

Study Information Form

Study Title: 'The role of footwear in the experiences of autistic children¹ and their parents'.

The following research study led by Aneta Kuczynska is being conducted as part of a PhD research in the Department of Science and Health at the South East Technological University. This study is being supervised by Dr. Peter Francis (SETU), Dr. Sharon Kinsella (SETU) and Dr. Ashley Jones (Leeds Beckett University).

Introduction

Autistic individuals very often have sensory processing difficulties, and their fine, gross, and generalised motor skills differ from non-autistic groups. That means some autistic children may experience hyper or hypo-reactivity to sensory stimuli or exceptional attention to sensory elements of the environment, i.e. physical, audio or visual or proprioceptive (Baum Miller et al., 2015; Tomchek & Dunn, 2007). For instance, some autistic children tend to be sensory seekers and seek sensory input through touch, whereas others may try to avoid it. Sometimes the sensory stimulation associated with footwear use may contribute to behavioural difficulties commonly observed in autistic children, refusal to wear shoes and reluctance to engage in social-physical activities. That can be a challenging task for parents to purchase appropriate and adaptive footwear that children would wear. All that can profoundly impact the health outcomes and quality of life of autistic children and their parents.

What is this study about, and what will be involved?

The aims of the research are:

1. To survey the experience of parents of autistic children and young autistic people (where appropriate) about challenges related to footwear in Ireland and the UK
2. To survey the experience of parents of autistic children and young autistic people (where appropriate) about the purchase of suitable footwear in Ireland and the UK

¹ This questionnaire will be using an identity-first language [autistic (person)] which has been demonstrated to be preferred by most autistic people (Monk et al., 2022)

To get an answer to aims 1 and 2, the schools/organisations/ groups /charities will be asked to forward information about it to parents/ publish the information about it (link, QR code), i.e. by email, or post on social media.

Participants (parents and young people) will be asked to fill out an online questionnaire that takes roughly 10 – 15 minutes to complete. The questionnaire asks about factors that may affect footwear habits, challenges related to wearing footwear, sensory issues, injuries to the lower limb and the purchase of suitable footwear.

Parents will be asked to complete the questionnaire for those between 4-12 years old. However, young people 13-to 18 can fill it in themselves if they wish, and their parents have consented to it. Due to the nature of the questions, part 1 of the young person version of the questionnaire is directed to parents/ guardians and will need to be filled out by the parent/guardian.

Each household is asked to fill out one of the available questionnaire versions—either the adult version OR the young person version.

Benefits of partaking in this study

To the researcher's knowledge, this research has never been conducted before. Therefore, the results will be ground-breaking and provide evidence of how different types of footwear affect behaviour in autistic children and what footwear is most suitable for that population. These findings will provide a valuable guide for parents and families of autistic children and sensory-sensitive children regarding suitable footwear. Likewise, the proposed research results can inform future research, public views, and product development (shoe wear). Specifically, this study may provide a basis for brands and retailers for more adaptive, more inclusive and functional shoes for children with sensory sensitivities.

Risks associated with partaking in this study

To the researchers' knowledge, there is no risk associated with filling out this questionnaire.

Inclusion Criteria

Autistic children and young people with different support needs are welcome to participate in this study. Likewise, there is no exclusion of any ethnic backgrounds, and all are welcome to participate in this study.

Exclusion from Participation

Parents of non-autistic children and non-autistic young people are excluded from this research. After careful consideration, children/young people with foot deformities (i.e. clubfoot) and medical conditions that may affect their gait pattern, footwear habits and needs (i.e. orthosis) are excluded from this research.

Confidentiality and Data Protection

The data from the online questionnaire will be gathered and stored in the Qualtrics software system. Therefore, the questionnaire will be anonymous and will not collect personal details or identifiable information about participants. Access to the data will be password protected using the Single Sign-On option available only to the primary researcher.

All data collected throughout the study will be stored for up to five years, confidentially and securely.

Voluntary Participation

Even if parental permission was granted for their child to participate in the study, the child is free to refuse to participate. If the child agrees to participate, they are free to withdraw their participation, as are the parents on their child's behalf. The decision to withdraw or not participate in this study will not be penalised.

Further Information

Ethical approval was granted for this research project by the SETU Research Committee on 2nd June 2022 (Ethical Application Number: 309). If you require further information or have questions regarding participation in the study or the study itself, you can contact Aneta Kuczynska, who can be emailed at aneta.kuczynska@itcarlow.ie. Should you wish to make a complaint about handling your data, you may email gdpr@itcarlow.ie.