

Between withdrawal and resistance

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Between withdrawal and resistance: parents strategies in navigating preschool education in Russia for children with developmental disabilities and autism

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**Between withdrawal and resistance: parents’ strategies in navigating preschool
education in Russia for children with developmental disabilities and autism**

Abstract

- Purpose

The paper aims to fill the gap in social sciences research on parents’ strategies in navigating preschool education in Russia. It focuses on the barriers that children with developmental disabilities and autism face in preschool education in Russia and highlights the emerging facilitators of inclusive education.

- Design/methodology/approach

It employs a modified labelling approach analysing strategies of withdrawal and resistance. The research included semi-structured interviews with parents of children with Down syndrome, Rett syndrome and autism spectrum disorders (ASD) in 2013–2014 and 2018–2019 and semi-structured interviews

with professionals in Tatarstan, Russia. The data analysis was based on constructivist methods and grounded theory.

- Findings

Although Russian law guarantees equal access to education for every child and requires the development of inclusive education, children with developmental disabilities, including autism, are often stigmatised at the preschool stage, both in special needs and mainstream institutions. Parents use various strategies to navigate access to preschool education and try more than one strategy from secrecy and withdrawal to resistance. Parents challenged the mainstream educational structures in Kazan and established groups for children with autism in some mainstream kindergartens and classes in mainstream schools.

- Practical implications

The research findings can be useful for countries which have recently recognised ASD and do not have inclusive preschool educational practices and where labelling towards children with developmental disabilities is still common. The study

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recommends that resources are required to provide free or affordable preschool education for children with developmental disabilities. It is also crucial to help parents navigate preschool education and select the best options for each child’s needs.

- Social implications

This study's findings add value to the importance of addressing the stigma towards people with disabilities within professional groups and broader society, which form barriers for preschool education and in some case result in withdrawal from preschool education. To overcome the stigmatisation of children with developmental disabilities in preschool education, it is necessary to establish modern targeted pedagogical approaches and training for professionals and informational campaigns for the broader audience.

- Originality

The paper is novel as there was no sociological research into preschool education of children with developmental disabilities in Russia. It argues that the parents’ experiences are much broader than just interactions with special needs or mainstream education. Parents navigate across special needs institutions, specialised groups in mainstream and private kindergartens,

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3 mixed groups in mainstream kindergartens and home education with various
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7 strategies from secrecy and withdrawal to resistance and challenge.
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10 Preschool education for children with developmental disabilities in Russia is
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13 hindered by a lack of professional resources and the stigma embedded into
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17 professional and societal responses.
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24 **Implications of the research for policy and practice**

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27 1. There should be informational support for parents with different options for
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31 special needs education, providing integrative and inclusive education.
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- 35 2. It is necessary to increase the number of trained specialists in special needs
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38 and mainstream kindergartens in Russia for children with developmental
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41 disabilities and ASD.
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- 45 3. More work is required to overcome stigmatisation and increase tolerance
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48 towards persons with developmental disabilities in Russia both on a national
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51 and local level.
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59 **Keywords**

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Autism, parents, developmental disabilities, preschool education, inclusive education, special needs education, Russia, stigma

Introduction

Children with disabilities face barriers in accessing primary education across the globe, which, together with prejudices towards people with disabilities and the lack of an inclusive culture, creates further inequalities. As Barton pointed out: ‘Globally, the vast majority of disabled people live in poverty, have no access to education and are disproportionately unemployed, underemployed and underpaid’ (cite from Allan 2012, p. 116).

It is widely recognised that one of the most significant means of achieving an inclusive society is establishing an inclusive education system. The Universal Declaration of Human Rights and the World Declaration on Education for All (UNESCO 1990) pro-claimed the right of every child to an education which has been reaffirmed by The Salamanca statement (1994), issued by the representatives of 92

