Social Science & Medicine 351 (2024) 116991

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Perceived discrimination among caregivers of children with disabilities in China: Unraveling the effects of social determinants

Ling Li Leng [a], Shixin Huang [b,*], Lin Gang Zhou [c,**]

[a] The Department of Sociology, Zhejiang University, Hangzhou, China
[b] Department of Applied Social Sciences, Hong Kong Polytechnic University, Hong Kong
[c] Center for Disability Studies, Shenzhen University, Shenzhen, China

ARTICLE INFO

Handling editor: Susan J. Elliott

ABSTRACT

Purpose: Although discrimination has gained increasing attention in research and practice intervention for family caregivers of children with disabilities, little is known about the social determinants that associate with the perceived discrimination among caregivers, especially in non-Western contexts. This study aims to examine the socio-familial and child-level determinants of perceived discrimination among family caregivers of children with disabilities in China.
Method: This study drew from a population-based cross-sectional survey in Shenzhen, China. Proportional quota sampling was conducted to get data from 2500 family caregivers of children with disabilities in rehabilitation service centers (response rate = 94.9%, n = 2373), accounting for 25% of the total population of children with disabilities receiving service in Shenzhen. Latent profile analysis was conducted to categorize three perceived discrimination groups among caregivers (i.e., severe perceived discrimination group, moderate perceived discrimination group, and low perceived discrimination group). The multinomial logistic regression models were conducted to test the association between these social determinants and perceived discrimination.
Results: Most caregivers (82.9%) reported moderate or severe levels of perceived discrimination. Caregivers of children with moderate and severe impairments and children with mental and multiple disabilities were more vulnerable to perceiving severe social discrimination. Socio-familial characteristics, particularly the intersectionality between gender and employment, influence caregivers' perceived discrimination.
Conclusion: Caregivers of children with disabilities experience pervasive social discrimination in contemporary urban China. Our study demonstrates that the social construction of disablism and the affiliate discrimination against family caregivers of children with disabilities is complex and multidimensional and depends upon the children's disability and the caregivers' socio-demographic characteristics.

1. Introduction

Approximately one in ten children aged 0–17 years, or 240 million children across the globe, have one or more forms of disability (UNICEF, 2021). In resource-limited international contexts such as China, health and social care systems for children with disability(CWD) and their families are largely underdeveloped, leaving them vulnerable to poverty, stigmatization, social exclusion, and poor health and well-being outcomes (Grech, 2019; Pan and Ye, 2015; Shang and Fisher, 2014). Parents of CWD play essential roles in nurturing the developmental needs and well-being of their children, particularly in contexts absent of health and social care services. Yet, they constantly experience directly or by proxy the discriminatory attitudes and practices on the basis of their children's disability (Ryan and Runswick-Cole, 2008). For example, a scoping review has indicated that the parents of children with physical disabilities endure negative attitudes, comments, and prejudice coming from other children and adults, and such discrimination is a significant social barrier for parents in undertaking CWD caregiving roles (Piškur et al., 2012). In response, discrimination has gained increasing attention in research and in prompting practical interventions for family caregivers of CWD, as a result of the paradigm shift in disability research from a biomedical model toward a social

---

* Corresponding author.
** Corresponding author.

E-mail addresses: 0021452@zju.edu.cn (L.L. Leng), daisy.huang@polyu.edu.hk (S. Huang), zhoulingang88@126.com (L.G. Zhou).

https://doi.org/10.1016/j.socscimed.2024.116991
Received 28 February 2024; Received in revised form 5 May 2024; Accepted 15 May 2024

model that addresses the attitudinal and environmental barriers that families of CWD face (Kröger, 2009; MacCarthaigh, 2020; Oliver and Barnes, 2010).

