

Autistic adults' reflections of Scottish mainstream education

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Introduction

Renfrewshire's Inclusive Communication Environments (RICE) is a joint initiative developed by Renfrewshire Council's Educational Psychology Service and Renfrewshire's Health and Social Care Partnership Speech and Language Therapy Service. It was based on work developed by Glasgow Educational Psychology Service and Health and Social Care Partnership to create Language and Communication Friendly Environments. The purpose of RICE is to develop the capacity of practitioners within education establishments to support the speech, language, and communication needs (SLCN) of children and young people. Our focus is centred on how practitioners can adapt the environment and their individual practice to remove barriers to learning, communication, and interaction.

RICE was initially designed to be a universal intervention suitable for both children with and without identified SLCN. Evidence suggests that there is a strong link between SLCN and other additional support needs (ASN), including children and young people with learning difficulties, those who are care experienced, and those who have social, emotional, and behavioural needs (Hancock et al., 2023; Windsor et al., 2011). Therefore, it is vital in Scotland that we support these children and young people in a way that respects the foundations inherent to The United Nations Convention on the Rights of the Child (UNICEF, 1989). and acknowledges the rising number of those with identified ASN. Research also highlights a strong link between social disadvantage (e.g. deprivation) and SLCN (Locke et al., 2002; Law et al., 2011); this consistent finding forms the bedrock of the rationale for RICE. Within Renfrewshire, 24% of children and young people are identified as living in low-income families, this is a rise of 5% over the last 8 years (Renfrewshire Children's Services, 2024).

Implementation of RICE started in 2019 with the delivery of training to whole establishment staff groups in early years and primary. Over the last two years within Renfrewshire, Support and Development Groups have been delivered and facilitated by Educational Psychologists and Speech and Language Therapists.

Work delivering RICE has been structured around the three RICE indicators which are:

- Adult communication (verbal and non-verbal) that promotes interaction and responds to individual needs
- A physical environment that enhances and promotes opportunities for speech, language, and communication for all learners
- The use of supportive learning and strategies to develop language and communication skills and promote meaningful participation from all learners.

A consistent theme discussed in these groups is the relevance practitioners have placed on the RICE framework in helping them support autistic learners in their classrooms. Evidence states that while some autistic individuals have exceptional language ability, they commonly experience communication barriers as a result of their individual differences in communication style across their lifespan (Vogindroukas et al., 2022). These differences may present as a preference for literal or direct language, use of echolalia (repeating vocalisations made by another person or heard elsewhere), repetitive language phrases, or responding differently to verbal and non-verbal interactions (Bogdashina, 2022).

Rationale

Capturing the voices and experiences of autistic adults who had experienced mainstream schooling was a logical next step to explore given the prevalence of autistic children and young people that are being supported in Renfrewshire's classrooms. The researchers appreciated that only autistic people are true experts in autism and recognise that research often represents neurotypical voices and priorities rather than those of neurodivergent individuals (Pellicano et al., 2014). This research aims to highlight the voices of neurodivergent adults at the centre and explore their school experiences and their thoughts on the suitability of the RICE framework. In addition, we seek to ensure a collaborative and inclusive approach is used to support children and young people currently in school.

There has been a move toward including autistic individuals in the design and implementation of support and services across healthcare and social services (Fletcher-Watson et al., 2019; Mathur, 2021) and this research is in keeping with this approach.

For this research, five autistic adults (four male, one female) were selected via purposive sampling and expressed their consent to participate in the research. Given the participatory nature of this research, adaptive communication tools were utilised and the environment in which it took place was carefully considered to ensure meaningful participation of all the individuals.

Methodology

Ethical Considerations

In line with the British Educational Research Association's (BERA) Ethical Guidelines for Educational Research (2024), the researchers gained ethical approval from Renfrewshire Council's ethical committee. Following ethical approval, the researchers acted in accordance with the Health and Care Professions Council (HCPC) Standards of Conduct, Performance and Ethics and ensured that the information was communicated effectively to the participants through a Team Leader within adult services who works closely with all the participants (HCPC, 2016). Verbal consent was provided to ensure all participants were informed and were satisfied that they knew how their data was being used in the research (BERA, 2024). This was reiterated by the researchers immediately prior to conducting the focus group discussion. All the data was stored on an encrypted laptop on the local authority's secure server. Only the Educational Psychologists conducting the study had data access throughout this process. Participants were made aware that they could withdraw from the research at any time and could be selective in the questions that they wished to contribute to. Furthermore, participants were made aware that their responses would be anonymised during the analysis of results and their data would not be recognisable in any potential publications.

Participants

Five participants (four males, one female) were selected using purposive sampling as having experienced mainstream education and being between 18-40 years old. Both gender and age distributions arose naturally based on our study criteria, not from any intentional selection of participants by gender or age. Participants had been educated in three different local authorities but were now living in Renfrewshire as adults. Participants were not required to have had any prior knowledge of RICE. Two members of staff who work closely with all the participants acted as facilitators as they are attuned to each participants' unique needs and communication style. They were selected to be present to ensure that participants felt empowered to share their wide range of views and share their unique perspectives.

