Journal of Autism and Developmental Disorders (2021) 51:3586–3599
https://doi.org/10.1007/s10803-020-04818-4

ORIGINAL PAPER

Children with Autism Spectrum Disorders in Low-Resource Settings: Reported Experiences and Needs of Parents in Mongolia

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Accepted: 25 November 2020 / Published online: 2 January 2021

Abstract

Although it is well-documented that families of children with autism in developed nations report hardships, few researchers have focused on families who live in less-developed, low-resource settings. Using five focus groups with 30 parents of children with autism in Mongolia, a low- resource setting, the purpose of this study was to provide detailed accounts of their experiences, challenges, and needs. Participants reported severe challenges related to raising their children with autism in their country. Parents shared barriers related to the limited availability of services and support, exacerbated financial burdens, and a lack of enforcement of relevant laws. Parents also shared their perceived needs including more services for their children, more sustainable training and coaching programs for parents, and parents' collective advocacy.

Keywords Parent perceptions · Children with autism · Low-resource settings

Introduction

It is well known that families of children with Autism Spectrum Disorder (ASD) face a myriad of challenges in raising their children (Meadan et al. 2010). These challenges may be influenced by difficulties related to childrearing, aggravated by daily challenges associated with children's disabilities including limited social-communication skills and excessive challenging behaviors (Hastings et al. 2005; Meadan et al. 2010). According to the Centers for Disease Control and Prevention (CDC 2020), one in 54 children is diagnosed with ASD in the United States (US). This estimate is a significant increase from previous estimates of one in 110 children in 2008 and one in 69 children in 2012 (CDC 2020). Researchers who examined the prevalence of ASD in other nations reported an increasing trend of ASD diagnosis similar to the US, and suggested that it has become an epidemiological, public health challenge around the globe with one in 160 children diagnosed with ASD (Elsabbagh et al. 2012; World Health Organization [WHO] 2013).

Low-Resource Settings

The hardships of families are increasingly reported to be exacerbated in developing nations where there are few resources for parents of children with disabilities (Tomlinson et al. 2014), including access to diagnosis and assessment, skilled professionals who can provide treatment, and inclusive settings for educating children with ASD (Lee and Meadan 2020).

For example, in a qualitative study by An et al. (2020), parents of children with ASD in Kazakhstan reported barriers of (a) insufficient social support, (b) professionals' limited understanding of needs of children with ASD, and (c) social isolation and lack of support for the families. Other researchers also depicted difficulties of raising children with ASD in various parts of the world, including limited access to reliable resources and educational opportunities, and feeling of isolation and experiencing social consequences due to having a child with ASD (Heys et al. 2016; Samadi and McConkey 2011). Many nations attempt to ensure the rights of children with disabilities within the constraints of available resources (Chataika et al. 2012). For example, 92

Supplementary Information The online version of this article (https://doi.org/10.1007/s10803-020-04818-4) contains supplementary material, which is available to authorized users.

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Member States of the United Nations Educational, Scientific, and Cultural Organization (UNESCO) convened and confirmed their commitment to educating children with disabilities in their respective nations via the Salamanca Statement in 1992 (UNESCO 1994). These Member States proclaimed that every child has a fundamental right to education and that children with special needs “must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs” (UNESCO 1994, viii). Some years later, the historic Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN General Assembly in 2006, which promotes rights of people with disabilities around the globe, including the educational rights of children with disabilities (Shogren and Turnbull 2014). Despite the efforts of international communities, however, a nation’s success in treating their children with disabilities seemingly depends on multiple factors, including the government’s level of commitment, available infrastructure, income and development status, cultural views on disabilities, and stigmatization. In the literature, researchers are increasingly identifying these countries as low-resource settings (LRS) instead of a mere income-based classification, such as low- to middle-income countries (e.g., Divan et al. 2015; Juneja et al. 2012; Stewart and Lee 2017). Lee and Meadan (2020) provided a framework for defining low-resource settings (LRS) that is based not only on the income level of a nation, but also the level of availability of services, level of stigmatization, financial burden for stakeholders, and level of efforts of dissemination of treatment. One of the purposes of such framework is to recognize that the low level of resources and its effects on stakeholders may transcend cultural or geographical borders (de Leeuw et al. 2020) and to focus more on the experiences of the stakeholders of children with ASD.

LRS Example: Mongolia

For a deeper exploration of the experiences of families in LRS, Mongolia was selected as an example of an LRS. Mongolia is an exemplar for other LRS due to its recent economic development, limited level of resources available for families of children with ASD, and active involvement of the government, parent-led nongovernmental organizations (NGO), and international development agencies. As a post-communist, lower-middle income country that is landlocked in Central and East Asia, Mongolia’s economy has grown rapidly in recent years with its political reforms of a market-oriented system with an average of 3.75% real Gross Domestic Product growth in the past 3 years (Asian Development Bank 2019). In addition, there is a phenomenon of parents of children with ASD uniting to form NGOs and developing support systems for other parents in Mongolia, which is also reported in other LRS (e.g., Tekola et al. 2016) and promotes strong collaborations among stakeholders such as parents, professionals, policy makers, and international agencies.

Unique Challenges in Mongolia

To date, there is no published data of ASD prevalence in Mongolia. It is reported that Mongolian educational policies and legislation for children with ASD are limited, and many Mongolian children with disabilities are in need of systemic assistance (Disabled People’s Organizations of Mongolia [DPOM] 2015; Mongolian National Federation of the Blind [MNFB] 2014). Albeit limited, literature examining the conditions of Mongolian families and children with disabilities points to arduous situations. In a report examining the well-being of children with disabilities in four Asian countries, Llewellyn et al. (2012) stated that Mongolian children with disabilities were much more disadvantaged than their peers on the majority of indicators related to their rights to education, health, and adequate standard of living. They also reported that children with sensory impairments or cognitive delays (i.e., intellectual or developmental disability) are greatly disadvantaged, compared to their peers with other types of disabilities (Llewellyn et al. 2012).