Perceived discrimination, defined as "the awareness of public stereotypes and discrimination experienced by members of a group" (Recio et al., 2020, p. 367), can adversely influence the health and well-being of parents of CWD. A recent study found that the perceived discrimination of family caregivers of children with developmental disabilities is positively associated with affiliate stigma, which in turn leads to a lower level of self-esteem among those caregivers (Recio et al., 2020). In addition to the negative influence that the perception of discrimination has on caregivers' psychological well-being, a meta-analysis has indicated that perceived discrimination is also negatively associated with physical health through triggering heightened stress responses and risky health behaviors (Pascoe and Richman, 2009). Furthermore, a variety of qualitative and mixed-methods research provides rich insights into the detrimental impacts of caregivers' perceived discrimination. Most noticeably, perceived discrimination results in social isolation and exclusion of family caregivers in many aspects of life such as interpersonal relationships, access and utilization of social services, recreational activities etc., which in turn exacerbate their emotional distress and quality of life in general (Aguerre et al., 2019; Ali et al., 2013; Green et al., 2005; Stanton-Chapman and Schmidt, 2019).

Although previous studies explored the health impacts of perceived discrimination among caregivers of CWD, they paid limited attention to unraveling the social determinants that predict the perception of discrimination among family caregivers of CWD. Whereas caregivers share a commonality in their performance of caregiving roles, their diverse social backgrounds and identities, in terms of gender, race, age, and socioeconomic status (SES), shape their caregiver outcomes differently—which is a largely understudied theme in informal care research, according to a recent scoping review (Hengelaar et al., 2023). The overlapping sociodemographic identities can create compounded forms of risk for parents of CWD and thus have implications for practitioners in child welfare (Flynn, 2021). In that light, understanding the relevant sociodemographic factors will enable a better understanding of the pathways that lead to perceived discrimination and its health impacts, as well as of the social construction and manifestation of the power structure that produces and reproduces discrimination (Stuber et al., 2008) against caregivers and the CWD for whom they care.

Preliminary findings from a few qualitative studies on caregivers' perceived discrimination, in conjunction with quantitative research on the predictors of affiliate stigma, suggest that there may be two strands of social determinants—parent-level determinants and child-level determinants—that underlie caregivers' perception of discrimination. To the best of our knowledge, no quantitative study has drawn from representative data dedicated to investigating the social determinants of perceived discrimination among family caregivers of CWD, although a few qualitative studies have provided preliminary evidence about the implications of caregiver characteristics on such discrimination. Gender is the most common caregiver characteristic that has been shown to influence the perception of discrimination in these studies, as mothers are more often blamed for giving birth to and failing to properly raise their CWD due to the gendered role in the distribution of caring responsibilities (Frederick, 2017; Gray, 2002; Green, 2007; Knight, 2013). Other parent-level factors identified were pertinent to caregivers' SES, such as marital status, education attainment, employment, and household incomes. Yet, the intersectional impacts of these social factors on caregivers' vulnerability to social discrimination remain uninvestigated. Moreover, existing qualitative studies also suggest that child-level characteristics, including sex, age, and the type and severity of the child's disability, might lead to divergent perceptions of discrimination among caregivers. For example, a study on the parents of children with cerebral palsy found that barriers to physical accessibility were the primary source of discrimination perceived by those caregivers (Vadivelan et al., 2020). The perception of discrimination for parents of children with autism can vary from those of children with physical disabilities, because the atypical and challenging behaviors of autistic children can lead to perceived discrimination at the interpersonal level for caregivers, according to a meta-synthesis of qualitative studies (Shorey et al., 2020).

