

Between withdrawal and resistance

Kuznetsova, Irina; Garapshina, Layla; Mukharyamova, Laysan

DOI:

[10.1108/JCS-08-2020-0051](https://doi.org/10.1108/JCS-08-2020-0051)

License:

Creative Commons: Attribution-NonCommercial (CC BY-NC)

Document Version

Peer reviewed version

Citation for published version (Harvard):

Kuznetsova, I, Garapshina, L & Mukharyamova, L 2021, 'Between withdrawal and resistance: parents strategies in navigating preschool education in Russia for children with developmental disabilities and autism', *Journal of Children's Services*. <https://doi.org/10.1108/JCS-08-2020-0051>

[Link to publication on Research at Birmingham portal](#)

General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.



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

Journal:	<i>Journal of Children's Services</i>
Manuscript ID	JCS-08-2020-0051.R2
Manuscript Type:	Research Paper
Keywords:	Developmental disabilities, autism, Russia, preschool education, inclusive education, stigma

SCHOLARONE™
Manuscripts

1
2
3 **Between withdrawal and resistance: parents' strategies in navigating preschool**
4
5
6
7 **education in Russia for children with developmental disabilities and autism**
8
9
10
11
12
13

14 **Abstract**
15
16
17
18
19
20

21 • Purpose
22
23

24 The paper aims to fill the gap in social sciences research on parents'
25
26
27
28 strategies in navigating preschool education in Russia. It focuses on the
29
30
31 barriers that children with developmental disabilities and autism face in
32
33
34
35 preschool education in Russia and highlights the emerging facilitators of
36
37
38 inclusive education.
39
40

41 • Design/methodology/approach
42
43
44

45 It employs a modified labelling approach analysing strategies of withdrawal
46
47
48 and resistance. The research included semi-structured interviews with parents
49
50
51 of children with Down syndrome, Rett syndrome and autism spectrum
52
53
54
55 disorders (ASD) in 2013–2014 and 2018–2019 and semi-structured interviews
56
57
58
59
60

1
2
3
4 with professionals in Tatarstan, Russia. The data analysis was based on
5
6
7 constructivist methods and grounded theory.
8
9

10
11 • Findings

12
13
14 Although Russian law guarantees equal access to education for every child
15
16
17 and requires the development of inclusive education, children with
18
19
20
21 developmental disabilities, including autism, are often stigmatised at the
22
23
24 preschool stage, both in special needs and mainstream institutions. Parents
25
26
27 use various strategies to navigate access to preschool education and try more
28
29
30
31 than one strategy from secrecy and withdrawal to resistance. Parents
32
33
34 challenged the mainstream educational structures in Kazan and established
35
36
37 groups for children with autism in some mainstream kindergartens and
38
39
40
41
42 classes in mainstream schools.
43
44
45
46
47
48

49 • Practical implications

50
51
52 The research findings can be useful for countries which have recently recognised
53
54
55 ASD and do not have inclusive preschool educational practices and where labelling
56
57
58 towards children with developmental disabilities is still common. The study
59
60

1
2
3 recommends that resources are required to provide free or affordable preschool
4
5
6
7 education for children with developmental disabilities. It is also crucial to help parents
8
9
10 navigate preschool education and select the best options for each child's needs.
11

- 12
13
14 • Social implications

15
16
17 This study's findings add value to the importance of addressing the stigma towards
18
19
20 people with disabilities within professional groups and broader society, which form
21
22
23 barriers for preschool education and in some case result in withdrawal from
24
25
26 preschool education. To overcome the stigmatisation of children with developmental
27
28
29 disabilities in preschool education, it is necessary to establish modern targeted
30
31
32 pedagogical approaches and training for professionals and informational campaigns
33
34
35 for the broader audience.
36
37
38
39

- 40
41
42 • Originality

43
44
45 The paper is novel as there was no sociological research into preschool
46
47
48 education of children with developmental disabilities in Russia. It argues that
49
50
51 the parents' experiences are much broader than just interactions with special
52
53
54 needs or mainstream education. Parents navigate across special needs
55
56
57 institutions, specialised groups in mainstream and private kindergartens,
58
59
60

1
2
3 mixed groups in mainstream kindergartens and home education with various
4
5
6
7 strategies from secrecy and withdrawal to resistance and challenge.
8
9

10 Preschool education for children with developmental disabilities in Russia is
11
12 hindered by a lack of professional resources and the stigma embedded into
13
14
15
16
17 professional and societal responses.
18
19
20
21
22
23

24 **Implications of the research for policy and practice**

- 25
26
27 1. There should be informational support for parents with different options for
28
29
30
31 special needs education, providing integrative and inclusive education.
32
33
- 34
35 2. It is necessary to increase the number of trained specialists in special needs
36
37
38 and mainstream kindergartens in Russia for children with developmental
39
40
41 disabilities and ASD.
42
43
- 44
45 3. More work is required to overcome stigmatisation and increase tolerance
46
47
48 towards persons with developmental disabilities in Russia both on a national
49
50
51 and local level.
52
53
54
55
56
57
58

59 **Keywords**

60

1
2
3
4 Autism, parents, developmental disabilities, preschool education, inclusive
5
6
7 education, special needs education, Russia, stigma
8
9
10
11
12
13
14
15
16
17

18 Introduction

19
20
21 Children with disabilities face barriers in accessing primary education across the
22
23
24 globe, which, together with prejudices towards people with disabilities and the lack of
25
26
27 an inclusive culture, creates further inequalities. As Barton pointed out: 'Globally, the
28
29
30 vast majority of disabled people live in poverty, have no access to education and are
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

disproportionally 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

1
2
3 governments. The statement recognised the urgency of providing education for
4
5
6
7 people with special educational needs within the regular educational system and
8
9
10 accentuated the role of early education of children before 6 year old as 'the success
11
12
13 of the inclusive school depends considerably on early identification, assessment and
14
15
16 stimulation of the very young child with special educational needs' (UNESCO 1994,
17
18
19
20
21 p.15). The transition to inclusive education for children with special needs is not
22
23
24 straightforward. Both professionals and parents have concerns about preschool
25
26
27 teachers' education and preparedness to meet children's needs (Seery *et al.*, 2000).
28
29
30
31 In China, for instance, many teachers do not have sufficient information about autism
32
33
34 spectrum disorder (ASD) and special education needs of children with autism (Deng
35
36
37 and Poon-McBrayer, 2012; Liu *et al.*, 2016).
38
39
40
41
42
43
44

45 Russia is still in a transitional stage towards providing inclusive education. Despite
46
47
48 some success after Perestroika and the efforts of non-governmental organisations
49
50
51 (NGOs) and parents (see Iarskaya-Smirnova *et al.*, 2008 among others) and the
52
53
54 reforms associated with the ratification of the Convention on Disability Rights in
55
56
57
58
59 2012, inclusive education is not available for many children with disabilities. In 2012,
60

1
2
3
4 Central and Eastern Europe and the Commonwealth of Independent States had the
5
6
7 highest rate of institutionalised children globally with 219 thousand children with
8
9
10 disabilities in institutions. It was estimated that 1.1 million children with disabilities
11
12
13 are invisible as '[they] are likely kept out of school, and are out of the public eye'
14
15
16 (UNICEF, 2012, p. 3). In Russia, as the Human Rights Watch states: 'If you are a
17
18
19 child living with a disability in Russia, there is a significant chance that you will not
20
21
22 receive a quality education or even any education at all' (2015, p. 1). Although
23
24
25 children with disabilities comprised 2.1 per cent of children up to 18 years of age in
26
27
28 2015, the share of children with disabilities residing in orphanages was 25.7 per cent
29
30
31 (Kuchmaeva, 2016). There is no data on children with different types of
32
33
34 developmental disabilities in Russia, but it is known that 7.8 per cent of children with
35
36
37 Down syndrome in Russia live in orphanages [detsky dom] (Downside Up, 2018).
38
39
40 Thus, these children are deprived of family care and have little chance of social
41
42
43 inclusion as they grow up in boarder institutions.
44
45
46
47
48
49
50
51
52
53
54
55