Two consortia of Mongolian NGOs (DPOM 2015; MNFB 2014) respectively submitted a *List of Issues* to the United Nations, with both reports highlighting the dire needs of families of children with ASD. The MNFB (2014) stated that there were “no services for parents with children with disabilities” in terms of counseling, training, information about their children’s rights as citizens (p. 13). In addition, there are limited diagnosis options for children with ASD and many parents seek diagnosis for their children in other countries. The DPOM (2015) similarly reported that there were no services available for parents on parenting strategies or how to facilitate their children’s development.

Despite the potential of intervention effects and its unique challenges, to date there is no literature exploring the experiences or perceptions of Mongolian parents of children with disabilities, more specifically children with ASD. To develop an appropriate and effective system of supports and specific interventions, we must first understand the unique needs of the families. Therefore, the purpose of this study was to examine the perceptions of Mongolian parents of children with ASD using these guiding research questions: (1) What are the experiences of parents of children with ASD in Mongolia related to the services and supports their children and families receive? and (2) What do parents of children with ASD in Mongolia report as the needs and barriers related to services and supports for their children and families?

Method

Qualitative Research

Focus group is a qualitative method used to gain an in-depth understanding of complex social issues, which enables researchers to study a social phenomenon from a perspective of the group participants (Nyumba et al. 2018; Wibeck et al. 2007). To allow participants to freely engage in a group discussion on the topics of raising their children with ASD in Mongolia, such method was employed in order to obtain "high-quality data in a social context where people can consider their own views in the context of the views of others" (Patton 2014, p. 915). Conducting a qualitative research in an LRS with little extant research allows us to enhance our understanding of the parents' perceptions. In addition, such focus groups may also create rich discussions among the participants than individual interviews with a foreign researcher who does not have existing rapport with them. Focus groups have been frequently utilized in extant ASD-related studies and reported to be effective in gaining insight of stakeholders' experiences (Koffer Miller et al. 2018). It is also known to allow "homogeneous strangers with similar experiences to tell their stories" (Raulston et al. 2019, p. 695).

Conceptual Framework

Ecological systems theory (Bronfenbrenner 1979) provided the conceptual framework for this study. According to ecological systems theory, different subsystems in a child's life are nested one within another. Five subsystems were considered in this study, including the individual child, microsystem, mesosystem, exosystem, and macrosystem. With these subsystems, it is necessary to look at other "systems" that may affect optimal child development. It emphasizes the importance of looking at the "whole picture" of a child's development including other stakeholders in the child's environment. In an LRS, when a child with a disability has a family with limited means to support the child, the subsystems (e.g., teachers and parents) may have negative interactions with each other due to limited awareness on ASD or limited inclusion opportunities. In addition, when there is little access to public health, and the child lives in a cultural context where disability is highly stigmatized, it is unlikely that the child will achieve optimal development due to the external factors (i.e., macrosystem). Thus, examining the experiences and needs of children with ASD and their families in an LRS through the lens of ecological systems theory becomes critical. In terms of data collection and analysis, questions in the interview protocol addressed different subsystems and the coded data from the interviews were organized based on the different subsystems.

Participants

Following an approval from the university's Institutional Review Board (IRB), five focus group sessions were conducted with a total of 30 Mongolian caregivers of children with ASD. Caregiver participants must have met the following inclusion criteria: (a) having a child with ASD (based on parent report), (b) able to participate in an hour-long focus group session, and (c) willing to complete all aspects of research, including completing questionnaires. As this was an exploratory study and the goal was to explore the general experiences of parents with children with ASD in Mongolia, there were no inclusion criteria related to the child age. Recruitment activities were carried out by the Autism Association of Mongolia (AAM), a parent-led nongovernmental organization (NGO) for Mongolian children with ASD and their families. This connection was critical as the researchers do not speak Mongolian. Parents were recruited with a flyer in Mongolian that was posted on the AAM's social media, as well as by verbal announcements. Participants' eligibility was screened by the NGO when the participants called to reserve a spot for the focus group sessions. No incentive was offered for participating in this study. Participants were informed during the recruitment process and at the beginning of the focus groups about the purpose of the study.

Across all groups, 76% of the participants ($n = 23$) were mothers of children with ASD, and over 90% of the participants ($n = 27$) reported having at least some college education. Over 66% of the participants ($n = 20$) reported household incomes higher than the average Mongolian household of $400 (Asian Development Bank 2019). In terms of services for the children with ASD, 80% of the participants ($n = 24$) reported receiving no services, 16.7% ($n = 5$) reported having some private services, and 13.3% ($n = 4$) reported having some educational services. As for services for the families, 46.7% of participants ($n = 14$) reported receiving financial support from the government, 10% ($n = 3$) reported receiving some support from the NGO, and 43.3% ($n = 13$) reported not receiving any services for their families. See Table 1.

Data Collection and Measures

Four in-person focus group sessions were conducted in Mongolia in June 2019, and an additional online focus group session was conducted in September 2019 via a videoconferencing application (Zoom). Each focus group had five to seven people, and the four in-person focus groups were conducted in the AAM's office, a location that was familiar

Table 1 Participant demographics

Characteristic	Total sample % ($N=30$)
Primary role to the child	
Mother	76.7% (23)
Father	16.7% (5)
Grandparent	3.3% (1)
Extended family member	3.3% (1)
Caregivers' highest level of education	
High school diploma	6.7% (2)
Technical/vocational college	3.3% (1)
College graduate	46.7% (14)
Graduate/professional degree	40% (12)
No response	3.3% (1)
Household monthly income (in USD)[a]	
\$70–\$280	23.3% (7)
\$281–\$490	40.0% (12)
More than \$491	36.7% (11)
Where the child got ASD diagnosis	
Mongolia	40% (12)
Korea	16.7% (5)
China	3.3% (1)
No response	40% (12)
Child's age	
0–8 years old	83.3% (25)
8–17 years old	13.3% (4)
18 and above	3.3% (1)
Types of services for child[b]	
Educational services	13.3% (4)
Private (counseling, developmental, speech, recreational)	16.7% (5)
No services	80% (24)
Types of services for family[b]	
Governmental financial aid	46.7% (14)
Support from NGO	10% (3)