In addition to the exploratory qualitative evidence, several studies have reported parent-level and child-level determinants of affiliate stigma among caregivers of CWD (Chiu et al., 2013; Lovell and A. Wetherell, 2018; Tilahun et al., 2016; Zhou et al., 2018). Affiliate stigma refers to the individual's internalization of a socially discredited identity, which is a caregiver outcome related to discrimination (Goffman, 1963; Mak and Cheung, 2008). Discrimination and affiliate stigma are interrelated social processes that both uncover the manifestation of unequal power systems such as disability, gender, race etc. (Stuber et al., 2008). Yet perceived discrimination stresses on individual's evaluation of unfavorable *external* treatment at the interpersonal, societal, and structural levels rather than individual's *internal* identity formation (Liamputtong and Rice, 2021), and thereby is usually studied as an antecedent of affiliate stigma (Recio et al., 2020). The evidence about affiliate stigma thus may inform our understanding of perceived discrimination. For example, Lovell and A. Wetherell (2018) found that the relationship status of caregivers (i.e., partnered or single) was a significant predictor of affiliate stigma among caregivers of children with autism. Interestingly, their findings did not support other parent-level characteristics, including gender, age, and employment status as determinants of affiliate stigma. Among other investigations, an earlier study on caregivers of children with intellectual disabilities in China found that age was negatively associated with the behavioral dimension of affiliate stigma, while SES was also negatively associated with affiliate stigma (Chiu et al., 2013). Kwok et al. (2014) studied mothers of preschool children with autism and/or intellectual disabilities in Hong Kong and found that mothers of children with autism showed more significant stigma than the mothers of children with intellectual disabilities did. Yang (2015) similarly found that SES was negatively associated with affiliate stigma, while children with prenatal developed intellectual disabilities were significantly related to the affiliate stigma of their caregivers in China.

In summary, while emerging findings suggest that parent- and child-level characteristics, such as gender, SES, employment status, the child's disability type, and related factors, may be social determinants of perceived discrimination among caregivers of CWD, their conclusions have been inconsistent. The ambiguity of evidence is also attributed to the fact that most of the existing studies in that subject area adopted qualitative methods, and quantitative evidence is lacking except in studies that have explored the predictors of affiliate stigma. Moreover, the existing studies on affiliate stigma have only focused on the parents of children with intellectual and developmental disabilities, and we lack a comprehensive exploration of how child-level variations, and particularly the children's age, disability types, and severities, may influence their parents' perception of discrimination. To address the limitations of prior literature, the primary objective of this study was therefore to examine the socio-familial and child-level determinants of perceived discrimination among family caregivers of CWD, with a specific focus on China.

Exploring the social determinants of the discrimination experienced by caregivers of CWD in the sociocultural context of China will have implications on the theoretical and practical understanding of discrimination and health equity in the international contexts and beyond.

1.1. Family care of children with disabilities in China

The case of China provides an invaluable opportunity to delve into the perceived discrimination of caregivers of CWD in resource-limited and cross-cultural settings. In China, where the world's largest population of people with disabilities reside (i.e., 86 million), the latest national sample survey statistics shows that there are approximately 5 million CWD under 15 years old (National Bureau of Statistics, 2006). In the Chinese context, an array of intersectional economic and socio-cultural factors has profoundly influenced family caregivers of CWD, which in turn guided us to develop research hypothesis about child- and parent-level determinants of caregivers' perceived discrimination.

Disability has been socially constructed as a diminished social category affecting the whole family historically and contemporarily in China. Whereas disability is stigmatized as an individual deficit in Western societies, body-mind impairments are perceived as "a family affair and a lineage tragedy" in China (Stone, 1998, p. 71). Within the Chinese sociocultural context, disability in a child may lead to "a loss of face for the family as a whole" (Chiu et al., 2013, p. 9). In addition to perceiving discrimination from the public, Chinese parents have often reported being marginalized by their families because of the cultural belief that having a CWD is bad karma or ancestral punishment (Feaster and Franzen, 2021; Yang, 2015). In contemporary Chinese society, the national discourses of family's responsibilities in cultivating children into citizens with human capital (suzhi), further shaped the society's discriminatory attitudes towards disability as an unproductive and undesirable social category, and parents of CWD who fail to raise healthy children as incompetent and failing parents, especially for mothers (Wu, 2020). Because of the interweaving relationships between children's disability and the moral standing of their family caregivers in Chinese society, we hypothesize that.