56 In Russia, the period of preschool education is one of the longest in the world. It
57
58
59 includes children from the age of three years old till seven years (or eight if a child is
60

1
2
3 considered to have disabilities impacting intellectual development). Even though
4
5
6 preschool education is not compulsory, its role in developing and choosing further
7
8
9
10 education pathways for children with developmental disabilities and ASD is
11
12
13 significant (see Fontil *et al.*, 2019, for example). However, there have been no
14
15
16 sociological studies on children with developmental disabilities and ASD in Russia
17
18
19 and the accessibility of state preschool inclusive education for them. This paper aims
20
21
22
23 to fill this lagoon and focus on the barriers in social inclusion that children with
24
25
26 developmental disabilities face in preschool education in Russia and highlights the
27
28
29 emerging facilitators of inclusive education.
30
31
32
33
34
35
36
37

38 As Thoits (2011) argues, there is lack of attention towards the role of resistance in
39
40
41 the stigma and labelling literatures. While the researchers' focus on labelling in the
42
43
44 context of ASD and developmental disabilities is mainly on persons with special
45
46
47 needs, we look at the impact of stigma on parents, and aim to address the gap in
48
49
50
51
52 studies regarding resistance to labelling.
53
54

55
56 The paper draws on the qualitative research on parents of children with Down
57
58
59 syndrome, Rett syndrome and ASD in the Tatarstan republic in Russia. The structure
60

1
2
3 of the paper is as follows: first, we will provide an overview of the education of
4
5
6
7 children with disabilities in Russia including education for children with
8
9
10 developmental disabilities; secondly, we will present the theoretical framework of the
11
12
13 study based on the modified labelling approach (Link *et al.*, 1989; Thoits, 2016) and
14
15
16 the methodological approach. Then we will draw on parents' experience and
17
18
19 strategies regarding preschool education such as resistance strategies of secrecy,
20
21
22 withdrawal, deflection and challenge. Finally, the paper reflects on the role of
23
24
25 parents' resistance strategies against special needs education in establishing
26
27
28 inclusive education.
29
30
31
32
33
34
35
36
37
38

39 **Education of children with disabilities in Russia**

40
41 The importance of early years education for the children's development is
42
43
44 indisputable. The social inclusion of children with disabilities refers to the broad
45
46
47 spectrum of social relations starting from birth and embracing the wide range of
48
49
50 enabling and disabling environments (Hall *et al.*, 2010) including education (Leyser
51
52
53 and Kirk, 2004). Education is an arena where the state establishes 'biopower', and
54
55
56 special needs education is the most criticised for its medical approach towards
57
58
59
60

1
2
3 disabilities. As Allan demonstrates, 'frameworks of accountability and performativity
4
5
6
7 are defended by governments on the basis of inclusion, entitlement and equity when
8
9
10 evidence points to the injustice produced by such frameworks for both professionals
11
12
13
14 and those for whom they are responsible' (Allan, 2012, p. 79).
15
16
17
18
19
20

21 For a long time, education for children with disabilities was based on Soviet
22
23
24 'defectology principles', and even in 1990 special needs education was very resistant
25
26
27
28 to change (Grigorenko, 1998; Thomson, 2002; Iarskaia-Smirnova and Romanov,
29
30
31 2007). The stigma associated with mental health, in general, in Russia (see Shek *et*
32
33
34
35 *al.*, 2010), makes the situation regarding access to education for children with
36
37
38
39 developmental disabilities very complex. Overall, families of children with disabilities
40
41
42 are discursively constructed as 'unfortunate' and thus undesirable for the state
43
44
45 (Iarskaia-Smirnova and Romanov, 2012; Iarskaia-Smirnova *et al.*, 2015). As
46
47
48 Iarskaia-Smirnova *et al.* (2015) mentioned in their seminal paper on parenting
49
50
51
52 children with disabilities in Russia, 'the post-Soviet situation for children with
53
54
55
56 disabilities and their families has inherited legacies of the biopolitics of the past'
57
58
59 (2015, p. 1628). Such a framework 'has inherited a medical model of disability,
60

1
2
3
4 where the most significant task of the state is to provide medical help' which 'is
5
6
7 manifested in social attitudes perpetuating stigma and misunderstanding' (2015, p.
8
9
10 1,629) Moreover, in Russia, social inclusion, in general, is challenging because of
11
12
13 'the deeply vertical health structures, an intensely bureaucratic legacy that
14
15
16 discourages intersectoral liaison, and the financial disincentives to change' (Jenkins
17
18
19
20
21 *et al.*, 2010, p. 224).
22
23
24
25
26
27

28 While educational pathways for children with such developmental disabilities as
29
30
31 Down syndrome and Rett syndrome were limited mainly by the lack of special needs
32
33
34 schools, such as schools for children with intellectual disabilities, for a long time
35
36
37 there was no particular approach towards children with ASD. This was because
38
39
40
41
42 ASD is quite a novel term for both medical and educational professionals in Russia
43
44
45 (Mukharyamova *et al.*, 2021). Autism has become part of Russia's vocabulary only
46
47
48 since 1999, when Russia adopted the International Statistical Classification of
49
50
51
52 Diseases and Related Health Problems (Sorokin, 2015). As recently as 2017,
53
54
55
56 Russian doctors connected schizophrenia and children's autism, and it was common
57
58
59
60

1
2
3
4 for young patients with ASD to be diagnosed with schizophrenia after they reached
5
6
7 the age of 18 (Minszrav Rossii 2017).
8
9

10
11
12
13
14 Despite being not compulsory, preschool education in Russia is the first level in the
15
16
17 national system of general education, including primary, basic and secondary levels
18
19
20 (Bodrova and Yudina, 2018). Children with disabilities in Russia receive preschool
21
22
23 education in general groups or special groups in mainstream kindergartens, or in
24
25
26 special needs kindergartens – for blind and visually impaired children, for children
27
28
29 with hearing issues, children with intellectual disabilities, deaf children and others.
30
31
32

33
34
35 The staff–children ratio is better than in mainstream schools, and staff should have a
36
37
38 qualification to work with special needs children.
39
40
41

42
43
44
45 This system corresponds with the three main models of educating children with
46
47
48 disabilities: 'segregation' in (non) residential special schools and 'integration' in
49
50
51 mainstream schools in special classes and inclusive education in mainstream
52
53
54 classes (Frederickson and Cline, 2009). There is a prevalence of special needs
55
56
57 education (SNE) for children with disabilities in the Russian education system,
58
59
60