[a] Average household monthly income in Mongolia is about \$400 (Asian Development Bank 2019)

[b] Participants had the option to choose more than one response

to the participants. Sources of data included a demographic questionnaire and the focus group interviews. The questionnaire included basic demographical items (e.g., name, role, age, gender, and household income) and questions regarding the participant's child (e.g., age). A semi-structured interview protocol was utilized to encourage conversations that captured a wide range of perspectives (see Supplementary material for the full interview protocol). Prior to data collection, the questionnaire and interview protocol were sent to a few native Mongolian speakers to ensure their cultural appropriateness. The researchers facilitated the interview discussion and encouraged all participants to share their experiences and voice their thoughts in the context of other participants discussion (Nyumba et al. 2018). The questions focused on the families' experiences, needs, and barriers related to raising children with ASD, specifically related to the level and availability of services in Mongolia. For example, parents were asked: "What services is your child with ASD receiving and how satisfied are you with the services?" and "Have you experienced barriers to accessing services for your child?" As expected, participants' input to these questions naturally elicited responses from others in the same group, which created richer atmosphere for discussion.

Procedures

AAM staff, who were fluent English-speakers, served as interpreters during the focus groups. Along with the researcher, they greeted participants as they came in, thanked them for their time, and provided an overview of the agenda and the purpose of conducting a focus group session. Participants then read and signed the informed consent form and completed the demographic questionnaire. Focus group interviews lasted from 40 to 50 min, and all groups were conducted with at least one interpreter. During each of the in-person focus group interviews, questions were asked in English, then interpreted in Mongolian. As parents were responding, the information was interpreted for the first author to allow him to ask follow-up questions. For the online focus group session, the same procedures were followed, except that the discussion was conducted in English as participants reported being fluent in English.

Transcriptions and Translations

Four Mongolian-English bilingual speakers were hired to assist with transcriptions and translations. After the focus group sessions, the recorded audio files were uploaded to a secure, online storage (Box). The translated transcripts were verified by an independent, bilingual research assistant who was not involved with the study and only made very small corrections. After all the transcripts were completed, translated, and verified, the first author sent the AAM contact person a summary of all focus group sessions for them to share with the participants and to suggest any necessary changes as part of the member check process (Brantlinger et al. 2005). The contact person reported that there was no response from any participants.

Credibility and Trustworthiness

Several measures were taken to promote the credibility and trustworthiness of this study (Brantlinger et al. 2005). These measures included: (a) utilizing field notes from the focus group sessions, (b) providing thick descriptions of the data, and (c) collaborative work between two researchers to analyze and interpret the data and collaborating with AAM throughout the study. Several quality indicators of qualitative research (Brantlinger et al. 2005) also were addressed in this study. For the focus groups, participants were selected based on the inclusion criteria that are stated above, and the details about the recruitment process were provided. There was an adequate number of participants in each focus group (5–7 participants), and questions were not leading. In addition, multiple people worked on transcription and translation, and measures were taken to ensure participants' confidentiality as approved by the IRB. Furthermore, the researchers worked closely with the AAM throughout the study (e.g., recruitment of participants, conducting focus groups, identifying translators and interpreters). At the end of the coding process, the summaries of each group and the overall interpretation were reviewed by the primary contact person at the AAM who reported that these accurately reflect the experiences of the families they work with.

Data Analysis

Data from the demographic questionnaires were analyzed to provide descriptive information about the participants. Transcripts were read, analyzed, and synthesized as a collaborative effort by both authors to promote accurate and impartial interpretation of the data. A constant comparative method (Strauss and Corbin 2015) was used in which the researchers started with an open-coding process whereby they identified units independently. These codes were labeled as they emerged within the data, and new codes were compared to the existing codes to examine if they warranted new code labels. After the independent coding process, the researchers met and discussed the codes, reach a consensus, and organized them into categories. These categories were further grouped into themes. Furthermore, the aforementioned ecological systems theory helped guide the analysis of the data in terms of examining the caregivers' perceptions at different systems. Specifically, how different ecological subsystems affect development of a child with ASD in Mongolia (e.g., microsystems, mesosystem, exosystem) were examined.

Findings

During the five focus group sessions, parents shared their experiences on raising their children with ASD in Mongolia. Three main themes, including families' experiences, barriers, and needs were identified (see Fig. 1), and are discussed. See Table 2 for additional sample quotes for each subcategory.

Experiences

The reported experiences of families of children with ASD were further dichotomized into positive and negative experiences. Positive experiences included: (a) getting helpful support from interacting with other parents, (b) accessing information and resources with the NGO's help, and (c) schools' attempts to help the children and families. Negative experiences of families included: (a) rejection and social isolation, (b) not being able to trust the professionals or the government, and (c) societal expectations of parents as primary caregivers and teachers.

Positive Experiences

Interactions with Other Parents Many parents reported that it was very helpful for them to interact with other parents of

