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| Institution: The Open University | | |
| Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy | | |
| Title of case study: Autism: promoting understanding, professional practices and well-being | | |
| Period when the underpinning research was undertaken: 2000-2020 | | |
| Details of staff conducting the underpinning research from the submitting unit: | | |
| Name(s): | Role(s) (e.g. job title): | Period(s) employed by submitting HEI: |
| Dr Ilona Roth | Lecturer/Senior Lecturer Honorary Associate | 1973-2019 2019-present |
| Period when the claimed impact occurred: 2013-2020 | | |
| Is this case study continued from a case study submitted in 2014? N | | |
| 1. Summary of the impact | | |
| <p>Research at The Open University (OU) has promoted better understanding of autism through innovative studies capturing autistic people's voices, perspectives and strengths, embracing inter-disciplinary methodology and exploring particular challenges in a non-western low-income setting. The findings have informed effective autism resources with UK and global roll-out to wide audiences. Impacts in the areas of Awareness and Understanding, Professional Practices and Health and Well-being include:</p> <ul style="list-style-type: none"> • Diverse end-users: better understanding of the profiles of challenges and strengths in autism; • Professionals including in education and health: better equipped to engage with autistic people; • Family members and autistic individuals: greater insight, empowerment and self-acceptance. | | |
| 2. Underpinning research | | |
| <p>Autism has traditionally been characterised in terms of disabling features or 'deficits', and from a Western cultural perspective. To address erroneous stereotypes, and poor understanding of autistic people's diverse experiences and needs, Dr Ilona Roth has:</p> <ul style="list-style-type: none"> • conducted innovative research capturing autistic people's voices, insights and creativity to help reframe ideas about autistic cognition. • explored and worked on special challenges for autistic people and their families in a low-income non-western setting. <p>Reframing autistic cognition</p> <p>Since 2000, Roth has developed innovative methodology and interdisciplinary perspectives aimed at challenging the common assumption that autistic people lack imagination, self-insight and other cognitive skills. Through methods foregrounding the voices and experiences of autistic people, her work has helped to promote a more positive and differentiated profile of autism.</p> <p>i. <u>Evaluating creativity and self-awareness in poetry by autistic writers</u></p> <p>Starting in 2004, with British Academy funding, Roth conducted an in-depth study of poetry by autistic writers. She elaborated a content analysis method to compare poetry by autistic and non-autistic writers, evaluating use of metaphor and mental state language and exploring the poets' preferred poetic styles and themes. This pioneering study revealed substantial imagination and self-awareness in the autistic poets' work [O1], enriching the growing critique of deficit models.</p> <p>ii. <u>Autistic cognition in interdisciplinary perspective</u></p> <p>Roth's poetry work also inspired her British Academy funded interdisciplinary initiative [O1], juxtaposing evolutionary and cognitive sciences with the arts and humanities in a pioneering contribution to the newly emerging cognitive humanities field. She has evolved the arts/science paradigm in her autism work, focusing on the creativity, ways of thinking and lived experience of autistic people to foreground epistemological, methodological and ethical issues in the study of autistic imaginative cognition [e.g. O2].</p> <p>iii. <u>Autistic people's perspectives on their special interests</u></p> <p>In 2011, Roth started research on another well-recognised but little researched autistic trait: pursuit of unusual and highly focused interests. While such narrow interests were often described by parents and clinicians as detrimental to an autistic person's socialisation and learning opportunities, Roth and her colleague Dr Rosa Hoekstra, now at Kings College,</p> | | |

London, took the then novel approach of collecting first person data. Their newly designed online survey demonstrated that adult autistic participants had exceptionally high levels of motivation for, and commitment to, their topics of interest compared with control participants [O3, O4]. Yet the data also suggested that special interests play a benign or positive role in autistic adults' lives, again questioning the prevailing view of their negative consequences.

Autism in a low-income non-Western culture

Mindful of the profound and distinctive challenges for autistic people in culturally diverse, low income settings, in 2012 Roth joined an Autism Speaks funded project, led by Hoekstra, and constituting the first autism research in Ethiopia. The multi-disciplinary Addis Ababa University and Open University team documented low awareness of autism, stigma and minimal provision [O5]. Roth and colleagues developed text and audio-visual training materials, providing simple guidance on identification for Ethiopian frontline health workers, and support strategies for families and individuals. After training, 97 health workers demonstrated significantly fewer negative beliefs about autistic individuals and less desire for social distance from them [O6].

3. References to the research

All cited outputs can be made available on request.