1
2
3 including developmental disabilities (see Thompson, 2002). Such schools are called
4
5
6
7 'schools of correction' which were rooted in the USSR. Nowadays, Russia
8
9
10 guarantees every child equal access to education (Federal'nyi zakon, 2012). The law
11
12
13 defines inclusive education as the 'provision of equal access to education for all
14
15
16
17 students, given a diversity of special educational needs and individual capabilities'
18
19
20 (Federal'nyi zakon, 2012, art. 2, par. 27). It is also reflected in the law on social
21
22
23 protection of people with disabilities in Russia that guarantees persons with
24
25
26
27 disabilities access to free preschool, school-level, professional and higher education,
28
29
30
31 and obligates regional and city-level governments to create the conditions for people
32
33
34
35 with disabilities to access these forms of education (Federal'nyi zakon, 1995). Law
36
37
38 also states that the education of children with disabilities can be organised in
39
40
41
42 different ways, including together with other learners, as well as in separate classes,
43
44
45
46 groups or in special needs schools (Federal'nyi zakon, 1995, art. 19, par. 1–2) and
47
48
49 should provide accessible infrastructure and information to people with disabilities
50
51
52 (Federal'nyi zakon, 1995, art. 14,15).
53
54
55
56
57
58
59
60

1
2
3
4 Recently, a Federal standard has been adapted for primary education of children
5
6
7 with ASD in mainstream schools (Ministry of Education of Russia, 2014), including
8
9
10 some measures for the transition from preschool to primary education. Despite the
11
12
13 legal guarantees of inclusive education, its implementation is still very problematic.
14
15

16
17 For example, the above-mentioned standard does not make it compulsory to include
18
19
20 a teacher's assistant or a tutor. The dependence of schools on regional budgets is
21
22
23 also very problematic because of Russia's economic diversity and inequality.
24
25

26
27
28
29
30
31 There are still many issues in children's access to education, and as the Human
32
33
34 Rights Watch stressed, 'Children and adults living with disabilities in Russia
35
36
37 encounter numerous obstacles to getting a quality, inclusive education, at all levels
38
39
40 of the education system, from preschool through higher education' (2015, p. 21).
41
42
43

44
45 There is not much data about the access of children with ASD and developmental
46
47
48 disabilities to preschool education in Russia, though it is known that children with
49
50
51 disabilities comprise 6.8 per cent of the pupils in preschool educational institutes in
52
53
54 Russia (Ministry of Education of Russia, 2019). Still, the available statistics make it
55
56
57
58
59
60

1
2
3 possible to see the vast disparity in preschool education access between children
4
5
6
7 with disabilities and other children.
8
9

10
11
12
13
14 Most of the children with disabilities who attend mainstream kindergartens are
15
16
17 enrolled in so-called 'compensatory groups' which have only children with disabilities
18
19
20 – 78.4 per cent in 2017 (Abankina *et al.*, 2019, p. 132) and 20.2 per cent in so-called
21
22
23 'combined groups' (groups for children with and without disabilities). Even children
24
25
26 without a formal disability status but identified as having special needs have low
27
28
29 accessibility to mainstream preschool education, as among those who attend
30
31
32 mainstream kindergartens, only 18.2 per cent are enrolled to 'combined groups'
33
34
35 (Abankina *et al.*, 2019, p. 131). On a regional level, in Kazan, among 306 children
36
37
38 with ASD, only 9.5 per cent, are enrolled in mainstream schools, 19.3 per cent are in
39
40
41 mainstream schools but on distance-learning courses. One-fourth of the children with
42
43
44 ASD are within integrative education – in so-called resource classes in mainstream
45
46
47 schools. The rest of the children with ASD are in special needs schools (42.2 per
48
49
50 cent), 1.9 per cent in boarding schools for children with speech disorders and 1.9 per
51
52
53 cent in orphanages (Saifutdinova, 2020). The situation with preschool education is
54
55
56
57
58
59
60

1
2
3
4 different – the mainstream kindergartens are attended by 29.4 per cent of children
5
6
7 between 3 and 7 years with ASD, special groups in mainstream kindergartens by
8
9
10 18.6 per cent, while the one-third of the children with ASD are within special needs
11
12
13 education – 29.4 per cent in SN kindergartens and 2.5 per cent in a private centre for
14
15
16 curative pedagogy. Over one-third of the children with autism in Kazan are not
17
18
19 enrolled in any kind of preschool educational institutes (Saifutdinova, 2020).
20
21
22
23
24
25
26
27

28 The prevalence of special needs and integrative preschool education over inclusive
29
30
31 education might be partly explained by the lack of methodological support and
32
33
34 funding for qualified teaching staff. Also, as Abankina *et al.* state, some regions
35
36
37 reduced the number of positions for specialists – psychologists, speech therapists,
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
32.2 per cent of kindergartens required major repairs (Tatstat, 2018).

1
2
3
4 Simultaneously, in some cities there are initiatives to improve access to mainstream
5
6
7 education for children with disabilities. Parents' organisations and NGOs play a
8
9
10 crucial role in this process (Bindman, 2015; Bogdanova and Bindman, 2016;
11
12
13 larskaia-Smirnova *et al.*, 2015; Abankina *et al.*, 2019). For example, recently,
14
15
16
17 children with autism were provided with new opportunities for education for in Kazan.
18
19
20
21 One mainstream school opened a special class, and seven kindergartens started to
22
23
24 provide integral and inclusive education (Gorozhaninova 2019). However, as our
25
26
27
28 study shows, the preschool education for children with developmental disabilities is
29
30
31
32 still challenged by the lack of professional resources and stigma embedded into the
33
34
35 professionals' and society's responses.
36
37
38
39
40
41

42 **Stigma, labelling and the production of inequalities in the education of children with** 43 44 45 **disabilities**

46
47
48 The stigmatisation of children with disabilities at schools and preschool institutions is
49
50
51
52 part of the prevailing injustice produced by professionals and broader society. In our
53
54
55
56 research we adopt Link and Phelan's (2001, p. 377) definition of stigma 'when
57
58
59 elements of labelling, stereotyping, separation, status loss and discrimination occur
60

1
2
3
4 together in a power situation that allows them' to proliferate. According to Tyler and
5
6
7 Slater (2018), such a power situation is possible due to the character of
8
9
10 stigmatisation, which is a 'consequential and injurious form of action through
11
12
13 collective representation fastened on people and on places' (p. 740). The social
14
15
16 impacts of stigma towards people with disabilities vary between social awkwardness
17
18
19 in some social encounters and acts of hostility and social shunning, entailing
20
21
22 violence in extreme cases and emerging from a strong sense of otherness (Green *et*
23
24
25 *al.*, 2005). It is not uncommon that primary schools informally reject and stigmatise
26
27
28 children with autism, as shown by research in Sydney (Lilley, 2013). The recent
29
30
31 studies among children with intellectual disability showed that stigma might be
32
33
34 recreated or sustained within the family and school settings (O'Byrne and Muldoon,
35
36
37
38
39
40
41
42 2019).

43
44
45
46
47
48 In our research we are particularly interested in how stigma impacts parents'
49
50
51 trajectories regarding preschool education. In this respect, we find it useful to engage
52
53
54 with the modified labelling approach which considers that persons with mental
55
56
57
58
59 disorders endorse strategies of secrecy, withdrawal and education to cope with the
60

1
2
3 threat of discrimination they perceive via labelling (Link *et al.*, 1989). The modified
4
5
6
7 labelling approach has been widely used in disability and health studies and,
8
9
10 therefore, is not only limited to the research of psychiatric patients (see Green, 2003;
11
12
13 Ciciurkaite and Perry, 2018, among others). Following Goffman (1963), Link *et al.*
14
15
16
17 (1989) revealed the secrecy strategy that aims to hide disability to 'avoid rejection'
18
19
20 (p. 403). The withdrawal strategy involves 'limiting social interaction to those who
21
22
23 know about and tend to accept one's stigmatised condition' (p. 403), while the
24
25
26
27 education strategy aims to make other people understand what it means to be a
28
29
30
31 psychiatric patient. According to Link *et al.*, these tactics can have negative
32
33
34
35 consequences. Withdrawal 'may lead to more constricted social networks and fewer
36
37
38 attempts at seeking more satisfying, higher-paying jobs' (1989, p. 403).
39
40
41
42
43
44