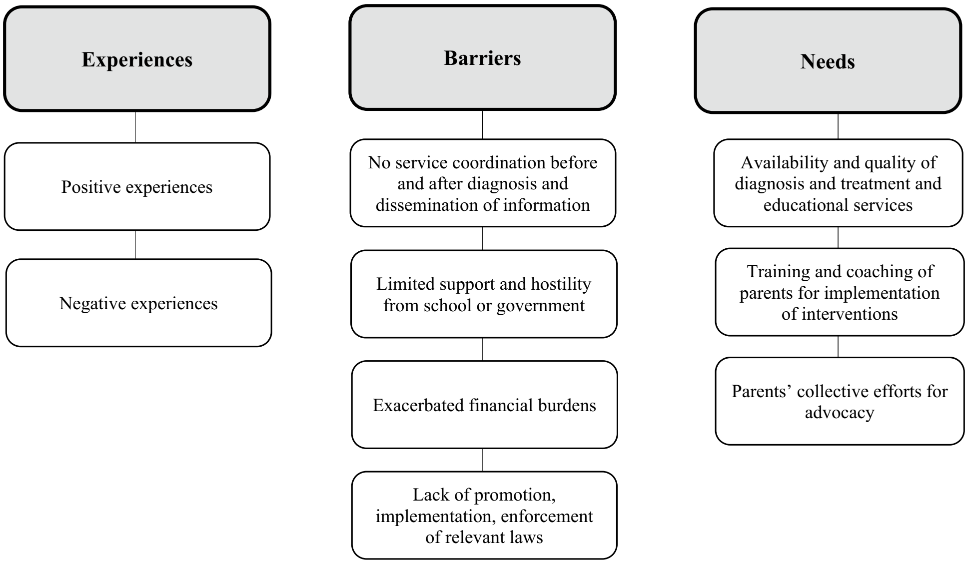

Fig. 1 Themes that emerged from the focus group discussions

Table 2 Additional sample quotes

Negative experience	Rejection and social isolation	"Our kids [with ASD] are not able to be a part of the society from the beginning... Whenever they start going to kindergarten or school, they become an outcast... They [schools] all rejected us and did not enroll my child. I begged them to try and told them if it is not feasible then we could privately hire a teaching assistant [just for him]" "She [social worker] asks, "Why do your windows have metal bars like prisons?" We live on the 9th floor and I have no control over my children. They climb up on windows and hang their legs from the windows. Then we took off all the door handles and screwed them in [for their safety]. So, we now live in a vacuumed place like an aquarium"
	Distrust of professionals and the government	"People in general, doctors, psychologists, special education teachers, they have very shallow understanding of what autism is... they are not educated and informed on that [autism]. You can't get any assistance in this area, so we have even talked about going to Russia or Korea for special education, because in Mongolia, you can't go for that, it's really not an option"
	Expectations of parents	"We should work with our children ourselves so that we have a clue about what our children are like, or what is needed from them... I think we should sacrifice everything, such as our jobs, to work with our children to avoid losing any time"
Barriers	Coordination of services and information	"While we get the information from the internet, this is impossible for the families who do not speak English. There is no information in Mongolian at all. English- or Russian- speaking families get the information and share with other parents. This is the only method we have"
	Limited support and hostility	"They really don't like the information [about the child's disability] getting spread to others... my grandma doesn't like it when I let my kid go outside... They talk as if my kid is going to get better [cured] as time goes on, or it's going to fix itself... they don't let the information go outside... they'll say their grandkid is a great child [to others]. If my closest circle can't understand, how are strangers going to understand?" "I was very hurt when municipal government people told me that my kid looked okay, so they just thought he did not need the aid. They also said that they would give me the financial aid up to 1 year and no more after that. They did not know that autism did not show up as a physical appearance. There are so many people like them out there working in government agencies. I think disbursing government aid in such a way should be prohibited in the law... We are pressured and threatened by these government workers who have no idea about autism. They know nothing. When they come to my place, their attitude is–like–we are trying to get free support or money from the government. What can we do? We face that kind of issue all the time" "They [school] kept calling me all the time and bothered me [to complain about the child's behavior at school]. I blocked the teacher's phone number because she kept calling me... Their attitude was not good"
	Exacerbated financial burdens	"200,000 or 300,000 Tugrik [Mongolian currency; approximately 110 USD a month] cannot really fulfill even the simple daily needs... If a kid attends any kindergarten, that alone costs 200,000 Tugrik. We are able to pay only half of that tuition fee with the money we receive from the government. That's it; there is nothing more than that"
Needs	More services for children	"We need enough professionals for all Mongolian children. There isn't anyone who is capable of teaching and treating our children even if we offer money. I have tried for many years, but there isn't any improvement. I just lose my money and time, so I thought I am the only one who can work with my child" "There are no professionals in Mongolia. We should prepare these professionals who can work with our children. When we see some people try to get some therapy, there are no professionals here. No one here is doing speech or physical therapy. Specifically, there is no ABA therapy. So, what we do is we watch YouTube channels and try to do it [ABA] by ourselves. We are not sure if we are doing it right or not, so we are losing lots of time. This is not right. The right professional people should guide us... We should prepare more professionals"

Table 2 (continued)

	Training and coaching for parents	"It's crucial that parents get trained. I want a training that is specific to me and my child. Since there's no opportunity for my child to get 4–5 h of therapy a day, I need help from an expert. If someone tells me what to do and how to do it, then we can all do it and take care of our children"

children with ASD. A few participants reported that other parents are often the only source of information and shared, "I get help only from other mothers." Some parents reported engaging in an online form of advocacy for each other. For example, one parent shared, "We opened a Facebook group and we share everything on it. We also help each other psychologically. We turned out to be a very big community, and we understand each other. That is a big support to us." Other parents mentioned that they provided advice to parents of newly diagnosed children with ASD about the things that they had gone through themselves. A parent of a boy with ASD shared, "I come to the NGO to provide advice to other parents; I also learn from them in return." Another mother stated, "I didn't have any information on how to communicate with my child. By getting involved, volunteering at my association, and sharing experiences with other moms, I gained more experience. Sometimes I am the teacher, sometimes I am the student." These data suggest that parents perceive interacting with other parents as a positive aspect of their lives.

Getting Help from the Parent-led NGO Another commonly reported positive experience was getting information and resources from the parent-led NGO. A mother reported, "I learned how to raise my child [with autism] from the classes taught and organized by the autism association." Similarly, a mother from a different focus group reported, "These associations are a big help for parents of newly diagnosed children with ASD, and these associations connect us and give us support, and we get lots of information, whereas we didn't get anything from the government." Another parent corroborated this by stating, "they [NGOs] provide lots of training sessions for the parents … They bring people from outside the country."