- O1.** Roth, I. (2007) 'Autism and the imaginative mind' In: Roth, I, (ed) *Imaginative Minds*. Proceedings of the British Academy, vol.147; Oxford: Oxford University Press, pp.277–306. <http://oro.open.ac.uk/26532/>
- O2.** Roth, I. (2019) 'Evaluating Atypical Imagination and Cognition in Autism: Working in the Arts/Science Interspace' in Shaughnessy, N, and Barnard, P (eds) *Performing Psychologies: Imagination, Creativity and Dramas of the Mind* Bloomsbury, pp.69–84. <http://oro.open.ac.uk/59798/>
- O3.** Grove, R., Roth, I., and Hoekstra, R.A. (2016) 'The motivation for special interests in individuals with autism and controls: Development and validation of the special interest motivation scale' *Autism Research*, 9(6) pp.677–688. <https://doi.org/10.1002/aur.1560>
- O4.** Roth, I.A., Roelfsema, M.T., and Hoekstra, R.A. (2015) *Measuring Commitment to Special Interests in Adults on the Autism Spectrum*, Paper presented at the International Society for Autism Research, Salt Lake City Meeting, 13th-16th May 2015. <http://oro.open.ac.uk/60328/>
- O5.** Tekola, B., Baheretibeb, Y., Roth, I., Tilahun, D., Fekadu, A., Hanlon, C., and Hoekstra, R.A. (2016) 'Challenges and opportunities to improve autism services in low-income countries: lessons from a situational analysis in Ethiopia' *Global Mental Health*, 3(e21). <https://doi.org/10.1017/gmh.2016.17>
- O6.** Tilahun, D., Fekadu, A., Tekola, B., Araya, M., Roth, I., Davey, B., Hanlon, C., and Hoekstra, R.A. (2019) 'Ethiopian community health workers' beliefs and attitudes towards children with autism: Impact of a brief training intervention' *Autism*, 23(1) pp.39–49. <https://doi.org/10.1177/1362361317730298>

Roth's poetry study [O1] was funded by a British Academy small grant. Her interdisciplinary symposium and resulting edited volume [O1] were hosted and funded by the British Academy. Her poetry study was selected as an exemplar of British Academy scholarship, appearing in the Academy's annual review (2008, Issue 11). The special interests paper [O3] appeared in the official journal of the International Society for Autism Research, while the conference paper [O4] was one of a small proportion of submissions accepted for oral presentation at the Society's annual international meeting. The Ethiopian work [O5, O6] was funded by Autism Speaks, in collaboration with the Ethiopian Federal Ministry of Health, with additional UK government funding within the international Programme for Improving Mental Health Care (PRIME).

4. Details of the impact

The lives of autistic people are often adversely affected by poor public understanding, lack of professional training and diminished individual and family well-being. Building on her research and distance learning expertise, Roth has addressed these problems with autism training resources reaching a large and diverse range of end-users, including educators, health care professionals and employers, as well as autistic individuals and family members. Key impact areas are: **Awareness and Understanding; Professional Practices; Health and Well-being.**

Pathway to impact: formative steps towards the free online course *Understanding Autism*

An OU blended learning autism course developed by **Roth** in 2009 was chosen to deliver key national goals of the Scottish Government Strategy for Autism. The Government allocated GBP150,000 across the years 2012-2015, to fund free study for three annual cohorts of around 170 individuals in Scotland. A survey of the 2012 cohort indicated positive effects on awareness and understanding. For the numerous funded learners with relatively low socio-economic status and substantial parent/carer commitments, free home studying produced life-relevant benefits.

Roth's Ethiopian research and training insights [O5, O6], led to participation at the 2013 World Health Organisation consultation on autism and other developmental disorders, calling for global campaigns to raise public awareness, remove stigma and share best practices and knowledge.

Through these Scottish and international activities, **Roth** identified a key role for free online autism resources, informed by her research insights and accessible to different family, professional and cultural audiences. This recognition was fundamental to the concept and development of the autism resources that form the core of this impact case (see below).

The free online course *Understanding Autism*

In 2016 **Roth** secured OU and Dangoor Foundation funding to develop the open access Badged Open Course (BOC) [Understanding Autism](#). The course was launched worldwide on the OU's OpenLearn platform on September 5th 2018, and its training utility was formally endorsed by the UK CPD Standards Office in December 2018.

Mirroring the blend of scientific and 'insider' methods in her autism research, **Roth** commissioned a psychologist and an OU science graduate, both parents of autistic offspring, as co-author and critical reader. Throughout the course, learners engage with scientific and health perspectives alongside the challenges, strengths and diverse experiences of autistic children, adults and their families, as featured in video, audio and textual testimony.