H1. The nature of the child's disability (e.g., severity, types, sex, age) will influence parent' perception of discrimination.

In addition to these child-level factors, a number of factors manifested at the parent-level may be relevant to shape parents' perception of discrimination in China. Like family caregivers in other Global South countries, Chinese parents of CWD are particularly influenced by economic vulnerabilities and gender inequality. In the Global South contexts, the vicious cycle of disability and poverty can affect the whole family and transform them into "disabled families" (Grech, 2019). In China, families of CWD are among one of the most economically deprived and socially excluded groups. In 2018, the average income of an individual in disability household was 16,112 Chinese dollars (equivalent to about $2225), which was only 57% of the national average income (i.e., 28,228 Chinese dollars, equivalent to $3898), and 38.4% disability household live under poverty (Li et al., 2020).

Within the family unit, mother tends to be more vulnerable to the influence of discrimination towards CWD as well as impoverishment. In the patrilineal culture of China, the children's disability is widely seen to be coming from the mother's body and therefore cast extra shadow on the mother's moral standing (Wu, 2020). In addition, the gendered nature of care compounds with the inadequacy of social support services in China, making mothers of CWD bear significantly higher burden of care at the expense of their career compared to other male members of the family (Huang et al., 2023).

As such, these unique socio-cultural and economic factors manifested at the parent-level may contributed to the social exclusion and inequality of parents of CWD and engender perception of discrimination. We therefore develop the second research hypothesis.

H2. Socio-familial characteristics of parents (i.e., relationship with the child, marital status, employment status, financial status, migrant status, residence status) will influence their perception of discrimination.

2. Methods

2.1. Setting

This study was conducted in Shenzhen, the third most populous metropolis by urban population in mainland China, following Shanghai and Beijing. The city had a population of 17.7 million in 2021. Shenzhen is a young city, with residents aged 15–59 accounting for 79.3% of the population, 16.2% higher than the national average (Bureau of Statistics of Shenzhen Municipality, 2021). CWD represent 17.4% of all persons with disabilities in Shenzhen, a number that is much higher than the national rate of 6.4% (Li et al., 2020).

The Shenzhen Disabled Persons' Federation has designated 166 rehabilitation organizations as qualified to provide rehabilitation services for people with disabilities (China Disabled Person's Federation Shenzhen, 2019). These organizations include rehabilitation centers, special or general education institutions, child welfare institutions, and medical institutions. The local government offers subsidies for families of CWD to use toward the rehabilitation services provided by the designated organizations. Local CWD and their families are eligible to apply for the subsidies if they have medical records dated within one year of the application and with confirming diagnoses issued by clinicians in authorized hospitals.

2.2. Study design and participants

We conducted a population-based cross-sectional survey in Shenzhen from July to October 2021 as part of a larger investigation to critically review the services and management of all the rehabilitation organizations for individuals with disabilities in the city. The total number of CWD receiving rehabilitation services at the designated organizations in Shenzhen in 2021 was 10,015, according to the data provided by the Shenzhen Disabled Persons' Federation. The study aimed to sample 25% of the children receiving rehabilitation services at these organizations, with approximately 2500 participants. The participants were recruited using proportional quota sampling, and the quota for each designated organization was set according to their total number of service users.

After calculating the sampling quota for each designated organization, a research assistant (RA) randomly selected individuals from each organization's service user list (CWD aged <18) according to the disability ratio of the service users in that particular organization by using block sampling. Then, a team of RAs delivered an online questionnaire to each selected service user's primary caregivers through a WeChat/Email/Text message. The RAs also provided guidance and assistance during the questionnaire-filling process. We surveyed 2500 caregivers for the investigation, and 2373 questionnaires were valid (response rate = 94.9%). Fig. 1 depicts the recruitment process. Written informed consent was obtained from all respondents. The study obtained approval from the Ethics Committee of one of the corresponding authors' affiliated institutions.