45 Not only people with disabilities but also their parents and carers can experience
46
47
48 stigmatisation, which in turn impacts children's experiences. For example, adapting a
49
50
51
52 modified labelling approach in her research of mothers of children with disabilities,
53
54
55
56 Green (2003) argued that that perceived stigma increased the subjective burden of
57
58
59 mothers and decreased the frequency with which children interact with age peers.
60

1
2
3
4
5
6
7 The educational environment has a significant impact, including teachers' attitudes
8
9
10 towards children with disabilities, which can produce labelling. For instance, Lavlani
11
12
13 (2005), in her study of parents' and teachers' perspectives on disabilities in the
14
15
16 United States, revealed that teachers often defined the disability of their pupils by
17
18
19 physical, neurological or cognitive limitations while parents' understandings, instead,
20
21
22 were more situated in the cultural meanings ascribed to disability.
23
24
25
26
27
28
29
30

31 In our study, we are particularly interested in stigma and how parents cope with
32
33
34 stigma in navigating their children's preschool education and resist stigma in
35
36
37 traditional educational settings. We engaged with Thoits's (2011) understanding of
38
39
40 resistance strategies in the form of deflecting and challenging and the role of labelled
41
42
43 individuals' agency. Deflections embrace strategies that minimise the negative
44
45
46 psychological effects of stigmatisation while maintaining the social order.
47
48
49
50

51
52 Conversely, challenging resistance strategies against stigmatising structures might
53
54
55 include both interpersonal confrontation and political mobilisation. In contrast to the
56
57
58 education strategy suggested by Link and colleagues (1989), Thoits' concept of a
59
60

1
2
3 challenging form of stigma resistance 'is more direct and assertive than educating'
4
5
6
7 (2011, p. 15). These coping strategies can be used in combination and change
8
9
10 under some conditions.
11
12
13
14
15
16

17 **Methodology**

18
19
20 The research took place in the Republic of Tatarstan, Russia. At the first stage of the
21
22
23 project in 2013–2014, 30 semi-structured interviews were conducted with parents of
24
25
26 children with Down syndrome, Rett syndrome and ASD. The informants were
27
28
29
30
31 selected using the snowball technique, a method widely used in studying confidential
32
33
34 topics or hidden communities; each time a person gave multiple referrals, only one
35
36
37 new subject was recruited (Atkinson and Flint, 2001). Initially, the informants were
38
39
40
41 found among acquaintances and also via social media parental groups. The
42
43
44 informants were selected based on the principle of being primary caregivers, and,
45
46
47 because in most of the families women had this role, most of the respondents were
48
49
50
51 women.
52
53
54
55
56
57
58
59
60

1
2
3
4 The second stage of the project (ongoing from 2018) addresses the identification of
5
6
7 new opportunities for children to receive an inclusive education in Tatarstan and
8
9
10 included ten interviews with parents of children with autism who receive preschool or
11
12
13 a school education and 25 semi-structured interviews with professionals working in
14
15
16 local ministries, special needs schools, social workers, and medical doctors via
17
18
19 purposive sampling. Along with an analysis of secondary data and legislation, the
20
21
22 interviews with professionals helped us to analyse the state policy towards children
23
24
25 with developmental disabilities.
26
27
28
29
30
31
32
33
34

35 In both studies a briefing has been provided for the participants to cover the purpose
36
37
38 of the research and ethical points including assured anonymity (Dowling, 2016) and
39
40
41 the ability to withdraw participation at any given moment. Following this, informed
42
43
44 consent was obtained from all informants. Consequently, the data has been
45
46
47
48 anonymised, excluding representatives of some NGOs and kindergartens who
49
50
51
52 wished to remain anonymous while reference is made to their organisations.
53
54
55
56
57
58
59
60

1
2
3
4 When the neurologist has written 'autism-like behaviour', I have not brought
5
6
7 this note to our doctor. If I told the doctor this diagnosis, I thought that my
8
9
10 child would not receive a driving licence later and not be given credit by a
11
12
13 bank. You know it is one of the myths. But will he need that credit and driving
14
15
16 licence if he will stay in such condition? It took time for me to come to this
17
18
19 understanding (mother of a child with autism, Kazan, 2019).
20
21
22
23

24 The necessity of special needs educational support and the lack of a learning
25
26 environment for children with ASD influenced this mother to go via the route of an
27
28 official recognition of ASD and receive the status of disability for her child. That
29
30
31 status provided him with an opportunity to have state-funded therapy and
32
33
34 rehabilitation and access special needs kindergartens. Thus, this case demonstrated
35
36
37 a change from the secrecy strategy when special needs are hidden and not
38
39
40 positioned to another type of strategy as withdrawal. Some other parents have to
41
42
43 come to terms with accepting an official status of disability for their child after being
44
45
46 exposed to negative experiences in municipal kindergartens, which leads them to be
47
48
49 willing to secure a place in special needs kindergartens.
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4 Traditionally, in Russia, children with developmental disabilities attend special needs
5
6
7 kindergartens such as kindergartens for children with intellectual disabilities,
8
9
10 kindergartens for children with mental disabilities and so-called 'logopaedic' ones for
11
12
13 children with speech issues. There are some kindergartens for children with ASD in
14
15
16 Russia, and recently several groups have been established in mainstream preschool
17
18
19 institutions in Kazan for children with ASD. However, because of lack of available
20
21
22 places, some children with autism have to attend kindergartens for children with
23
24
25 speech problems or with intellectual disabilities. Therefore, they do not have support
26
27
28 explicitly designed for their needs.
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54

55
56 The research showed that the different types of behaviour exhibited by children with
57
58 developmental disabilities have been 'inconvenient' for staff who considered it
59
60 unacceptable when children were crying 'too much' or 'misbehaved'. In one case,
such 'inconvenience' was followed by the staff placing a child at immediate health
risk, when staff gave a girl with Down syndrome unprescribed sedative medicine:

We came to take our child from kindergarten, and we noticed an allergy on
her skin. As we realised afterwards, it was an allergy from a powerful sedative

1
2
3
4 drug, which staff used to calm down children without telling us at all. In the
5
6
7 end, we just took her from kindergarten and taught her by ourselves (interview
8
9
10 with mother, Kazan, 2013).

11
12
13
14 Some parents do not deny that they are afraid of sending their children to
15
16
17 educational institutions since they may become subject to hostility and
18
19
20 discrimination. There are proven facts that children with severe physical and mental
21
22
23 disabilities do not receive the necessary attention and are left unattended. For
24
25
26 example, one of the nursery school teachers described an ordinary day for children
27
28
29 with developmental disabilities: 'Like in the case with ordinary children, they sit and
30
31
32 play. What can you expect of them? No wits, it is useless to teach them at least
33
34
35 something' (interview, Kazan 2014). Such an attitude towards children with mental
36
37
38 disabilities occurs in many institutions, both in preschool and in schools.
39
40
41
42
43
44
45
46
47
48

49 In some cases, staff consider children with intellectual and developmental disabilities
50
51
52 a burden and do not support parents. It is even not uncommon to blame parents for
53
54
55 neglecting parental duties. As one of the teachers from one of the kindergartens
56
57
58 explained her point of view:
59
60

1
2
3 Often, parents want their child to go to kindergarten not for the sake of his/her
4
5
6
7 development, not for the sake of being with others, but because they cannot
8
9
10 properly educate and be involved with their child. Many parents openly
11
12
13 declare that they are tired to be with their sick child and take care of this child
14
15
16
17 in a round-the-clock mode, and they already want to "relax" (Kazan, 2014).
18
19