Understanding Autism was listed as OpenLearn's top course 2019-2020 [C1]; evidence of **extensive reach** includes:

- 61,818 enrolments between September 5th 2018 and 31 December 2020 [C1]
- an estimated 4,265 non-UK enrolments across 6 continents – based on the pre-course survey [C2, ps.2,127, 129]
- diverse types of learner: of 2,936 post-course survey respondents [C3, p.1] 61% gave study purpose as professional development for their autism-related work [C3, p.30], including in education, medicine, mental health, social care, sports, hairdressing and prison work [C3]; further learner categories included autistic individuals, family members and friends; trainees, school and university students [C2, C3].

The pre- and post-course surveys [C2, C3] provided both quantitative and qualitative (free text) impact evidence. The free text data along with learners' course review page comments were compiled as a specialist thematic analysis in August 2020 [C4]. The following sub-sections describe quantitative and supporting qualitative evidence of the **significance of impacts**.

Impacts of *Understanding Autism* on Awareness and Understanding

90% of post-course survey respondents reported improved knowledge of autism and 83% reported improved understanding of autistic people [C3, p.89-90]. According to the analysis [C4, p.21], these outcomes informed: "[...] *improved working with autistic children and adults in employment and voluntary settings. Specifically, respondents described being better able to support autistic adults and children (and their families) in their professional roles*". One course review cited in [C4, p.22] stated: "*This course helped me to better understand Autism. I'm a special education teacher in Alaska and work with students on the spectrum every day. [...] I will share the information with my staff and families. Thank you!*".

61% reported changed perception of autism and 56% felt encouraged to raise awareness of autism [C3, p.90 and p.94]. Respondent comments include: "[*The course*] *has changed my views entirely on the problems that autistic people and their families face on a day to day basis.*" [C4, p.781].

"*The course challenged me by putting autism in a global context which was something I hadn't thought about. The course was balanced by being both positive about what autistic people can excel at and discussing the negative aspects.*" [C4, p.17].

Impacts of *Understanding Autism* on Professional Practices

63% of survey respondents reported impacts on their work [C3, p.90]. [C4, p.22] identified changes to professional practices including: “*adjusting the environment to incorporate new knowledge of sensory overload, supporting social interactions and making changes to lesson planning*”.

A practising psychotherapist [C5] stated that she felt enabled: “[...] *to offer a more informed and inclusive approach in my work as a psychotherapist [...]. I feel more confident in exploring and thinking about issues of neurodiversity, and tailoring my interventions to the individual needs of clients who may have an ASC [Autism Spectrum Condition] or who support those who do*”.

Impacts of *Understanding Autism* on Health and Well-being

30% of respondents reported impacts on their approach to supporting an autistic family member or friend [C3, p.90]. [C4] summarised gains including reduced sense of isolation, and empowerment to deal with challenges and stigma. Relevant feedback comments included: “*as a parent of an autistic child [...] it has help me personally by reading accounts of parents, gave me a feeling of ‘you’re not alone’ type of thing.*” [C3, p.111].

“*I found a new support forum from your course [...] so thank you!*” [C4, p.24].

“*I feel more empowered to cope with an autistic family member and how to ignore negativity from people with less awareness.*” [C4, p.24].

20% reported improved understanding of self, citing gains such as self-acceptance and making better sense of life experiences [C3, p.90]. Relevant feedback comments included: “*I’m probably one of the borderline individuals that will never be diagnosed, but it supported my own acceptance.*” [C4, p.633].

“*I finally understand myself and why my family were so uncomfortable with me!*” [C3, p.112].

“[...] *reading this has helped make sense of things throughout my own life.*” [C4, p.26].

Impacts of *Understanding Autism* in UK and International Settings

Scotland: Scottish Government and Autism Network Scotland

Building on her earlier collaboration with the Scottish Government, during the current REF assessment period **Roth** has broadened Scottish engagement to include both national and regional government (Dumfries and Galloway (D&G)), and the Autism Network Scotland. These agencies promote *Understanding Autism* as a resource for understanding and capacity building in Scotland and course enrolments are relatively high in this UK nation [C2, p.125, C3. p.178].

Scottish Government Senior Policy Manager for Autism and Learning Disabilities stated [C7, p.3]: “*This year marks the 10th year of the Scottish Strategy for Autism and its impact is currently being independently evaluated [...] we know that the 6000 plus students in Scotland [have] helped to bring about changes in knowledge and understanding in Scotland [...]. This work has been well received by professionals and has led to welcome service improvements across Scotland. The Scottish Government are committed to promote The Open University free autism resource*”.

