnosis, treatment and ongoing management of sleep apnoea in this group of patients, with accompanying easy read leaflets, sensory clinic room and adjustments to CPAP initiation.

NHS England have recorded a short film to highlight and share good practice in the service, including the patients voice. A tool kit has been developed, which is transferable across other specialties and primary care, to share good practice.