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3 governments. The statement recognised the urgency of providing education for
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7 people with special educational needs within the regular educational system and
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10 accentuated the role of early education of children before 6 year old as 'the success
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14 of the inclusive school depends considerably on early identification, assessment and
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17 stimulation of the very young child with special educational needs' (UNESCO 1994,
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21 p.15). The transition to inclusive education for children with special needs is not
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24 straightforward. Both professionals and parents have concerns about preschool
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27 teachers' education and preparedness to meet children's needs (Seery *et al.*, 2000).
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30 In China, for instance, many teachers do not have sufficient information about autism
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33 spectrum disorder (ASD) and special education needs of children with autism (Deng
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36 and Poon-McBrayer, 2012; Liu *et al.*, 2016).
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45 Russia is still in a transitional stage towards providing inclusive education. Despite
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48 some success after Perestroika and the efforts of non-governmental organisations
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51 (NGOs) and parents (see Iarskaya-Smirnova *et al.*, 2008 among others) and the
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54 reforms associated with the ratification of the Convention on Disability Rights in
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57 2012, inclusive education is not available for many children with disabilities. In 2012,
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Central and Eastern Europe and the Commonwealth of Independent States had the highest rate of institutionalised children globally with 219 thousand children with disabilities in institutions. It was estimated that 1.1 million children with disabilities are invisible as '[they] are likely kept out of school, and are out of the public eye' (UNICEF, 2012, p. 3). In Russia, as the Human Rights Watch states: 'If you are a child living with a disability in Russia, there is a significant chance that you will not receive a quality education or even any education at all' (2015, p. 1). Although children with disabilities comprised 2.1 per cent of children up to 18 years of age in 2015, the share of children with disabilities residing in orphanages was 25.7 per cent (Kuchmaeva, 2016). There is no data on children with different types of developmental disabilities in Russia, but it is known that 7.8 per cent of children with Down syndrome in Russia live in orphanages [detsky dom] (Downside Up, 2018). Thus, these children are deprived of family care and have little chance of social inclusion as they grow up in boarder institutions.

In Russia, the period of preschool education is one of the longest in the world. It includes children from the age of three years old till seven years (or eight if a child is

considered to have disabilities impacting intellectual development). Even though preschool education is not compulsory, its role in developing and choosing further education pathways for children with developmental disabilities and ASD is significant (see Fontil *et al.*, 2019, for example). However, there have been no sociological studies on children with developmental disabilities and ASD in Russia and the accessibility of state preschool inclusive education for them. This paper aims to fill this lagoon and focus on the barriers in social inclusion that children with developmental disabilities face in preschool education in Russia and highlights the emerging facilitators of inclusive education.

As Thoits (2011) argues, there is lack of attention towards the role of resistance in the stigma and labelling literatures. While the researchers' focus on labelling in the context of ASD and developmental disabilities is mainly on persons with special needs, we look at the impact of stigma on parents, and aim to address the gap in studies regarding resistance to labelling.

The paper draws on the qualitative research on parents of children with Down syndrome, Rett syndrome and ASD in the Tatarstan republic in Russia. The structure

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of the paper is as follows: first, we will provide an overview of the education of children with disabilities in Russia including education for children with developmental disabilities; secondly, we will present the theoretical framework of the study based on the modified labelling approach (Link *et al.*, 1989; Thoits, 2016) and the methodological approach. Then we will draw on parents' experience and strategies regarding preschool education such as resistance strategies of secrecy, withdrawal, deflection and challenge. Finally, the paper reflects on the role of parents' resistance strategies against special needs education in establishing inclusive education.

Education of children with disabilities in Russia

The importance of early years education for the children's development is indisputable. The social inclusion of children with disabilities refers to the broad spectrum of social relations starting from birth and embracing the wide range of enabling and disabling environments (Hall *et al.*, 2010) including education (Leyser and Kirk, 2004). Education is an arena where the state establishes 'biopower', and special needs education is the most criticised for its medical approach towards

disabilities. As Allan demonstrates, 'frameworks of accountability and performativity are defended by governments on the basis of inclusion, entitlement and equity when evidence points to the injustice produced by such frameworks for both professionals and those for whom they are responsible' (Allan, 2012, p. 79).

For a long time, education for children with disabilities was based on Soviet 'defectology principles', and even in 1990 special needs education was very resistant to change (Grigorenko, 1998; Thomson, 2002; Iarskaia-Smirnova and Romanov, 2007). The stigma associated with mental health, in general, in Russia (see Shek *et al.*, 2010), makes the situation regarding access to education for children with developmental disabilities very complex. Overall, families of children with disabilities are discursively constructed as 'unfortunate' and thus undesirable for the state (Iarskaia-Smirnova and Romanov, 2012; Iarskaia-Smirnova *et al.*, 2015). As Iarskaia-Smirnova *et al.* (2015) mentioned in their seminal paper on parenting children with disabilities in Russia, 'the post-Soviet situation for children with disabilities and their families has inherited legacies of the biopolitics of the past' (2015, p. 1628). Such a framework 'has inherited a medical model of disability,

where the most significant task of the state is to provide medical help' which 'is manifested in social attitudes perpetuating stigma and misunderstanding' (2015, p. 1,629) Moreover, in Russia, social inclusion, in general, is challenging because of 'the deeply vertical health structures, an intensely bureaucratic legacy that discourages intersectoral liaison, and the financial disincentives to change' (Jenkins *et al.*, 2010, p. 224).