2.3. Measures

2.3.1. Perceived discrimination

Perceived discrimination was measured by the aggregate of four items reflecting the caregiver's perception of discrimination resulting from his/her child's disability. The four-item scale measured both personal-level and group-level discrimination generally experienced daily. We adopted the conceptualization of perceived discrimination from the Multidimensional Perceived Discrimination Scale (MPDS), which categorized perceived discrimination into two dimensions, including individual and group perceived discrimination (Molero et al., 2013). The individual perceived discrimination measures the perception of being personally discriminated against, whereas the group perceived discrimination measures the extent to which caregivers perceive discrimination towards the disability group. A panel of experts in disability studies developed the current scale with reference to the MPDS. Conciseness of the scale was prioritized to reduce the respondent's burden and ensure response quality because the scale was among a list of other measurements. Participants were asked to indicate their agreement with the following statements on a five-point Likert scale—two statements that assessed personal discrimination: "In daily life, because of my child's disability, I often suffer from all kinds of

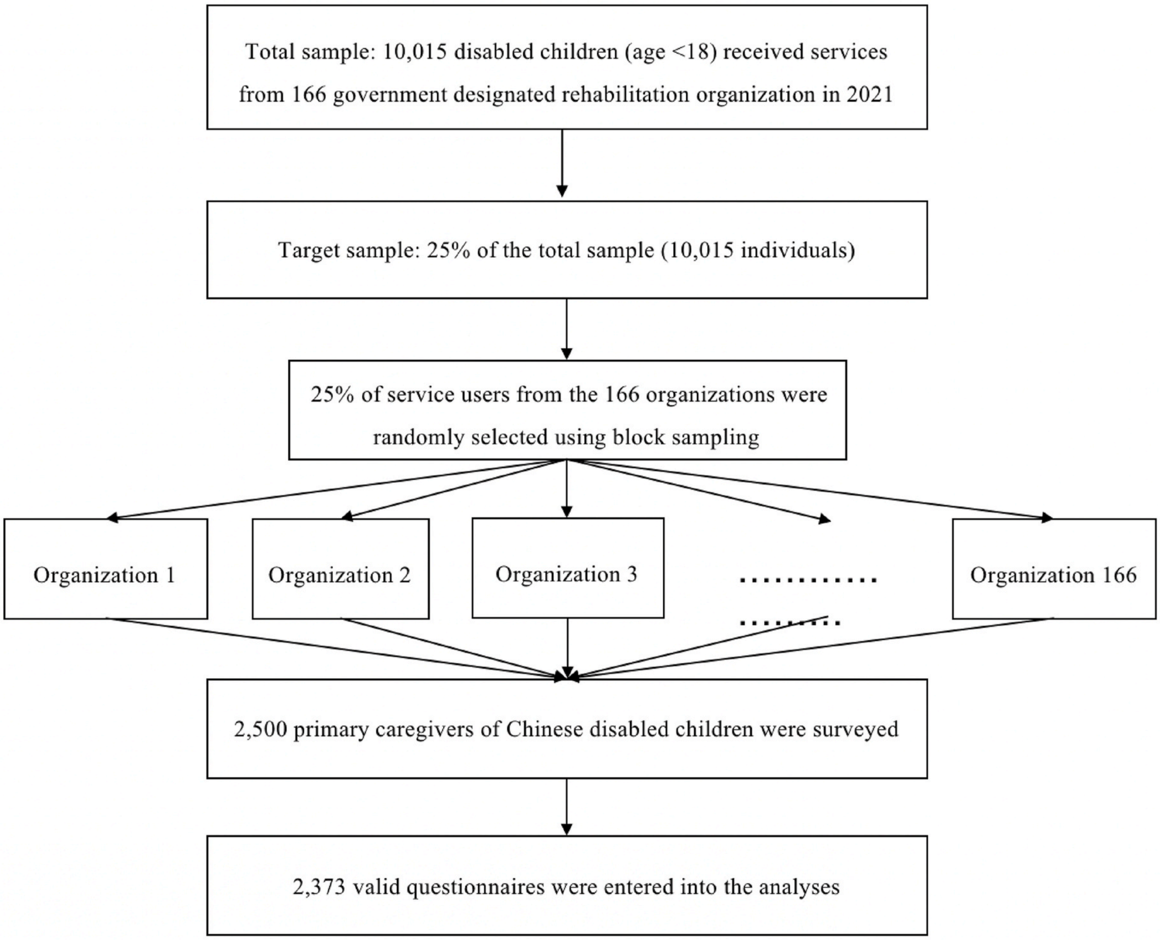

Fig. 1. Participant recruitment process.

exclusion," and "Because of my child's disability, people often look at me differently," and also two statements that assessed group discrimination: "Discrimination against children with disabilities is severe," and "The problem of children with disabilities is rooted in social exclusion." The responses ranged from 1 (strongly disagree) to 5 (strongly agree). The sum of the four items was used to measure caregivers' perceived discrimination, with a higher score indicating more severe discrimination. The Cronbach's alpha for the four-item measure was 0.87, thus demonstrating high internal reliability.

2.3.2. *The children's characteristics*

In the survey, each caregiver was asked to self-declare the sex and age of the CWD. They were also asked to specify their child's clinical conditions, including the age at disability diagnosis, disability type, and disability severity. Disability in China is conceptualized as one or more abnormalities in the anatomical structure, or the loss of a particular organ or function (either physical or psychological) affecting an individual's ability to perform a regular activity and to participate fully in social life. Disability is further defined and categorized using the medical models of specific disabilities, including vision disability, hearing disability, speech disability, physical disability, intellectual disability, mental disability, and multiple disabilities.