Design

This work utilised a qualitative research design where non-validated questions were asked to all participants via a focus group. A focus group was selected because they are a useful method for exploring attitudes, thoughts and ideas in a forum that allows for further elaboration and explanation of ideas. Two Educational Psychologists co-facilitated the focus group to ensure that the discussion was between the participants rather than with the researchers, being cognisant of the power dynamics inherent in that method. It was decided that a focus group was less demanding of communication compared to, for example, a one-to-one interview. Participants could decide when they wanted to contribute without requiring responses to all questions and prompts. Participants took centre stage in the focus group discussion, with the Educational Psychologists being more on the periphery. The focus group discussion was carried out using the following questions as prompts:

1. What did teachers/adults do to help you at school?
2. Was there anything about the school environment which helped you?
3. Was there anything about the teachers/adults or environment which did not help you at school?
4. If you could change things to help children and young people in schools just now, what would these be?

Questions were provided in text format with supporting visual symbols for participants to refer to during the discussion. Research with autistic people has reflected that providing multiple ways to engage verbally and non-verbally may support participation (Harrington et al., 2014).

Participants were also given the opportunity to look at the RICE framework and provide feedback on the strategies contained in this. Green dots were used to indicate they agreed with the strategy and felt this is helpful for autistic individuals, and red dots were used to indicate they did not agree with the strategy and felt it may be harmful for individuals.

Analysis

The qualitative data was analysed using Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2019). RTA acknowledges the need for the researchers to continually reflect and question assumptions about the data. Three Educational Psychologists completed an initial analysis of the data using RTA and then reviewed the themes to minimise bias and assumptions to increase reliability. The data analysis process followed the 6 phases of RTA and was a recursive process with movement back and forth between phases. The 6 steps are:

1. Familiarising yourself with the data set
2. Coding
3. Generating initial themes
4. Developing and reviewing themes
5. Refining, defining, and naming themes
6. Writing up

The dots placed on the framework were also coded in line with the themes which emerged from the participants' comments. No red dots were placed on the framework by the participants.

Results

Following collection of data, Educational Psychologists completed RTA from the focus group discussion where 6 themes were found:

- Spaces
- Participation
- Adapted Communication
- Relationships
- Individual Needs
- Visuals.

An overview of the themes can be found below:

Spaces

Participants highlighted the importance of spaces in the school environment that they felt safe in and that were appropriately staffed to support them. A desire to feel a sense of belonging in school was clearly articulated throughout the focus group discussion. Examples of participants expressing where they felt comfortable in school but that they were discouraged from being in suggests that there should be opportunities for learners to jointly design the spaces they access.

Quotes

“They could have quieter zones that are staffed properly.”

“I used to feel safe in craft and design, but I would always get detention for being found in there by teachers.”

“I couldn’t even go to the toilet in high school.”

“I just felt like there was nowhere to go.”

“I spent most of my time away from everyone reading books.”

“I used to hang out in the library with all the other rejects because at least nobody else would be in there because they found it boring.”

Participation

It is clear that meaningful participation in school was a challenge for participants due to a variety of factors that were raised (e.g. bullying, not feeling included, feeling unwanted and declining levels of mental health).

Quotes

“My high school forced me to leave due to my performance so they told me I couldn’t stay on.”

“The only reason I didn’t fall behind at school was because my mother was a teacher.”

“I had an option to stay on at school, but my mental health meant that I needed to get out.”

Adapted communication

Emphasis was placed on the importance of creating an environment that is optimally adapted to ensure that children can meaningfully communicate and engage.

Furthermore, participants recognised the power of supportive teachers and teaching staff in adapting language and communication to facilitated meaningful engagement.

Quotes

“Some support teachers helped me by explaining things to me in different ways so that I could understand.”

“Using translators on phones (specific example referenced was Google Translate which will read pieces of scanned text back to you).”

“Pull some children aside separately to make sure they understand things.”

Relationships

Participants valued the high-quality relationships that teachers and school staff tried to cultivate with them to support them personally and educationally. Importantly participants also noted the detrimental effects of practitioners not investing in their development or supporting them appropriately. In addition, participants acknowledged the importance of language and advised practitioners to be mindful of what they commit to writing about learners, for example in school reports, as these effects can be longstanding.

Quotes

“Teachers recognised my creativity.”

“They (teachers) just point out my flaws.”

“They (teachers) always took the bullies’ sides.”

“Some teachers tried to talk to me and remind me that they were there to listen to me.”

“Teachers spent more time praising others when they were actually bullying me.”

“I was upset about some of the stuff written about me in reports so it is important to know what we will read. I went on Google Translate to understand it and I was not happy.”

Visuals

Participants expressed that they relied on visual information in school and that even greater emphasis placed on these supportive visuals would have been beneficial for them. Visuals can foster greater independence, reduce anxiety levels, and improve confidence.