While educational pathways for children with such developmental disabilities as Down syndrome and Rett syndrome were limited mainly by the lack of special needs schools, such as schools for children with intellectual disabilities, for a long time there was no particular approach towards children with ASD. This was because ASD is quite a novel term for both medical and educational professionals in Russia (Mukharyamova *et al.*, 2021). Autism has become part of Russia's vocabulary only since 1999, when Russia adopted the International Statistical Classification of Diseases and Related Health Problems (Sorokin, 2015). As recently as 2017, Russian doctors connected schizophrenia and children's autism, and it was common

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4 for young patients with ASD to be diagnosed with schizophrenia after they reached
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7 the age of 18 (Minszrav Rossii 2017).
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14 Despite being not compulsory, preschool education in Russia is the first level in the
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17 national system of general education, including primary, basic and secondary levels
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20 (Bodrova and Yudina, 2018). Children with disabilities in Russia receive preschool
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23 education in general groups or special groups in mainstream kindergartens, or in
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26 special needs kindergartens – for blind and visually impaired children, for children
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29 with hearing issues, children with intellectual disabilities, deaf children and others.
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35 The staff–children ratio is better than in mainstream schools, and staff should have a
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38 qualification to work with special needs children.
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46 This system corresponds with the three main models of educating children with
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49 disabilities: 'segregation' in (non) residential special schools and 'integration' in
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52 mainstream schools in special classes and inclusive education in mainstream
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55 classes (Frederickson and Cline, 2009). There is a prevalence of special needs
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58 education (SNE) for children with disabilities in the Russian education system,
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3 including developmental disabilities (see Thompson, 2002). Such schools are called
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7 'schools of correction' which were rooted in the USSR. Nowadays, Russia
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10 guarantees every child equal access to education (Federal'nyi zakon, 2012). The law
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13 defines inclusive education as the 'provision of equal access to education for all
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17 students, given a diversity of special educational needs and individual capabilities'
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20 (Federal'nyi zakon, 2012, art. 2, par. 27). It is also reflected in the law on social
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23 protection of people with disabilities in Russia that guarantees persons with
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27 disabilities access to free preschool, school-level, professional and higher education,
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31 and obligates regional and city-level governments to create the conditions for people
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35 with disabilities to access these forms of education (Federal'nyi zakon, 1995). Law
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38 also states that the education of children with disabilities can be organised in
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42 different ways, including together with other learners, as well as in separate classes,
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46 groups or in special needs schools (Federal'nyi zakon, 1995, art. 19, par. 1–2) and
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49 should provide accessible infrastructure and information to people with disabilities
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52 (Federal'nyi zakon, 1995, art. 14,15).
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3 Recently, a Federal standard has been adapted for primary education of children
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7 with ASD in mainstream schools (Ministry of Education of Russia, 2014), including
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10 some measures for the transition from preschool to primary education. Despite the
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13 legal guarantees of inclusive education, its implementation is still very problematic.
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17 For example, the above-mentioned standard does not make it compulsory to include
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20 a teacher's assistant or a tutor. The dependence of schools on regional budgets is
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23 also very problematic because of Russia's economic diversity and inequality.
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31 There are still many issues in children's access to education, and as the Human
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34 Rights Watch stressed, 'Children and adults living with disabilities in Russia
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37 encounter numerous obstacles to getting a quality, inclusive education, at all levels
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40 of the education system, from preschool through higher education' (2015, p. 21).
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45 There is not much data about the access of children with ASD and developmental
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48 disabilities to preschool education in Russia, though it is known that children with
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51 disabilities comprise 6.8 per cent of the pupils in preschool educational institutes in
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55 Russia (Ministry of Education of Russia, 2019). Still, the available statistics make it
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possible to see the vast disparity in preschool education access between children with disabilities and other children.