Disability severity was measured on the basis of the caregiver's self-report of the child's disability diagnosis and disability severity grading. In mainland China, children with medical records of disability diagnosis are graded into different impairment levels by the local authorized medical institutions. After making the disability diagnosis according to the Chinese National Standard of Classification and Grading Criteria of Disability (CGCD) (GT/T26341-2010), medical professionals classify CWD into four levels. Disability severity grading is an indispensable index associated with the level of rehabilitation subsidy the family can receive from the local government. The four severity levels are: very severe, severe, moderate, and mild. The disability severity rating evaluation cannot be performed on children under two years of age for mental disability and on children under three years of age for hearing and speech disability. Specifically, mental disability severity is rated on the basis of the degree of impairment in adaptive behaviors using the Infant-Junior Middle School Students Social-Life Abilities Scale. The grading of intellectual disability is based on the evaluation of the developmental quotient for children <6 years using the revised version of Gesell Developmental Schedules, and the intellectual quotient for those >6 years as measured by the Wechsler Intelligence Scale for children (Ministry of Civil Affairs of the People's Republic of China, 2011).

2.3.3. *Socio-familial characteristics*

The socio-familial characteristics assessed in this study were the caregiver's relationship with the child, parental marital status, parental employment status, caregiver's educational attainment, the monthly family income, the family's basic living allowance, the migrant status of the caregiver, and the urbanity of the residence.

2.4. *Statistical analyses*

We summarized the sample characteristics using the mean (with standard deviation) for continuous variables and frequencies (%) for categorical variables. Latent profile analysis (LPA) was conducted to identify the symptom characteristics of perceived discrimination among the participant caregivers of CWD. Latent profile analysis is a person-centered statistical method that employs latent profile models (LPMs) to identify and categorize latent subpopulations within a population, using a set of continuous variables. We assessed the model fit between models with *k* classes and *k*–1 classes by using the bootstrap likelihood ratio test (BLRT), with significant *p*-values implying a better model fit with *k* classes. The optimal number of classes was evaluated by the entropy, Akaike Information Criterion (AIC), and Bayesian Information Criterion (BIC). An entropy value ≥ 0.80 represents adequate quality of classification. Because lower AIC and BIC indicates a better model fit of *k* latent classes of perceived discrimination, we selected the number of perceived discrimination classes associated with minimal AIC and BIC values.