20
21 Such attitudes on the part of the staff produce and strengthen the feeling of shame
22
23
24 and embarrassment, which is very typical for parents of children with ASD with non-
25
26
27 typical behaviour (see, for example, Gray, 2002; Ryan, 2010). This stigmatises not
28
29
30 only children but their parents too, which leads in some cases to strategies of
31
32
33
34 withdrawal from all preschool education and corresponds with the statistics
35
36
37 mentioned above in Kazan where 31 per cent of the children between three and
38
39
40
41 seven with autism are not enrolled in any kindergartens or children are enrolled in
42
43
44
45 SE kindergartens for just a few days per week.
46
47
48
49
50

51
52 In response, some parents establish resistance strategies to enrol their children in
53
54
55 mainstream preschool education or establish alternative special groups in
56
57
58
59 mainstream kindergartens. For example, a father of a boy with autism shared how he
60

1
2
3
4 was advised to 'stop going to the kindergarten' for children with special needs
5
6
7 because his child 'gnawed all toys, did not sleep, and overall was a problem for three
8
9
10 adults who looked after three children' (interview, Kazan, 2018). At first, the family
11
12
13
14 tried to confront staff's attitudes at the kindergarten, but then they were able to find a
15
16
17 mainstream kindergarten with a special group for children with autism where the boy
18
19
20
21 felt welcome.
22
23
24
25
26
27

28 At the same time, as we will show in the following section, the experiences in
29
30
31 mainstream kindergartens often produce stigma too, and parents have to navigate
32
33
34
35 between special needs, mainstream education and private children's services to find
36
37
38 an enabling educational environment for their children.
39
40
41
42
43
44

45 **Stigmatisation and othering of children in mainstream preschool education**

46
47

48 About half of the interviewed parents tried to enrol their children in mainstream
49
50
51
52 groups in mainstream kindergartens. However, most of them did not have a positive
53
54
55
56 experience and often ended up with home education or special needs groups or SN
57
58
59
60

1
2
3 kindergartens. The following example is quite typical and refers to the stigmatisation
4
5
6
7 of both a child and parents:
8
9

10 The psychologist [in the kindergarten] gave me such a look and asked if we
11 have official registration. I asked: 'Which registration?' She said: 'Well, you
12
13
14 have a special child'. And she said it aloud so that everyone could hear that. I
15
16
17
18 did not like it, obviously, and asked: 'What do you mean?' Psychologist: 'Is he
19
20
21
22 on medication?' Me: 'Why should I give him any medication?' Psychologist:
23
24
25
26
27
28 'Neuroleptics, sedatives [medication]'. I said that my child has good behaviour
29
30
31 usually at home, but of course, as it is the first day in kindergarten, it might be
32
33
34
35 stressful for him. That means he started to cry, and they were unable to calm
36
37
38 him down. But they have my phone number so why did they not call me?
39
40
41
42 (Mother of a five-year-old boy with autism, who tried to start at kindergarten at
43
44
45 the age of three, as in Russia three years' maternity leave is allowed, Kazan,
46
47
48
49 2019.)
50
51

52 As a result, the kindergarten administration made the parents stop taking their son to
53
54
55 the kindergarten. Thus, the kindergarten staff prevented a child from receiving
56
57
58
59 mainstream preschool education, and therefore barred his inclusion into children's
60

1
2
3 play, placing him in the position of 'undesirable'. The child's mother had to leave her
4
5
6
7 job to look after him. She used to take son to different activities several days per
8
9
10 week, including hippotherapy, speech development and swimming, since the family
11
12
13 has a good income. Many other families who experienced similar situations could not
14
15
16
17 provide such training for their children because of their poor financial condition.
18
19
20
21
22
23

24 Some parents with similar negative experiences in municipal kindergartens pay for
25
26
27 private ones where groups are smaller and children can receive more attention.
28
29
30

31 However, often it is not an option if their children are met negatively by parents of
32
33
34 children without special needs. As one of the informants who tried to enrol her son in
35
36
37 a private and expensive kindergarten mentioned:
38
39
40

41
42 I have discussed my child's special needs, his diagnosis [with the director of
43
44 the kindergarten]. Then the director said that she would talk with parents of
45
46 other children from the kindergarten. And then we were met with an adverse
47
48
49 reaction. Parents were totally against having our child in this kindergarten. So,
50
51
52 the director explained that she could not take us because other parents object
53
54
55
56 to it (Mother of a boy with autism, Kazan, 2019).
57
58
59
60

1
2
3
4 Similar to parents who have had negative experiences with mainstream preschool
5
6
7 education, the informant's family had to take their son to a kindergarten for children
8
9
10 with special needs. These stigmatisation and othering practices are very similar to
11
12
13 the removal of rejected students with disabilities from general education explored by
14
15
16
17 Lalvani (2015). She discovered the ambivalent notion of denial of disability which is
18
19
20 perceived by teachers as a denial of the diagnosis. Still, parents deny the label of
21
22
23
24 'disability' that bars their children from study.
25

26
27
28 Stigmatisation and the lack of an enabling educational environment in both
29
30
31 mainstream and SE institutions brought some parents to establish resistance
32
33
34 strategies which enabled them to achieve a visible success in access to an
35
36
37
38 integrated and inclusive preschool education.
39
40
41
42
43
44
45
46
47
48

49 **Parental strategies of resistance: establishing inclusive education**

50
51

52
53 Parents themselves, their social circles and, recently associations for children with
54
55
56 different special needs, have become an important resource in the coping tactics in
57
58
59 accessing education and providing peer-to-peer support. Our research showed that
60

1
2
3
4 parents must navigate among available services and specialists by themselves and
5
6
7 via parents' associations and networks. No respondent noted any help from social
8
9
10 workers, whose services are usually limited to providing advice regarding monetary
11
12
13 benefits for children with disabilities. However, such resources are very limited in
14
15
16 Russia with regard to the actual amount of financial support available for people with
17
18
19 special needs (Mukharyamova and Kuznetsova, 2011). Parents demonstrated
20
21
22 resistance to the traditional model of mainstream and special needs education and
23
24
25 aimed to establish access to mainstream education for children. There are some all-
26
27
28 Russian and regional organisations established by parents of children with ASD
29
30
31 including Vykhod [The Way Out], Autism-Regyony [Autism-Regions] which advocate
32
33
34 for rights for people with autism and participate in governmental committees on
35
36
37 education. Positive support becomes a crucial factor in reducing stigma arising from
38
39
40 discrimination and rejection in both special needs and mainstream kindergartens. In
41
42
43 Tatarstan's capital, Kazan, parents successfully established groups for children with
44
45
46 autism in mainstream kindergartens and classes in primary schools in 2017. As the
47
48
49 leader of an organisation of parents for children with autism mentioned:
50
51
52
53
54
55
56
57
58
59
60

1
2
3 All my life now relates to autism. My son has autism; he is eight years old now
4
5

6
7 If before I used to work in a different sphere, now I embrace this topic.
8
9

10
11 Several years ago, we established the organisation 'Prosto drugye' [Just
12
13 different] to support families of children with ASD, and now I lead it. Also, I
14
15

16
17 curate one kindergarten, as, from this year, a few kindergartens established
18
19

20
21 groups for children with autism (Kazan, 2018).
22
23

24 The newly established preschool educational opportunities for children with autism
25

26
27 reflect a more 'integrative' than an inclusive approach as children are placed into
28
29