Most of the children with disabilities who attend mainstream kindergartens are enrolled in so-called 'compensatory groups' which have only children with disabilities – 78.4 per cent in 2017 (Abankina *et al.*, 2019, p. 132) and 20.2 per cent in so-called 'combined groups' (groups for children with and without disabilities). Even children without a formal disability status but identified as having special needs have low accessibility to mainstream preschool education, as among those who attend mainstream kindergartens, only 18.2 per cent are enrolled to 'combined groups' (Abankina *et al.*, 2019, p. 131). On a regional level, in Kazan, among 306 children with ASD, only 9.5 per cent, are enrolled in mainstream schools, 19.3 per cent are in mainstream schools but on distance-learning courses. One-fourth of the children with ASD are within integrative education – in so-called resource classes in mainstream schools. The rest of the children with ASD are in special needs schools (42.2 per cent), 1.9 per cent in boarding schools for children with speech disorders and 1.9 per cent in orphanages (Saifutdinova, 2020). The situation with preschool education is

different – the mainstream kindergartens are attended by 29.4 per cent of children between 3 and 7 years with ASD, special groups in mainstream kindergartens by 18.6 per cent, while the one-third of the children with ASD are within special needs education – 29.4 per cent in SN kindergartens and 2.5 per cent in a private centre for curative pedagogy. Over one-third of the children with autism in Kazan are not enrolled in any kind of preschool educational institutes (Saifutdinova, 2020).

The prevalence of special needs and integrative preschool education over inclusive education might be partly explained by the lack of methodological support and funding for qualified teaching staff. Also, as Abankina *et al.* state, some regions reduced the number of positions for specialists – psychologists, speech therapists, defectologists [Russian term for teachers for special needs children] ‘who could help other pedagogical staff provide inclusion’ (2019, p. 132). The financial conditions of municipal kindergartens are very challenging – in Tatarstan, for example, in 2017, 32.2 per cent of kindergartens required major repairs (Tatstat, 2018).

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4 Simultaneously, in some cities there are initiatives to improve access to mainstream
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7 education for children with disabilities. Parents' organisations and NGOs play a
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10 crucial role in this process (Bindman, 2015; Bogdanova and Bindman, 2016;
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13 Iarskaia-Smirnova *et al.*, 2015; Abankina *et al.*, 2019). For example, recently,
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16 children with autism were provided with new opportunities for education for in Kazan.
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19 One mainstream school opened a special class, and seven kindergartens started to
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22 provide integral and inclusive education (Gorozhaninova 2019). However, as our
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25 study shows, the preschool education for children with developmental disabilities is
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28 still challenged by the lack of professional resources and stigma embedded into the
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31 professionals' and society's responses.
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42 **Stigma, labelling and the production of inequalities in the education of children with** 43 44 45 **disabilities** 46

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48 The stigmatisation of children with disabilities at schools and preschool institutions is
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51 part of the prevailing injustice produced by professionals and broader society. In our
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54 research we adopt Link and Phelan's (2001, p. 377) definition of stigma 'when
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57 elements of labelling, stereotyping, separation, status loss and discrimination occur
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4 together in a power situation that allows them' to proliferate. According to Tyler and
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7 Slater (2018), such a power situation is possible due to the character of
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10 stigmatisation, which is a 'consequential and injurious form of action through
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13 collective representation fastened on people and on places' (p. 740). The social
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16 impacts of stigma towards people with disabilities vary between social awkwardness
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19 in some social encounters and acts of hostility and social shunning, entailing
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22 violence in extreme cases and emerging from a strong sense of otherness (Green *et*
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25 *al.*, 2005). It is not uncommon that primary schools informally reject and stigmatise
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28 children with autism, as shown by research in Sydney (Lilley, 2013). The recent
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31 studies among children with intellectual disability showed that stigma might be
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34 recreated or sustained within the family and school settings (O'Byrne and Muldoon,
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42 2019).
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49 In our research we are particularly interested in how stigma impacts parents'
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52 trajectories regarding preschool education. In this respect, we find it useful to engage
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55 with the modified labelling approach which considers that persons with mental
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58 disorders endorse strategies of secrecy, withdrawal and education to cope with the
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3 threat of discrimination they perceive via labelling (Link *et al.*, 1989). The modified
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7 labelling approach has been widely used in disability and health studies and,
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10 therefore, is not only limited to the research of psychiatric patients (see Green, 2003;
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13 Ciciurkaite and Perry, 2018, among others). Following Goffman (1963), Link *et al.*
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17 (1989) revealed the secrecy strategy that aims to hide disability to 'avoid rejection'
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20 (p. 403). The withdrawal strategy involves 'limiting social interaction to those who
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23 know about and tend to accept one's stigmatised condition' (p. 403), while the
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27 education strategy aims to make other people understand what it means to be a
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31 psychiatric patient. According to Link *et al.*, these tactics can have negative
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35 consequences. Withdrawal 'may lead to more constricted social networks and fewer
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38 attempts at seeking more satisfying, higher-paying jobs' (1989, p. 403).
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45 Not only people with disabilities but also their parents and carers can experience
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48 stigmatisation, which in turn impacts children's experiences. For example, adapting a
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52 modified labelling approach in her research of mothers of children with disabilities,
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56 Green (2003) argued that that perceived stigma increased the subjective burden of
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59 mothers and decreased the frequency with which children interact with age peers.
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The educational environment has a significant impact, including teachers' attitudes towards children with disabilities, which can produce labelling. For instance, Lavlani (2005), in her study of parents' and teachers' perspectives on disabilities in the United States, revealed that teachers often defined the disability of their pupils by physical, neurological or cognitive limitations while parents' understandings, instead, were more situated in the cultural meanings ascribed to disability.