Schools' Help The last category within the positive experiences focused on interactions and success stories with schools and teachers. One parent shared that the private school offered her a discount for her son's tuition as they considered educating students with disabilities a "social responsibility," and enrolled both of her children with ASD there. This parent also shared that the teacher was helpful, "The teacher was very supportive, asking us how to interact with my son and what [she can do] to help him." A parent from a different group described her positive impressions of special education teachers when compared to general education teachers, because they "were trying to learn different types of therapies [for children with ASD]."

Negative Experiences

Although there were fortunately some positive aspects, Mongolian parents also reported some negative experiences of raising their children with ASD as expected.

Rejection and Social Isolation Parents reported social isolation of their children and their families caused by society's rejection of individuals with disabilities. The most commonly reported rejection and social isolation occurred at the children's schools. For example, one mother of a 6-year-old child reported that the administrators at her son's school said that he "should quit school" after a year of being enrolled, as he "would not fit there because he was extremely active." Another parent reported, "When I tried to enroll my child in kindergarten, they said 'if we can't work with your child, then it's impossible to continue'... I have never enrolled my child in a school." When attempting to enroll their children with ASD in general education settings, parents also reported having to deal with rejection from other parents in the class, possibly due to the stigma attached to disability. One parent reported, "parents of typically developing children are a major problem to us... they say that they paid to get into this kindergarten, so they don't want their children to be with children with 'problems.'" This negative experience also occurred in private, recreational settings. One parent of a girl with ASD shared that they tried to take their child to ballet, piano, or swimming classes, and they frequently heard negative comments from other parents. This parent stated, "Other parents approach us saying that, 'you know, we paid for this for my child. We would like our child to not be in the same class with this kind of child [with disabilities].'" Families also shared their experiences of isolation and stigmatization due to their children's problem behaviors. For example, one parent shared, "I'm afraid of going outside with my child... It became a big stress for me. Now, I try to avoid people because of the stress and pressure." A mother shared her sentiment about the social isolation of families due to a lack of support systems, "parents feel emotionally and physically lonely on this matter... We just assume ourselves as a minority group in the society, that we have no voice." This was corroborated by another parent who shared, "I don't have any friends. I only talk with parents like me or I don't talk with anyone when I go outside."

Distrust of Professionals and the Government Another negative experience reported by families was distrust of Mongolian schools, professionals, and the government on autism-related issues. Many parents across different focus groups reported a lack of autism-related knowledge of medical and school professionals. A parent reported that they could not trust the school due to their limited knowledge on autism and reported, "When we meet a teacher or an administrator and explain that our child has autism, they are like– 'what is that?' So, it makes it difficult to trust this person." Other parents reported their doubts about Mongolian doctors' ability to diagnose ASD and prescribe medication. For example, one parent said: "They said our son had to take this medication... I have no idea whether this is the correct medication to take. I have a hard time trusting them since they are known to prescribe the wrong drugs quite often." In response to this parent's comment, another parent said, "We must research and learn about the kinds of pills doctors are giving us." Some parents reported that they doubted the diagnoses given by Mongolian doctors, because they were considered "very inexperienced in autism," and parents also noted that they "have no place to go and no one to get advice from."

Expectations of Parents Many parents discussed the aggravated societal expectations of having to assume multiple roles, including the primary caregiver and the child's teacher, due to Mongolia's limited infrastructure. These expectations led to negative experiences, as many parents reported that they had to quit their jobs once their child was diagnosed with autism. One parent reported, "When he got into first grade, I had to quit my job due to the fear of him being left behind his classmates academically." Another parent shared that it is the parent's responsibility to learn how to educate their child due to limited available support. She shared, "This is something we have to do ourselves. The government cannot do it." Other parents noted that parents have to work with their children themselves due to services not being available for these children. Another parent shared, "Only one of the parents can work, and the other one has to be unemployed, forever taking care of their baby. We neither have the opportunity nor the time to work. Also, we cannot find a babysitter who can look after our children." A parent from a different group concurred and said, "Before, we both used to work and live a normal life. Then, we got the [autism] diagnosis. So, we needed to spend more time with my child, and I had to sacrifice my life." Another parent similarly shared, "My life shouldn't be sacrificed just because my kid has autism."

Barriers

The second identified theme was related to barriers perceived and reported by families, including the following categories: (a) no service coordination before and after diagnosis and dissemination of information; (b) limited support and hostility from schools or the government; (c) exacerbated financial burdens; and (d) a lack of promotion, implementation, or enforcement of relevant laws.

Coordination of Services and Information

Several families reported barriers related to not having centralized service coordination of diagnosis, treatment, and access to information. These barriers reportedly impeded parents' ability to get an early diagnosis and services, navigate the system, and access accurate information for their children. One parent stated, "There isn't a center dedicated for kids with disabilities in Mongolia. Or there isn't any opportunity for people to join different kinds of support groups or go to a therapist and ask for advice." Some parents also noted the lack of a governmental entity that is responsible for coordinating services for children with disabilities. Parents also focused on barriers related to the government's responsibility. For example, one parent reported, "The government should specifically classify what kinds of illnesses the hospital should address, and whether doctors in general should give advice about autism or only pediatricians should be focusing on autism... There is so much confusion."

Other parents reported barriers to accessing accurate information about autism. One parent who was also a teacher said: "Even though I work in the same field [of education], the information about that [autism] has not been accessible to me." Some parents discussed the limited and unreliable sources of information about autism. Mothers shared, "We surf through the internet as much as we can. We get all the information from the internet," and "Your only friend is Google." Although less common, a few parents noted that they only receive information about autism through TV shows. One parent shared her experience and said, "I have seen television broadcasting about autistic children and then found that my child has the same problems [symptoms]," which eventually led to the child's autism diagnosis.

Limited Support and Hostility

Parents frequently reported limited support and hostile attitudes at different levels, such as their own families, their children's schools, and the government. One parent shared how the stigma of disability affected their family: "They [other family members] are embarrassed [by the child's disability], or they don't know how to explain it to other people."