Quotes

“Colour coded storage organisers.”

“More focus on weekly timetable.”

Individual needs

Differentiation pertaining to curricular and wellbeing needs was noted by participants as a significant factor that was detrimental to their experiences of school. Not accounting for the unique needs of individuals led to frustration, avoidance, and apathy.

Quotes

“When I would ask for help, I was ignored.”

“Even when I got diagnosed (with autism) at 8 years old, nobody cared.”

“Teachers would always just say ‘he might be dyslexic’ rather than helping us.”

“I just didn’t bother to ask for help because I knew some of them didn’t care.”

“I felt like I needed to act out to get help from teachers.”

“It was always about what was easiest for the teachers rather than what would have been easiest for me.”

Transitions

Transition between establishments and stages was discussed as an important experience at school. Participants spoke about feeling that if these experiences were planned for in advance, then the experience would have been more positive.

Quotes

“There needs to be good planning between primary schools and secondaries.”

Summary

The comments provided during the focus group and dots placed on the framework were both analysed through the thematic analysis and a visual representation of the themes was created. The size of each theme represented the number of comments or strategies highlighted by participants, for instance adapted communication as the first theme in the visual representation had the most responses, followed by responding to individual needs. This visual is also included in a larger graphic as an appendix.



Figure 1: Visual representation of the scale of themes.

Discussion and implications

Participants spoke very openly about their experiences of school in line with the questions provided to prompt discussion. The themes which emerged through analysis reflect existing guidance and policies around supporting additional support needs, including neurodivergent learners, within schools. The National Autism Implementation Team (NAIT) published 'Key Messages for Staff Working in and with Primary Schools' in 2023. This guidance reflects the themes in this research: ensuring the environment is considered, providing predictability, and knowing needs in advance and making adjustments. Research which promotes neurodiverse voices also reflects a neuro-affirming approach that listens to autistic people and understands their distress (NAIT, 2023).

It is of note that the comments made by participants, and themes which emerged, focused on adaptations to the environment, interactions, and attitudes or ethos of schools rather than individual interventions. Similar findings have been published, such as Billington (2023) whose research involving autistic primary school-age children also found that environmental, cultural and attitudinal changes have more impact than interventions. This also reflects NAIT's 'Environment first' principle which outlines adaptations to physical and social environments such as the spaces available to autistic learners and reduced language (NAIT, 2023). Addressing inclusion and meaningful participation for autistic learners with the focus on what adults and systems can do to adapt demonstrates a move away from seeing autism as a deficit where the individual must change to fit in or comply with the existing environment or system. Participants clearly communicated during this research that adults who took time to get to know them and understood their needs, rather than attempting to fix their deficits, were crucial to positive experiences.

Relationships in education and learning are widely acknowledged to be important to participation and attainment (Lucas, 1999; March & Kearney, 2017; Nolan et al., 2021). Renfrewshire has been implementing a whole establishment Nurturing Relationships Approach since 2016 and it has been found to support the development of relationships between staff and learners (Nolan, 2020).

As relationships between staff and learners also emerged as an important theme in this research, a next step for developing this approach in Renfrewshire is ensuring that training on the importance of relationships in education also reflects the importance of staff understanding learners' needs and showing care and inclusion within learning for all additional support needs. Participants also commented on the language used in written reports regarding needs in education, with participants experiencing distress when reading old school information which commented negatively or disparagingly on their personality or ability. There is now more awareness and guidance on neuro-affirming report writing, such as the NAIT Neuro-Affirming Reports Guidance which highlights experiences of reading clinical reports and how reports can be written that affirm strengths as well as outlining needs and differences (Day et al., 2024).

Limitations

This was a small-scale participatory research study which has limitations as a result. The sample size was small and self-selected, participants were also all white, so no cultural diversity was represented. We are aware that the participants do not represent all autistic adults in Renfrewshire and that individual experiences of education are likely to have large differences due to the number of factors involved. We did not place criteria around the ages of participants, so some experiences of school were longer ago than other participants' experiences. We hope that these may not reflect current teaching and support practices with the work that has been embedded on nurturing approaches, trauma informed practice, and neuro-affirming practice. Further research with adults who have more recently left, or about to leave, education would provide further clarity on changing approaches. We also did not ask whether participants had any other additional support needs identified at school or as adults so experiences may not have solely been due to autistic learning needs. We took this decision for feasibility purposes and to reduce participant burden. However, we acknowledge that future research would benefit from a comprehensive investigation of any co-occurring ASN to facilitate a clearer exploration of the results.

Conclusion

Participants' feedback on the RICE framework which was developed by the Educational Psychology Service and Speech and Language Therapy reinforced that the existing advice is appropriate for meeting the needs of children and young people. A high number of green dot stickers were used to indicate agreements with the strategies, and no red dot stickers were used by participants. One participant also commented that the strategies would have supported their sibling who had different communication needs. This supports the delivery of this framework across Renfrewshire Council as being appropriate for a wide range of additional support needs where speech, language, or communication are barriers to participation.

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