In our study, we are particularly interested in stigma and how parents cope with stigma in navigating their children's preschool education and resist stigma in traditional educational settings. We engaged with Thoits's (2011) understanding of resistance strategies in the form of deflecting and challenging and the role of labelled individuals' agency. Deflections embrace strategies that minimise the negative psychological effects of stigmatisation while maintaining the social order.

Conversely, challenging resistance strategies against stigmatising structures might include both interpersonal confrontation and political mobilisation. In contrast to the education strategy suggested by Link and colleagues (1989), Thoits' concept of a

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challenging form of stigma resistance ‘is more direct and assertive than educating’ (2011, p. 15). These coping strategies can be used in combination and change under some conditions.

Methodology

The research took place in the Republic of Tatarstan, Russia. At the first stage of the project in 2013–2014, 30 semi-structured interviews were conducted with parents of children with Down syndrome, Rett syndrome and ASD. The informants were selected using the snowball technique, a method widely used in studying confidential topics or hidden communities; each time a person gave multiple referrals, only one new subject was recruited (Atkinson and Flint, 2001). Initially, the informants were found among acquaintances and also via social media parental groups. The informants were selected based on the principle of being primary caregivers, and, because in most of the families women had this role, most of the respondents were women.

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4 The second stage of the project (ongoing from 2018) addresses the identification of
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7 new opportunities for children to receive an inclusive education in Tatarstan and
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10 included ten interviews with parents of children with autism who receive preschool or
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13 a school education and 25 semi-structured interviews with professionals working in
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17 local ministries, special needs schools, social workers, and medical doctors via
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20 purposive sampling. Along with an analysis of secondary data and legislation, the
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23 interviews with professionals helped us to analyse the state policy towards children
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27 with developmental disabilities.
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35 In both studies a briefing has been provided for the participants to cover the purpose
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38 of the research and ethical points including assured anonymity (Dowling, 2016) and
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41 the ability to withdraw participation at any given moment. Following this, informed
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44 consent was obtained from all informants. Consequently, the data has been
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48 anonymised, excluding representatives of some NGOs and kindergartens who
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52 wished to remain anonymous while reference is made to their organisations.
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The data analysis was based on constructivist methods and grounded theory (Charmaz and Belgrave, 2012). Working with transcripts of interviews, we conducted initial (open) coding and focused coding (Charmaz, 2006). Initial coding and comparative practices enabled us to sort and cluster initial codes, which helped us reveal the most significant or frequent initial codes for analysis.

Results

The production of exclusion of children with developmental disabilities in special needs kindergartens and parents' strategies of deflecting and challenging

Our research demonstrates that preschool education is often a crucial point for parents of children with ASD to position children within the biological model of disability and go through the official procedure of disability evaluation. Initially, many parents are reluctant for their children to receive any medical diagnosis because the status of people with autism and other disabilities is so stigmatised in Russia and can limit children's abilities to receive an education and be fully abled citizens. So, those parents who decided not to access special support explained it as a measure to protect their children's future:

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4 When the neurologist has written 'autism-like behaviour', I have not brought
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7 this note to our doctor. If I told the doctor this diagnosis, I thought that my
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10 child would not receive a driving licence later and not be given credit by a
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13 bank. You know it is one of the myths. But will he need that credit and driving
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16 licence if he will stay in such condition? It took time for me to come to this
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19 understanding (mother of a child with autism, Kazan, 2019).
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24 The necessity of special needs educational support and the lack of a learning
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27 environment for children with ASD influenced this mother to go via the route of an
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30 official recognition of ASD and receive the status of disability for her child. That
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33 status provided him with an opportunity to have state-funded therapy and
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36 rehabilitation and access special needs kindergartens. Thus, this case demonstrated
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39 a change from the secrecy strategy when special needs are hidden and not
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42 positioned to another type of strategy as withdrawal. Some other parents have to
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45 come to terms with accepting an official status of disability for their child after being
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48 exposed to negative experiences in municipal kindergartens, which leads them to be
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51 willing to secure a place in special needs kindergartens.
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3 Traditionally, in Russia, children with developmental disabilities attend special needs
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7 kindergartens such as kindergartens for children with intellectual disabilities,
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10 kindergartens for children with mental disabilities and so-called 'logopaedic' ones for
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13 children with speech issues. There are some kindergartens for children with ASD in
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16 Russia, and recently several groups have been established in mainstream preschool
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19 institutions in Kazan for children with ASD. However, because of lack of available
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22 places, some children with autism have to attend kindergartens for children with
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25 speech problems or with intellectual disabilities. Therefore, they do not have support
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28 explicitly designed for their needs.
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38 The research showed that the different types of behaviour exhibited by children with
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41 developmental disabilities have been 'inconvenient' for staff who considered it
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44 unacceptable when children were crying 'too much' or 'misbehaved'. In one case,
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47 such 'inconvenience' was followed by the staff placing a child at immediate health
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50 risk, when staff gave a girl with Down syndrome unprescribed sedative medicine:
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56 We came to take our child from kindergarten, and we noticed an allergy on
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59 her skin. As we realised afterwards, it was an allergy from a powerful sedative
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4 drug, which staff used to calm down children without telling us at all. In the
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7 end, we just took her from kindergarten and taught her by ourselves (interview
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10 with mother, Kazan, 2013).

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14 Some parents do not deny that they are afraid of sending their children to
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17 educational institutions since they may become subject to hostility and
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20 discrimination. There are proven facts that children with severe physical and mental
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23 disabilities do not receive the necessary attention and are left unattended. For
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26 example, one of the nursery school teachers described an ordinary day for children
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29 with developmental disabilities: 'Like in the case with ordinary children, they sit and
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32 play. What can you expect of them? No wits, it is useless to teach them at least
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35 something' (interview, Kazan 2014). Such an attitude towards children with mental
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38 disabilities occurs in many institutions, both in preschool and in schools.
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49 In some cases, staff consider children with intellectual and developmental disabilities
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52 a burden and do not support parents. It is even not uncommon to blame parents for
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55 neglecting parental duties. As one of the teachers from one of the kindergartens
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58 explained her point of view:
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Often, parents want their child to go to kindergarten not for the sake of his/her development, not for the sake of being with others, but because they cannot properly educate and be involved with their child. Many parents openly declare that they are tired to be with their sick child and take care of this child in a round-the-clock mode, and they already want to "relax" (Kazan, 2014).

Such attitudes on the part of the staff produce and strengthen the feeling of shame and embarrassment, which is very typical for parents of children with ASD with non-typical behaviour (see, for example, Gray, 2002; Ryan, 2010). This stigmatises not only children but their parents too, which leads in some cases to strategies of withdrawal from all preschool education and corresponds with the statistics mentioned above in Kazan where 31 per cent of the children between three and seven with autism are not enrolled in any kindergartens or children are enrolled in SE kindergartens for just a few days per week.

In response, some parents establish resistance strategies to enrol their children in mainstream preschool education or establish alternative special groups in mainstream kindergartens. For example, a father of a boy with autism shared how he

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4 was advised to 'stop going to the kindergarten' for children with special needs
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7 because his child 'gnawed all toys, did not sleep, and overall was a problem for three
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10 adults who looked after three children' (interview, Kazan, 2018). At first, the family
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13 tried to confront staff's attitudes at the kindergarten, but then they were able to find a
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16 mainstream kindergarten with a special group for children with autism where the boy
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19 felt welcome.
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28 At the same time, as we will show in the following section, the experiences in
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31 mainstream kindergartens often produce stigma too, and parents have to navigate
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34 between special needs, mainstream education and private children's services to find
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37 an enabling educational environment for their children.
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45 **Stigmatisation and othering of children in mainstream preschool education**

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48 About half of the interviewed parents tried to enrol their children in mainstream
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51 groups in mainstream kindergartens. However, most of them did not have a positive
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54 experience and often ended up with home education or special needs groups or SN
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kindergartens. The following example is quite typical and refers to the stigmatisation of both a child and parents:

The psychologist [in the kindergarten] gave me such a look and asked if we have official registration. I asked: 'Which registration?' She said: 'Well, you have a special child'. And she said it aloud so that everyone could hear that. I did not like it, obviously, and asked: 'What do you mean?' Psychologist: 'Is he on medication?' Me: 'Why should I give him any medication?' Psychologist: 'Neuroleptics, sedatives [medication]'. I said that my child has good behaviour usually at home, but of course, as it is the first day in kindergarten, it might be stressful for him. That means he started to cry, and they were unable to calm him down. But they have my phone number so why did they not call me? (Mother of a five-year-old boy with autism, who tried to start at kindergarten at the age of three, as in Russia three years' maternity leave is allowed, Kazan, 2019.)