Other parents explained the barriers related to not receiving appropriate support and experiencing hostility from their children's schools. One parent shared her experiences with trying to include her child in the general education classroom, and she was asked, "Why don't you just go to a special education school–like–this is not for you, just go away. What is the problem?" Other parents shared similar experiences, "It was as if they [school] were telling me to get your crazy children out of here." This parent later stated that they transferred the child to another school because of these incidents. One parent shared her experience with including her child in the school and said, "My parents gave some extra money, bribery to this school. This is how you get accepted to the normal schools; otherwise, they are not going to accept our child."

Parents also pointed out the hostile attitudes of government workers. Many parents shared that there were limited resources that the government provided, such as, "From the government, we get a little welfare money, but other than that, we do not get anything else." Parents expected to receive some other types of support besides financial assistance, that did not happen. One parent reported, "The government doesn't have a plan dedicated to these kids [with disabilities]... the government doesn't have a good understanding of disability." Another parent shared her doubts about improvements within the government due to the local political climate: "They [government] can only do so much. I do not believe we could get good government support because our politics are not stable at this time."

Exacerbated Financial Burdens

Parents also discussed the exacerbated financial burden of raising a child with ASD in Mongolia. Related to the costs, one parent shared, "There aren't schools and therapies that are free to us. Everything requires money. It costs money to send them to school and get a home teacher," and "If we want to send them to something expensive, then there's no money…" Another parent similarly reported, "For an autistic child, as for the support for our child, it's all paid. We paid for it, paid for the assistance." Many parents also described the limited financial support they received from the government. Another financial barrier was caused by only one parent being able to work due to childrearing and the limited infrastructure to care for children with ASD. One parent reported, "One of us doesn't bring in income [due to childrearing]... To ensure a satisfying life for our children, there is financial hardship." Another parent from a different group noted, "I left my job to care [for my child] for about 5 or 6 years. Currently, I do not have any job other than taking care of my child."

Enforcement of Legislation

Another commonly reported barrier was the lack of implementation and enforcement of special education laws in Mongolia. Many parents expressed that the Mongolian laws that prohibit discrimination against students with disabilities in public schools are not well-promoted because these passed just recently. One parent shared, "If all the laws that passed work, it would be so useful to us." Another parent added "People who are supposed to implement these laws do not know anything about it. What changed in the law, and what happened? There is no knowledge on this thing." A parent shared their story about the lack of implementation of this law, "Even though equal treatment is written in law, it is not what we find in reality. The law in action does not match the law on the books." Another parent similarly shared, "Even though there is a law for these children, when parents come to kindergartens and schools to enroll their children, they usually reject these children."

Needs

The third identified theme was related to the parents' perceived needs and included: (a) the availability and quality of diagnosis and treatment and educational services, (b) training and coaching for parents, and (c) parent advocacy.

More Services for Children

Many parents across the five focus groups reported difficulties associated with obtaining an ASD diagnosis and accessing services and supports in Mongolia. One parent explained, "There isn't a reliable [place to get] diagnosis for autistic children." Another parent in a different group corroborated the perception: "The evaluation for autism diagnosis is very expensive, as autism is still new in Mongolia. We do not have any professionals. They used to diagnose these children as having schizophrenia; they didn't know about autism before." Because of the severely limited number of professionals who can diagnose ASD in Mongolia, many parents reported that they chose to go abroad to neighboring countries to receive diagnoses. In fact, over 30% of participants reported that they obtained their children's ASD diagnoses outside Mongolia. and that they had to travel to South Korea or China just to see a developmental pediatrician and get an ASD diagnosis. One parent shared, "When he was young, we went to so many places, but nobody could answer or provide a diagnosis [in Mongolia]. So, when we went to Korea; we could get a diagnosis."

In addition to the limited infrastructure for diagnosis, parents across different focus groups reported the dire need to have access to treatment options in Mongolia. One parent shared her concerns about her child's school: "There are

50, 60 students [in one classroom]. And teachers get paid very little... the hardest thing is that for the public school, we need more teachers." A parent from a different group also shared, "There are a few teachers who specialized in speech development, but the funny thing is they are not specialized in autistic children." Other parents also reported the need for other types of therapy services outside the school, with one parent noting that, "Therapist is the top priority." Some parents also shared their need for more specialized therapies, such as applied behavior analysis (ABA) services or speech therapy.

Training and Coaching for Parents

Due to the combination of a limited infrastructure and the expectation that parents be the primary caregivers and teachers, parents reported the need for training and coaching programs. One parent reported her experiences with some ABA training: "Just from a few [parent training] sessions, I learned so much. I used to not know what to do, and then I began to be like 'Ah, so this is what I'm supposed to do.'" Other parents similarly shared, "This type of support is the simplest; it doesn't cost anything and has the potential to save time." However, this need is also related to the lack of therapeutic or support systems for children with ASD in Mongolia.

Some parents also expressed their frustrations due to a lack of opportunities for training, "When I try to work with my child the way I imagined, my baby starts to yell, and we cannot understand each other." Other parents expressed the need for more sustainable efforts for disseminating knowledge from international specialists who are in Mongolia temporarily. One parent mentioned, "We attend these trainings when people sometimes come in [from overseas], but there is nothing more than this. These people eventually go back. So, my kids are losing lots of time between these trainings." Another parent explained:

> Since we are the parents, we have no choice but to work hard [with our children], but parents don't know what to do. We are not the professionals. When we are sick, we go and see the doctors. We do not search on Google or YouTube to see if we need medicine. We need professionals who are able to provide us with directions. We need exactly that.