30
31 special groups within the school. Interviewees whose children are enrolled in one of
32
33

34
35 the kindergartens mentioned above in 2018–2019 described the experience as a
36
37

38
39 positive one overall, except that for several months there were no permanent tutors
40
41

42
43 and children have to become accustomed to new people. It was mentioned the
44
45

46
47 children made progress in developing speech, and groups for children with autism
48
49

50
51 have some joint activities with other groups in the kindergarten and those for
52
53

54
55 different types of special needs. However, for a city with over a million people, seven
56
57

58
59 such groups are not enough. As a result, many of those children allocated to special
60

groups have to commute to kindergartens from one end of the city to another. Also,

1
2
3 the situation with access to preschool education of children with Down syndrome,
4
5
6
7 Rett syndrome and other developmental disabilities does not have such
8
9
10 transformations.
11
12
13
14
15
16
17

18 Discussion

19
20
21 Theoretically, following the modified labelling approach (Link *et al.*, 1989; Thoits,
22
23
24 2011) the paper contributes to debates on the role of stigma in preschool education
25
26
27 of children with developmental disabilities and ASD and parents' coping strategies. It
28
29
30 also addressed a gap in the literature on the role of resistance related to stigma, as
31
32
33
34 Thoits (2011) pointed out, it is rarely discussed in the stigma and labelling literatures.
35
36
37
38 Our findings are consistent with the understanding of modified labelling theory which
39
40
41 considers that individuals develop negative conceptions of what it means to be a
42
43
44 person with disability. We argue that the stigma regarding children with
45
46
47
48 developmental disabilities and labelling within preschool institutions impact on
49
50
51 parents' strategies, even among those who initially did not want to be associated
52
53
54
55 with stigma and rejected the status of disability for their children (deflection strategy
56
57
58
59
60

1
2
3
4 of resistance), and led to a withdrawal strategy which accepts their children's
5
6
7 stigmatised condition.
8
9

10
11
12
13
14 The educational experiences of parents of children with developmental disabilities
15
16
17 are much broader than just interactions with the special needs education or
18
19
20 mainstream educational spheres. Parents use various tactics to navigate access to a
21
22
23 suitable education, across special needs institutions, specialised groups in
24
25
26 mainstream institutions, private kindergartens, and mixed groups in mainstream
27
28
29 kindergartens and home education. These tactics are not mutually exclusive, and
30
31
32 some families try more than one strategy during the preschool period from strategies
33
34
35 of secrecy and withdrawal to a resistance strategy of challenging and vice versa.
36
37
38
39
40
41
42
43
44

45
46 Parents were able to challenge the mainstream educational structures in some cities,
47
48
49 for example, in Kazan, Tatarstan, and established groups for children with autism in
50
51
52 some mainstream kindergartens and classes in mainstream schools. It helped to
53
54
55 increase access to both preschool and primary integrative and inclusive education
56
57
58
59 for children with autism in Kazan and also in some other cities; however, the small
60

1
2
3
4 scale makes it impossible to address the needs all children with developmental
5
6
7 disabilities, including those with Down syndrome and Rett syndrome.
8
9

10
11
12
13
14 The modified labelling theory states that responses of secrecy and withdrawal are
15
16
17 often associated with the limitation of life chances via the constriction of people's
18
19
20 networks (Link *et al.*, 1989). We suggest that stigmatisation within preschool
21
22
23 education for children with developmental disabilities forces many parents to adopt
24
25
26 withdrawal or secrecy strategies and further disadvantages children. Making children
27
28
29 study in special needs institutions lowers their chances of a mainstream primary
30
31
32 education. Although in Russia mainstream schools do not have the right to reject a
33
34
35 school application, especially from a child registered in a school catchment area, and
36
37
38 Federal law states that they must create an inclusive environment for children with
39
40
41 disabilities, many schools have some selection criteria which might include
42
43
44 preferences for those who took voluntary evening or weekend courses at the school
45
46
47 or pass entrance exams, which is difficult if children have not received preschool
48
49
50
51
52
53
54
55
56 education.
57
58
59
60

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

1
2
3 context of the economic and social diversity of Russian regions. It would be also
4
5
6
7 beneficial to explore the impact of coping strategies regarding stigma on families'
8
9
10 well-being, as for example, as Thoits (2016) found out in the case of people with
11
12
13 mental disabilities, the deflection is positively associated with well-being for
14
15
16
17 individuals.
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51

The research findings can be useful for countries which have recently recognised
25
26
27
28 ASD and that have not established inclusive preschool educational practices and
29
30
31
32 where labelling towards children with developmental disabilities is still common. It
33
34
35 would be beneficial to conduct comparative studies not only between countries which
36
37
38
39 historically had similar approaches towards education for children with special needs
40
41
42 based on defectology, such as post-Soviet countries, but also among countries
43
44
45
46 which are starting to develop inclusive education.
47
48
49
50
51

52 **Conclusion**

53
54

55
56 Despite Russian law guaranteeing equal access to education for every child and
57
58
59 requiring the development of an inclusive education, children with developmental
60

1
2
3 disabilities, including autism, are often stigmatised in the preschool stage both in
4
5
6
7 special needs education and mainstream institutions. This impacts on parents'
8
9
10 strategies and those who initially did not accept stigma had to defer to withdrawal or
11
12
13
14 secrecy strategies after engagement with preschool institutions. While children with
15
16
17 non-typical behaviour are perceived as a burden in many preschool institutions, their
18
19
20
21 parents are often blamed for their 'inadequate' behaviour resulting in withdrawal of
22
23
24 their children from kindergartens. The parents are then forced to choose special
25
26
27
28 needs preschool education or home education as the only possible options. As a
29
30
31 result, parents have to navigate between special needs, mainstream education and
32
33
34 private children's services to find an enabling educational environment for their
35
36
37
38 children. Some parents develop challenging strategies of resistance establishing
39
40
41
42 inclusive education for children in Russia via parents' organisations and activism.
43
44
45
46
47
48

References

49
50
51
52 Abankina, I.V., Polivanova, K. and Frumin, I.D. (Eds.), (2019), *Ot universal'noj*
53
54
55
56 *Dostupnosti k sovremennomu kachestvu: doshkol'noe obrazovanie v Rossii* [From
57
58
59
60

1
2
3
4 Universal accessibility to the modern quality: preschool education in Russia]. HSE:
5
6
7 Moscow. available at: https://ioe.hse.ru/data/2019/06/25/1490049820/DO_text-tip.pdf
8
9

10 Allan, J. (2012), "The sociology of disability and inclusive education", Arnot, M. (Ed.),
11
12
13 *The Sociology of Disability and Inclusive Education. A Tribute to Len Barton.*
14
15

16
17 Routledge: London/New York, pp. 75-91.
18
19

20
21 Atkinson, R., and Flint, J. (2001) "Accessing Hidden and Hard-to-Reach Populations:
22
23
24 Snowball Research Strategies", *Social Research Update*, No. 33. Guildford:
25

26
27
28 Department of Sociology, University of Surrey.
29
30

31 Bindman, E. (2015), "The state, civil society and social rights in contemporary
32
33
34 Russia", *East European Politics*, Vol. 31 No. 3, pp.342-360.
35
36

37
38 Bodrova, E. and Yudina, E. (2018), "Early childhood education in the Russian
39
40
41 federation", Roopnarine, J.L., Johnson, J.E., Quinn, S.F. and Patte, M.M. (Eds.),
42
43
44
45 *Handbook of International Perspectives on Early Childhood Education*, Routledge:
46
47
48
49 London, pp. 59–69
50