Autism Network Scotland’s Business Development Officer completed the course in July 2019: “*it impacted my thinking [and] increased my understanding and awareness of autism, resulting in me having more confidence to engage with professionals, autistic individuals and their families.*” [C7, p.4].

Snowbility, The Snow Centre, Hemel Hempstead

Roth has provided guidance (2012 to present) for Snowbility’s snow sports programmes for children with autism and other additional needs. Since September 2019, the Director has adopted *Understanding Autism* for staff up-skilling and recommended it to parents. A staff member who took the course in April 2020 identified impacts on her perceptions of autism, understanding of autistic people and confidence engaging with autistic snow sports learners [C6, p.10-11]. She reported that she had adapted her strategies for enhancing autistic learners’ attention and snow sports acquisition and had plans to share her training with fellow staff [C6, p.10].

For another staff member: *“Having personal experiences of raising autistic children it’s easy to use your own methods and knowledge and apply it to others. The course reminded me to be open to different experiences and interpretations of the condition.”* [C6, p.40].

The Director’s testimonial [C6, p.46] describes Roth’s expert input and training materials as: *“[...] incredibly beneficial for the business and life changing for our students.”* and instrumental in the Snowbility programme *“[...] becoming Ofsted Registered [10/08/17] and also [...] awarded NAS (National Autistic Society) accreditation [15/08/2017] as well as then being awarded a commendation for [Snowbility’s] work”*. Regarding Snowbility’s virtual snow sports programme for lockdown 2020, successfully delivered weekly to fourteen SEN schools and a college, the Director again commends the beneficial influence of *“[...] the Open Learning course and the input from Dr Roth [...]”*.

The WeChange Centre, Bucharest, Romania

A Romanian course translation was prepared in consultation between **Roth** and the Director of the Bucharest WeChange centre for autistic children and their parents. During winter 2019 the course was presented offline, complemented by 8 weekly face to face workshops, to a group of WeChange staff and parents and other professionals. **Roth** joined some sessions via Skype and provided resources and suggestions for the study group. 69% of respondents to a customised survey reported impact on their perceptions of autism and understanding of autistic people, while 61% reported impact on their support for a family member or friend [C8, pp.2-3]. One participating parent commented: *“What I wanted [...] is to understand better my child’s actions, in particular why he is self-stimulating, and indeed I have started to understand his reactions”*.

31% reported an impact on their work [C8, p.2]. In her testimonial [C8, p.46] the WeChange Director states:

“Parents have supported each other and empathized with each other, gave each other ideas and information that were very useful and felt encouraged to do things differently [...]. And most important a community was created [...] I myself have learned new things, and structured the information I had differently after attending this course, and it gave me new ways to understand and explain autism [...]. As a result of our course a group was created to further support the parents in the questions and challenges they might have”.

Translated and adapted online course for France

Mindful of autism’s problematic history in France, **Roth** has orchestrated translation and versioning of the course for France. The Groupement National Centres Ressources Autisme (GNCRA) has reviewed the new course materials and confirmed institutional endorsement and support for French nationwide dissemination. In his testimonial [C9, p.3], the GNCRA Director states that the collaboration to date (2019-2020) has enabled GNCRA to: *“not only expand our partnerships but also to compare, and indeed reinforce, our knowledge and practice with regard to what is practised internationally. [...] this collaboration has also helped us progress considerably in the reflections on e-learning that we had only just begun at the time. Today, and even more so in times of health crisis, we are convinced of the importance of offering awareness-raising and training content online, and are working increasingly in this direction”*.

Note: Use of the phrase ‘autistic person/people’, rather than ‘person/people with autism’ in this impact case recognises the preference of a majority in the autism community.

Sources to corroborate the impact of *Understanding Autism*

- C1.** The OpenLearn annual report 2019-2020, p.5; course data summary 31-12-2020.
- C2.** Understanding Autism pre-course survey data from Survey Monkey with introductory note.
- C3.** Understanding Autism post-course survey data from Survey Monkey.
- C4.** Thematic Analysis of free text feedback comprising report, raw data and guide to quotes.
- C5.** Practitioner testimonial from Ganapathy Therapy.
- C6.** Snowbility evidence comprising staff feedback and Director’s Testimonial.
- C7.** Scottish testimonials: Scottish Government, Autism Network Scotland, D&G Council.
- C8.** WeChange evidence comprising course feedback, overview and Director’s Testimonial.
- C9.** French testimonial: Director, Groupement National des Centres de Ressources Autisme.