Collective Parental Advocacy

Many parents reported that they recognized the fact that there were limitations in advocating for their children at school or in the society individually, and they described the need for collective parental advocacy. Parents shared, "I think parents can make changes happen through the NGOs and by voting and sharing their voices," and "If we want everything to change, then the only way is to think as a whole." This was corroborated by other parents in the same group who said, "We can come together because we share a common feeling," and "If we are on the same stage, same goal, then we can effect changes... If we combine together and then work in an organized way." Some parents also suggested the notion of legislative advocacy with government officials for school services. A mother stated, "I should be able to go to the municipal government and request [that they] provide a special education teacher assistant for my child." Another parent shared her thoughts on expanding services in Mongolia: "We as parents should submit a proposal to the government, requesting them to send a professional to get trained properly abroad, and that person needs to come here and train many parents." A mother corroborated by saying, "All parents who have children with autism should join together and talk to government agencies." Lastly, a mother suggested that it is necessary to increase awareness of autism through collective efforts, "Parents have to work [for better awareness]. We can't just sit and wait for the people to accept our kids. That's what we have to do." As such, it was clear that parents were willing to advocate for themselves and other parents in Mongolia.

Discussion

The purpose of this study was to examine the lived experience and perceived needs of parents of children with ASD in Mongolia, a novice group that is not commonly represented in autism research. We have followed established procedures and quality indicators for analyzing the qualitative data (Brantlinger et al. 2005) to represent the participants lived experiences. Findings revealed that while parents reported having some positive experiences, they generally shared more negative experiences about the services and supports they received. Parents also reported facing multiple barriers and needs related to raising children with ASD in Mongolia. Overall, parents' reports across aforementioned themes illustrate a fairly negative landscape for children with ASD and their families in Mongolia.

Some of these findings are consistent with reports from the literature, and some are unique to the Mongolian context and this study. For example, the reported negative parental experience is consistent with prior literature (Goedeke et al. 2019; Meadan et al. 2010), and it is consistent with some of the literature published in other LRS. For example, Divan et al. (2012) revealed similar findings of the impact on Indian families due to the multiple roles required of them, social isolation, changes in family dynamics, and problems with the healthcare system. In addition, the exacerbated financial hardship of raising a child with ASD has been well-described in the literature (e.g., Lavelle et al. 2014). This "double-barrier" of residing in a middle-income country and being a parent to a child with various medical needs and appointments (e.g., diagnosis and treatment) is a finding that is consistent with other LRS-related literature (e.g., An et al. 2018; Desai et al. 2012). In a study by Gona et al. (2016), Kenyan parents of children with ASD also reported similar challenges related to limited treatment opportunities and burdens of caring for their children without much social support. The expectation that parents be their children's primary caregivers and teachers, simultaneously, is another finding consistent with literature from LRS (An et al. 2020; Divan et al. 2012). Combined with the parents' reported needs for more training and coaching, it is presumed that parents have no choice but to assume many of these roles themselves in a LRS with limited professional services, which is also corroborated by existing literature (Guler et al. 2018).

More importantly, Mongolian caregivers in this study reported some unique perspectives of their experiences, barriers, and needs. For example, parents reported their positive experiences with parent-led NGOs and their perceptions of the relevant laws. In a survey, Ethiopian parents of children with developmental disorders reported talking to family and friends as a coping mechanism (Tilahun et al. 2016). However, it was not reported as an organized group movement. While there are some studies reporting some positives of parents of children with ASD (e.g., Ooi et al. 2016), these dimensions of the parents' lives may not be necessarily translated into developing evidence-based treatment for their children with ASD. For example, Ooi et al. (2016) reported that some parents reported being content and expressed unconditional love for their children with ASD, but many still hoped that their children would "outgrow" ASD or continue their development with proper treatment. The Mongolian parents in this study, however, provided with more specific positive aspects of their lives, including providing and receiving online support with other parents within the NGO. In addition, parents' perceptions of the laws also suggest that while there are legal grounds to prohibit discrimination against students with disabilities in schools, there is limited implementation, enforcement, or follow-through with laws. This may be applicable to other LRS given the international emphasis on inclusion of children with autism or other disabilities due to several international efforts (e.g., Salamanca Statement) or reports from the WHO (2012). These perspectives of Mongolian parents also highlight the limited implementation even with the law's existence. Subsequently, parents in this study also reported a need for collective advocacy, which is seldom reported in LRS-related autism literature (c.f., Ruparelia et al. 2016).

The findings from this study may be interpreted based on the aforementioned ecological subsystems. The barriers and needs reported by Mongolian parents were related across different subsystems. For example, at the microsystem level, parents reported barriers related to diagnosis and services for their children and limited treatment options in Mongolia. In the mesosystem, parents reported little interactions between the major stakeholders of child's development, including family, school, and government agencies, which may result in lack of service coordination and limited support system for families. In the exosystem, parents reported that while there were relevant laws, these were not implemented or enforced, and schools and government officials had little knowledge about the laws or how it pertains to including children with ASD in public education. In the macrosystem, there was a reported barrier related to societal, cultural beliefs and stigma toward disability, which likely contributed to the exacerbated responsibilities of parents and isolation of families. Furthermore, the need for parental collective advocacy was observed both in the mesosystem as it represents interactions between the child's microsystems (i.e. parents), and in the exosystem, which reflects the parents' attempt to improve the system not just for their own children but for others (See Fig. 2).

Limitations

As with any other study, this study presents some limitations. First, even though field notes were utilized and interpreters tried to keep the first author informed of what was being discussed during the four focus groups conducted in Mongolian, the first author might have not caught all the nuances due to cultural and linguistic differences. Unfortunately, the interpretation may have resulted in some errors in the process, and having an interpreter from the NGO has a potential to have affected the discussions. Although the first author shares a broad East Asian cultural heritage as the Mongolian participants, having a foreigner who does not speak Mongolian may have produced some reactivity effects during the discussions. Second, participants were recruited through a Mongolian NGO of parents of children with ASD. As seen in the participants' demographic information, 66.7% of the participants reported higher household monthly incomes than average Mongolians, and 90% of the participants reported receiving at least some college education. It is, therefore, possible that the sample in our study is not representative of all Mongolian parents of children with ASD, and that the participants' views were biased. When considering the reported difficulties of obtaining a diagnosis and the financial burden associated with it, it is also possible that lower-income Mongolian families and families who live in rural areas of Mongolia are beyond the reach of the NGOs and underrepresented.