51
52 Bogdanova, E. and Bindman, E. (2016), "NGOs, policy entrepreneurship and child
53
54
55 protection in Russia: Pitfalls and prospects for civil society", *Demokratizatsiya: The*
56
57
58
59 *Journal of Post-Soviet Democratisation*, Vol. 24 No. 2, pp.143-171.
60

1
2
3 Charmaz, K. (2006), *Constructing Grounded Theory*. Sage: London.
4
5

6
7 Charmaz, K. and Belgrave, L. (2012), "Qualitative interviewing and grounded theory
8
9
10 analysis", Gubrium, J.F., Holstein, J. A., Marvasti, A.B. and McKinney, K.D. (Eds.),
11
12
13 *The SAGE Handbook of Interview Research: The Complexity of the Craft*, SAGE:
14
15
16
17 Los Angeles, pp.347-365.
18
19

20
21 Ciciurkaite, G. and Perry, B.L. (2018), "Body weight, perceived weight stigma and
22
23
24 mental health among women at the intersection of race/ethnicity and socioeconomic
25
26
27 status: Insights from the modified labelling approach", *Sociology of Health &*
28
29
30
31 *Illness*, Vol. 40 No. 1, pp.18-37.
32
33

34
35 Deng, M. and Poon-McBrayer, K.F. (2012), "Reforms and challenges in the era of
36
37
38 inclusive education: the case of China", *British Journal of Special Education*, Vol. 39
39
40
41
42 No. 3, pp.117-122.
43
44

45
46 Dowling, R. (2016), "Power, subjectivity, and ethics in qualitative research", I. Hay, I.
47
48
49 (Ed.), *Qualitative Research Methods in Human Geography*, 4th ed. Oxford: Oxford
50
51
52 University Press, pp.29-43.
53
54

55
56 Downside Up. (2018), Cifry i fakty o lyudyakh s sindromom Dauna v Rossii i mire
57
58
59 [Numbers and Facts about People with Down syndrome in Russia and a Globe].
60

1
2
3
4 available at: <https://downsideup.org/o-sindrome-dauna/cifry-i-fakty/> (accessed 15
5
6
7 December 2020).

8
9
10 Federal'nyi zakon (1995), O sotsial'noy zashchite invalidov v Rossiyskoy Federatsii
11
12 [Federal Law on social protection of invalids in Russian Federation] No. 181-F3, with
13
14 [Federal Law on social protection of invalids in Russian Federation] No. 181-F3, with
15
16
17 amendments.
18

19
20
21 Federal'nyi zakon (2012), Ob obrazovanii v Rossijskoj Federacii No. 273-FZ [Federal
22
23
24 Law on Education in Russian Federation, N 273-FL]. <http://zakon-ob-obrazovanii.ru>
25

26
27
28 Fontil, L., Gittens, J., Beaudoin, E. and Sladeczek, I.E. (2019), "Barriers to and
29
30
31 facilitators of successful early school transitions for children with autism spectrum
32
33
34 disorders and other developmental disabilities: A systematic review", *Journal of*
35
36
37
38 *Autism and Developmental Disorders*, 1-16.
39

40
41
42 Goffman, E. (1963), *Stigma: Notes on the Management of a Spoiled Identity*.
43
44
45 Prentice Hall: Englewood Cliffs.
46

47
48
49 Gorozhaninova, M. (2019) 'U nashih detej est' perspektivy': kak v Kazani v detsadah
50
51
52 stali zanimat'sja mal'yshami s autizmom ['Our children have prospects': how
53
54
55
56 Kazan's kindergartens started to work with kids with autism]. *Realnoye Vremya* 6
57
58
59
60

1
2
3
4 January, <https://realnoevremya.ru/articles/125031-reportazh-iz-detskogo-sadika-s->
5
6
7 gruppami-dlya-malyshey-autistov
8
9

10
11 Gray, D.E. (2002), “‘Everybody just freezes. Everybody is just embarrassed’: Felt
12
13 and enacted stigma among parents of children with high functioning
14
15
16
17
18 autism”, *Sociology of Health & Illness*, Vol. 24 No. 6, pp.734-749.
19
20

21
22
23 Green, S.E. (2003), “‘What do you mean ‘what's wrong with her?’: Stigma and the
24
25
26
27 lives of families of children with disabilities”, *Social Science & Medicine*, Vol. 57 No.
28
29
30 8, pp.1361-1374.
31
32

33
34
35 Green, S., Davis, C., Karshmer, E., Marsh, P. and Straight, B. (2005), “Living stigma:
36
37
38 The impact of labeling, stereotyping, separation, status loss, and discrimination in
39
40
41
42 the lives of individuals with disabilities and their families”, *Sociological Inquiry*, Vol.
43
44
45 75 No. 2, pp.197-215.
46
47
48
49

50
51 Grigorenko, E.L. (1998), “Russian ‘defectology’ anticipating Perestroika in the
52
53
54 field”, *Journal of Learning Disabilities*, Vol. 31 No. 2, pp.193-207.
55
56
57
58
59
60

1
2
3 Hall, E., Chouinard, V., Hall, E. and Wilton, R. (2010), *Towards Enabling*
4
5
6
7 *Geographies*. Routledge: Oxon and New York.
8
9

10
11 Human Rights Watch. (2015), "Left out? Obstacles to education for people with
12
13 disabilities in Russia", available at
14
15
16
17
18
19 https://www.hrw.org/sites/default/files/report_pdf/russia0915_4up.pdf (accessed 10
20
21
22 July 2017)
23
24

25
26 Frederickson, N. and Cline, T. (2009), *Special Educational Needs, Inclusion and*
27
28
29 *Diversity*. Open University Press, Mc Graw Hill: Berkshire; 2nd edition.
30
31

32
33 Iarskaya-Smirnova E., Antonova E. and Kuznetsova-Morenko, I. [Kuznetsova I.]
34
35
36 (Eds.), (2008), *Obrazovanie dlya vseh: politika i praktika inkluzii* [Education for
37
38
39
40 *Everybody: Policy and Practice of Inclusion*]. Saratov: Nauchnaya Kniga.
41
42

43
44 Iarskaia-Smirnova, E. and Romanov, P. (2007), "Perspectives of inclusive education
45
46
47 in Russia", *European Journal of Social Work*, Vol. 10 No. 1, pp.89-105.
48
49

50
51 Iarskaia-Smirnova, E. and Romanov, P. (2012), "Doing class in social welfare
52
53
54 discourses: 'Unfortunate families' in Russia", Salmenniemi S. (Ed.), *Rethinking Class*
55
56
57 *in Russia*, Routledge: London, pp.85-105.
58
59
60

1
2
3
4 larskaia-Smirnova, E., Romanov, P. and Yarskaya, V. (2015),"Parenting children
5
6
7 with disabilities in Russia: Institutions, discourses and identities", *Europe-Asia*
8
9
10 *Studies*, Vol. 67 No. 10, pp.1606-1634.

11
12
13
14 Kuchmaeva (2016). "Education for children with disabilities: a statistical aspect",
15
16
17 *Statistica and Economica*, 16, pp. 19-24, available at:
18
19
20
21 <https://cyberleninka.ru/article/n/obrazovanie-detey-invalidov-statisticheskiiy-aspekt>
22
23
24 (accessed 16 December 2020).