As a result, the kindergarten administration made the parents stop taking their son to the kindergarten. Thus, the kindergarten staff prevented a child from receiving mainstream preschool education, and therefore barred his inclusion into children's

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3 play, placing him in the position of 'undesirable'. The child's mother had to leave her
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7 job to look after him. She used to take son to different activities several days per
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10 week, including hippotherapy, speech development and swimming, since the family
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13 has a good income. Many other families who experienced similar situations could not
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17 provide such training for their children because of their poor financial condition.
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24 Some parents with similar negative experiences in municipal kindergartens pay for
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27 private ones where groups are smaller and children can receive more attention.
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31 However, often it is not an option if their children are met negatively by parents of
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34 children without special needs. As one of the informants who tried to enrol her son in
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37 a private and expensive kindergarten mentioned:
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42 I have discussed my child's special needs, his diagnosis [with the director of
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45 the kindergarten]. Then the director said that she would talk with parents of
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48 other children from the kindergarten. And then we were met with an adverse
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51 reaction. Parents were totally against having our child in this kindergarten. So,
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54 the director explained that she could not take us because other parents object
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57 to it (Mother of a boy with autism, Kazan, 2019).
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Similar to parents who have had negative experiences with mainstream preschool education, the informant's family had to take their son to a kindergarten for children with special needs. These stigmatisation and othering practices are very similar to the removal of rejected students with disabilities from general education explored by Lalvani (2015). She discovered the ambivalent notion of denial of disability which is perceived by teachers as a denial of the diagnosis. Still, parents deny the label of 'disability' that bars their children from study.

Stigmatisation and the lack of an enabling educational environment in both mainstream and SE institutions brought some parents to establish resistance strategies which enabled them to achieve a visible success in access to an integrated and inclusive preschool education.

Parental strategies of resistance: establishing inclusive education

Parents themselves, their social circles and, recently associations for children with different special needs, have become an important resource in the coping tactics in accessing education and providing peer-to-peer support. Our research showed that

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4 parents must navigate among available services and specialists by themselves and
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7 via parents' associations and networks. No respondent noted any help from social
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10 workers, whose services are usually limited to providing advice regarding monetary
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13 benefits for children with disabilities. However, such resources are very limited in
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16 Russia with regard to the actual amount of financial support available for people with
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19 special needs (Mukharyamova and Kuznetsova, 2011). Parents demonstrated
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22 resistance to the traditional model of mainstream and special needs education and
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25 aimed to establish access to mainstream education for children. There are some all-
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28 Russian and regional organisations established by parents of children with ASD
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31 including Vykhod [The Way Out], Autism-Regyony [Autism-Regions] which advocate
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34 for rights for people with autism and participate in governmental committees on
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37 education. Positive support becomes a crucial factor in reducing stigma arising from
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40 discrimination and rejection in both special needs and mainstream kindergartens. In
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43 Tatarstan's capital, Kazan, parents successfully established groups for children with
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46 autism in mainstream kindergartens and classes in primary schools in 2017. As the
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49 leader of an organisation of parents for children with autism mentioned:
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3 All my life now relates to autism. My son has autism; he is eight years old now
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7 If before I used to work in a different sphere, now I embrace this topic.
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10 Several years ago, we established the organisation 'Prosto drugye' [Just
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12 different] to support families of children with ASD, and now I lead it. Also, I
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17 curate one kindergarten, as, from this year, a few kindergartens established
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21 groups for children with autism (Kazan, 2018).
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24 The newly established preschool educational opportunities for children with autism
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27 reflect a more 'integrative' than an inclusive approach as children are placed into
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31 special groups within the school. Interviewees whose children are enrolled in one of
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34 the kindergartens mentioned above in 2018–2019 described the experience as a
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37 positive one overall, except that for several months there were no permanent tutors
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41 and children have to become accustomed to new people. It was mentioned the
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44 children made progress in developing speech, and groups for children with autism
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47 have some joint activities with other groups in the kindergarten and those for
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51 different types of special needs. However, for a city with over a million people, seven
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54 such groups are not enough. As a result, many of those children allocated to special
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57 groups have to commute to kindergartens from one end of the city to another. Also,
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the situation with access to preschool education of children with Down syndrome, Rett syndrome and other developmental disabilities does not have such transformations.