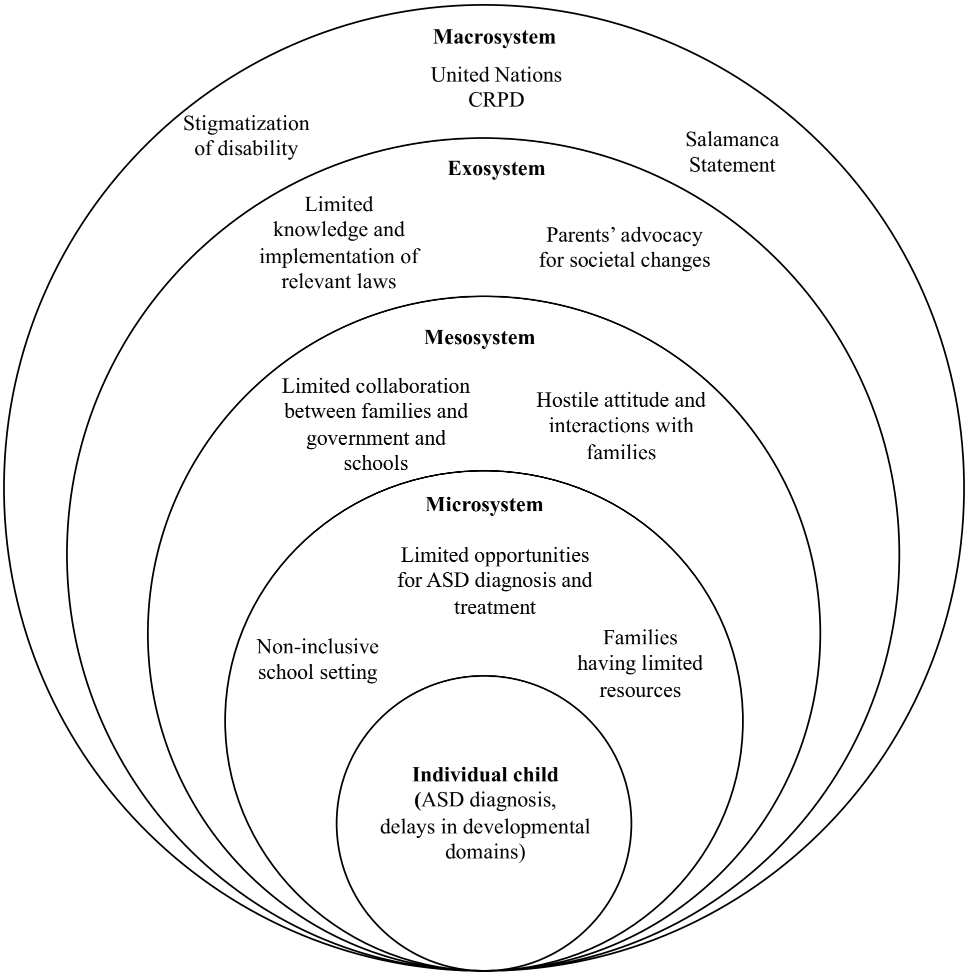

Fig. 2 Examples of ecological systems of a child with ASD in Mongolia

Implications

Notably, there are several implications for research and practice that align with some of the positive experiences reported by parents, which are interpreted based on the ecological subsystems (Bronfenbrenner 1979). First, as parents shared positive experiences about getting help by interacting with other parents of children with ASD, future research should examine the collective advocacy of parents and ways for parents to collaboratively and effectively help each other. Although some prior research (e.g., Burke and Sandman 2017) has examined the effectiveness of a parental advocacy program in the US, very little is known about parental legislative advocacy for their children with ASD in LRS. In addition, Mongolian parents from the current study repeatedly suggested that they should organize themselves to improve awareness of autism and effect societal changes. Therefore, more research is warranted to strengthen parental advocacy in LRS. Second, many participants described positive experiences of accessing information and resources with the help of parent-led NGOs and often described these organizations as the only source of support and information for them. This is consistent with the literature on other LRS (e.g., An et al. 2018), and more research is needed to strengthen the capacity of autism-related parent-NGOs to provide more services with local parents. From perspectives of mesosystem and exosystem, these NGOs help and interact with parents and would be able to reach out to more parents and effect larger, legislative changes to better the conditions for children of ASD and their families. Lastly, as parents reported the need for more training and coaching to deliver interventions themselves, future research must examine the effectiveness of such practices tailored for caregivers in LRS. Although the current literature (Divan et al. 2015; Lee and Meadan 2020; Reichow et al. 2013; WHO 2018) suggests that parent-mediated interventions may be feasible, acceptable, and effective in LRS, there have been no known efforts to disseminate treatment information to Mongolian parents.

Implications and recommendations for practice apply to different subsystems, and not just at individual children's levels. Most of the parent-reported barriers and needs identified in this study transcend the individual child's level, and span across the societal, macro level. This may imply that developing or adapting interventions in LRS should focus not only at the child's level; rather, they must take different subsystems into consideration. In addition, although this study was conducted in Mongolia and some phenomena are unique to Mongolia, some of the findings and implications may apply to other LRS. Moreover, the positive experiences and the reported needs of parents could be translated into practice to ensure acceptability and sustainability of potential interventions. Considering the increasing prevalence of ASD globally, it is imperative for researchers to listen to voices from the field and develop culturally relevant interventions in response to the low level of resources available to these stakeholders.

Acknowledgments There was no funding for this study. We express our sincere gratitude to Mongolian parents who shared their lives with us, and the Autism Association of Mongolia for its logistical assistance across all aspects of this study.

Author contributions Both authors contributed to the study conception and design. Material preparation and data collection were performed by JDL. The first draft of the manuscript was written by JDL, and HM commented on all versions of the manuscript and made revisions. All authors read and approved the final manuscript.

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