25
26
27
28 Jenkins, R., McDaid, D., Nikiforov, A., Potasheva, A., Watkins, J., Lancashire, S.,
29
30
31 Samyshkin, Y., Huxley, P. and Atun, R. (2010),"Mental health care reforms in
32
33
34 Europe: Rehabilitation and social inclusion of people with mental illness in
35
36
37 Russia", *Psychiatric Services* Vol. 61 No. 3, pp.222-224, available at
38
39
40
41
42 <https://ps.psychiatryonline.org/doi/full/10.1176/ps.2010.61.3.222>
43
44

45
46 Lalvani, P. (2015), "Disability, stigma and otherness: Perspectives of parents and
47
48
49 teachers", *International Journal of Disability, Development and Education*, Vol. 62
50
51
52 No. 4, pp.379-393.
53
54
55
56
57
58
59
60

1
2
3
4 Leyser, Y. and Kirk, R. (2004), "Evaluating inclusion: An examination of parent views
5
6
7 and factors influencing their perspectives", *International Journal of Disability,*
8
9
10 *Development and Education*, Vol. 51 No. 3, pp.271-285.

11
12
13
14 Lilley, R. (2013), "It's an absolute nightmare: maternal experiences of enrolling
15
16
17 children diagnosed with autism in primary school in Sydney", Australia. *Disability &*
18
19
20
21 *Society*, Vol. 28 No. 4, pp.514-526.

22
23
24 Link, B. and Phelan, J. (2001), "Conceptualizing stigma", *Annual Review of*
25
26
27
28 *Sociology*, Vol, 27 No. 1, pp.363-385.

29
30
31 Link, B.G., Cullen, F.T., Struening, E., Shrout, P.E. and Dohrenwend, B.P. (1989),
32
33
34
35 "A modified labeling theory approach to mental disorders: An empirical
36
37
38 assessment", *American Sociological Review*, Vol. 54, No. 3 pp.400-423.

39
40
41 Liu, Y., Li, J., Zheng, Q., Zaroff, C. M., Hall, B. J., Li, X. and Hao, Y. (2016),
42
43
44
45 "Knowledge, attitudes, and perceptions of autism spectrum disorder in a stratified
46
47
48 sampling of preschool teachers in China", *BMC Psychiatry*, Vol. 16 No. 1, p.142.

49
50
51
52 Ministry of Education of Russia. (2014), Prikaz ob utverzhdenii FGOS NOO
53
54
55 obuchauschihsya s ogranichennymi vozmozhnostyami zdorovia [Order on approval
56
57
58 of Federal State Educational Standards of Primary Mainstream Education of pupils with
59
60

1
2
3 disabilities]. available at:

4
5 <https://docs.edu.gov.ru/document/b903f8ab3dee1dc5e0835ee9f10b59a9/> (accessed 12
6
7 October 2020).

8
9
10 Ministry of Education of Russia (2019). *Deti s osobymi obrazovatel'nymi*
11
12
13 *potrebnostyami* [Children with special educational needs]. available at:

14
15
16
17 https://edu.gov.ru/activity/main_activities/limited_health/ (accessed 18 December
18
19
20
21 2020).

22
23
24 Minzdrav Rossii (2017), *Pis'mo zamministra S.A. Kraevogo ot 04 oktjabrja 2017 g.*

25
26
27 [Ministry of Health of Russia. The letter of deputy Minister S.A. Kraevoi from the 4th
28
29
30
31 of October 2017]

32
33
34 Mukharyamova, L. and Kuznetsova-Morenko [Kuznetsova], I. (2011), *Social'naja*
35
36
37 *rabota v zdravooхранenii* [Social work in Health Care]: Nizhny Novgorod State
38
39
40
41 University Publishing House: Nizhny Novgorod.

42
43
44
45 Mukharyamova, L., Saveleva, Zh., Kuznetsova, I, and Garapshina, L. (2021) Autism
46
47
48 in Russia: a contradictory field of diagnostics and statistics. *The Journal of Social Policy*
49
50
51 *Studies* (in press).

52
53 O'Byrne, C. and Muldoon, O.T. (2019), "The construction of intellectual disability by
54
55
56
57 parents and teachers", *Disability & Society*, Vol. 34 No. 1, pp.46-67.

1
2
3
4 Ryan, S. (2010), “‘Meltdowns’, surveillance and managing emotions; going out with
5
6 children with autism”, *Health & Place*, Vol. 16No. 5, pp.868-875.
7
8
9

10 Saifutdinova, F. (2020), “Organizacionnye aspekty psichiatricheskoj pomoschi detyam
11
12 i podrostkam v Respublike Tatarstan [Organisational aspects of psychiatric support
13
14 for children and adolescence in the Republic of Taratstan]”, *Conference 'Issues in
15
16 Children Psychiatry'*, Unpublished presentation. Kazan, 16 October.
17
18
19
20
21
22
23

24 Seery, M.E., Davis, P.M. and Johnson, L.J. (2000), “Seeing eye-to-eye: Are parents
25
26 and professionals in agreement about the benefits of preschoolism
27
28 inclusion?” *Remedial and Special Education*, Vol. 21 No. 5, pp.268-319.
29
30
31
32
33

34 Shek, O., Pietilä, I., Graeser, S. and Aarva, P. (2010), “Redesigning mental health
35
36 policy in post-Soviet Russia: A qualitative analysis of health policy documents (1992-
37
38 2006)”, *International Journal of Mental Health*, Vol. 39 No. 4, pp.16-39.
39
40
41
42
43

44 Sorokin, A. (2015), “Russia and autism”,. Volkmar, F. (Ed.), *Encyclopedia of Autism
45
46 Spectrum Disorders*. DOI: https://doi.org/10.1007/978-1-4614-6435-8_102022-3
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4 Tatstat. (2018), Doshkol'nye Obrazovatel'nye Organizacii [Pre-school Educational
5
6
7 Organisations], available at: <https://tatstat.gks.ru/storage/mediabank/i020033r.pdf>

8
9
10 (accessed 15 October 2020).

11
12
13
14
15 Thomson, K. (2002), "Differentiating integration: special education in the Russian
16
17
18 Federation", *European Journal of Special Needs Education*, Vol. 17 No. 1, pp.33-47,

19
20
21
22 DOI: 10.1080/08856250110099006

23
24
25
26
27 Thoits, P.A. (2011), "Resisting the stigma of mental illness", *Social Psychology*
28
29
30 *Quarterly*, Vol. 74 No. 1, pp.6-28.

31
32
33
34 Thoits, P.A. (2016) "I'm Not Mentally Ill': Identity deflection as a form of stigma
35
36
37 resistance", *Journal of Health and Social Behavior*, Vol. 57 No. 2, pp.135–151.

38
39
40 Tyler, I., Slater, T. (2018) "Rethinking the sociology of stigma", *The Sociological*
41
42
43 *Review*, Vol. 66, No. 4, pp. 721-743.

44
45
46
47 UNESCO (1990), "World Declaration on Education for All and Framework for action
48
49
50 to meet basic learning needs; working documents", available at:

51
52
53
54 <https://unesdoc.unesco.org/ark:/48223/pf0000086289>. (accessed 2 May 2021).

1
2
3 UNESCO (1994), "The Salamanca statement and framework for action on special
4 needs education", available at: <https://unesdoc.unesco.org/ark:/48223/pf0000098427>.
5
6
7
8
9

10 (accessed 5 March 2019).
11
12

13
14 UNICEF. (2012), "The right of children with disabilities to education:
15

16
17 A rights-based approach to inclusive education", available at:
18

19
20
21 https://www.unicef.org/disabilities/files/UNICEF_Right_to_Education_Children_Disabi
22

23
24 [litities_En_Web.pdf](https://www.unicef.org/disabilities/files/UNICEF_Right_to_Education_Children_Disabilities_En_Web.pdf) (accessed 5 March 2019).
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60