Discussion

Theoretically, following the modified labelling approach (Link *et al.*, 1989; Thoits, 2011) the paper contributes to debates on the role of stigma in preschool education of children with developmental disabilities and ASD and parents' coping strategies. It also addressed a gap in the literature on the role of resistance related to stigma, as Thoits (2011) pointed out, it is rarely discussed in the stigma and labelling literatures. Our findings are consistent with the understanding of modified labelling theory which considers that individuals develop negative conceptions of what it means to be a person with disability. We argue that the stigma regarding children with developmental disabilities and labelling within preschool institutions impact on parents' strategies, even among those who initially did not want to be associated with stigma and rejected the status of disability for their children (deflection strategy

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of resistance), and led to a withdrawal strategy which accepts their children's
stigmatised condition.

The educational experiences of parents of children with developmental disabilities
are much broader than just interactions with the special needs education or
mainstream educational spheres. Parents use various tactics to navigate access to a
suitable education, across special needs institutions, specialised groups in
mainstream institutions, private kindergartens, and mixed groups in mainstream
kindergartens and home education. These tactics are not mutually exclusive, and
some families try more than one strategy during the preschool period from strategies
of secrecy and withdrawal to a resistance strategy of challenging and vice versa.

Parents were able to challenge the mainstream educational structures in some cities,
for example, in Kazan, Tatarstan, and established groups for children with autism in
some mainstream kindergartens and classes in mainstream schools. It helped to
increase access to both preschool and primary integrative and inclusive education
for children with autism in Kazan and also in some other cities; however, the small

scale makes it impossible to address the needs all children with developmental disabilities, including those with Down syndrome and Rett syndrome.

The modified labelling theory states that responses of secrecy and withdrawal are often associated with the limitation of life chances via the constriction of people's networks (Link *et al.*, 1989). We suggest that stigmatisation within preschool education for children with developmental disabilities forces many parents to adopt withdrawal or secrecy strategies and further disadvantages children. Making children study in special needs institutions lowers their chances of a mainstream primary education. Although in Russia mainstream schools do not have the right to reject a school application, especially from a child registered in a school catchment area, and Federal law states that they must create an inclusive environment for children with disabilities, many schools have some selection criteria which might include preferences for those who took voluntary evening or weekend courses at the school or pass entrance exams, which is difficult if children have not received preschool education.

Implications for policy and future research

The study recommends that free or affordable preschool education is provided for children with developmental disabilities in Russia.

Parents and caregivers require a better response from preschool educational institutions. There should be informational support with different options regarding special needs education, integrative and inclusive education. To overcome the stigmatisation of children with developmental disabilities in preschool education, there is a need to develop modern targeted pedagogical approaches and training for professionals, and provide funding for the increasing the number of trained specialists both in special needs and mainstream kindergartens. It would be beneficial for more work to increase understanding and overcome the stigmatisation of people with developmental disabilities in Russia, both nationally and locally.

Further research on the accessibility of inclusive and integrative education for children with developmental disabilities in Russia should explore the intersections of the stigma of disability with other social identities including gender, class and ethnicity, and explore the differences between the urban and rural environments in a

context of the economic and social diversity of Russian regions. It would be also beneficial to explore the impact of coping strategies regarding stigma on families' well-being, as for example, as Thoits (2016) found out in the case of people with mental disabilities, the deflection is positively associated with well-being for individuals.

The research findings can be useful for countries which have recently recognised ASD and that have not established inclusive preschool educational practices and where labelling towards children with developmental disabilities is still common. It would be beneficial to conduct comparative studies not only between countries which historically had similar approaches towards education for children with special needs based on defectology, such as post-Soviet countries, but also among countries which are starting to develop inclusive education.

Conclusion

Despite Russian law guaranteeing equal access to education for every child and requiring the development of an inclusive education, children with developmental

disabilities, including autism, are often stigmatised in the preschool stage both in special needs education and mainstream institutions. This impacts on parents' strategies and those who initially did not accept stigma had to defer to withdrawal or secrecy strategies after engagement with preschool institutions. While children with non-typical behaviour are perceived as a burden in many preschool institutions, their parents are often blamed for their 'inadequate' behaviour resulting in withdrawal of their children from kindergartens. The parents are then forced to choose special needs preschool education or home education as the only possible options. As a result, parents have to navigate between special needs, mainstream education and private children's services to find an enabling educational environment for their children. Some parents develop challenging strategies of resistance establishing inclusive education for children in Russia via parents' organisations and activism.

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