After selecting the optimal latent classes model, we conducted bivariate and univariate analyses to detect child and socio-familial differences in different classifications of perceived discrimination, using an analysis of variance (ANOVA) for the continuous variables (i.e., age and age at diagnosis) and a Chi-square test for categorical variables (i.e., gender, age by interval, disability severity, disability types, the caregiver's relationship with the child, parental marital status, parental employment status, the caregiver's educational attainment, monthly family income, migrant status of the caregiver, and the urbanity of the place of residence). We entered statistically significant dependent variables into a stepwise multinomial logistic regression model as candidate predictors, in order to assess their associations with different latent classes of perceived discrimination. Likelihood ratio tests were computed to examine the contribution of the effect of each candidate predictor. Significant candidate predictors (i.e., disability severity, disability type, caregiver's relationship with the child, and parental employment) were retained in the final regression model, with adjusted odds ratio (AOR) and confidence intervals (95% CI) calculated to indicate the parameter estimates. In a multinomial logistic regression model, we also assessed the interaction effects of the caregiver's relationship with the child and parental employment on the caregiver's perception of discrimination. All statistical analyses were performed using the statistical software R, version 4.3.1, with the level of significance determined at a 0.05 value of *p*.

3. Results

3.1. Characteristics of the study sample

The study sample comprised 2373 primary caregivers of Chinese CWD (with each caregiver reporting on one child). The majority of the children (71.6%) were boys. Their average age was 6.6 ± 3.8 years, with preschool children (3–6 years old; 39.9%) and school-aged children (6–12 years old; 31.7%) accounting for the highest proportion of the sample. Approximately half of the children (48%) were diagnosed with mental disability, whereas children with physical disability made up the smallest percentage (5.1%) of the total sample. The majority were diagnosed as either severely disabled (45.9%) or moderately disabled (21.6%), whereas 19.8% had not had their disability severity graded. On average, the children of the present sample were diagnosed with a disability at age 2.0 ± 1.6 years (see Table 1).

In terms of socio-familial characteristics, most of the CWD were cared for by their mothers (78.5%), and the rest by their fathers (19.3%). The majority of the caregiver parents were married (93.3%). The study's caregivers were relatively well-educated, with 68.8% having obtained a junior college education or above, compared with a rate of 31.3% for the general population of Shenzhen (Bureau of Statistics of Shenzhen Municipality, 2021). Although the percentages of caregivers with a high school degree were similar to the proportion in the general population, our sample had a lower rate of caregivers with middle school and below education (8.2%) than the general population (46.0%). In most surveyed families, only one parent was working (60.3%), and in 11.2% of the families both parents were unemployed. Only one-third of the mothers

Table 1
Children's and socio-familial characteristics of the sample, by classification of the caregiver's perceived discrimination.

Variables	Total sample $N = 2373$	Caregiver's perceived discrimination			
		Class 1: Severe $n = 885$	Class 2: Moderate $n = 1082$	Class 3: Low $n = 406$	χ^2/*F*-test[a]
Children's characteristics					
Sex					0.8
Boys	71.6% (1699)	72.5% (642)	70.7% (765)	71.9% (292)	
Girls	28.4% (674)	27.5% (243)	29.3% (317)	28.1% (114)	
Age, years: Mean (SD)	6.6 (3.8)	7.1 (3.7)	6.5 (3.7)	5.9 (3.9)	14.5***
Age by interval, years					49.0***
≤3.0	18.6% (441)	14.2% (125)	18.6 % (202)	28.6% (116)	
3.1–6.0	39.9% (947)	38.2% (337)	42.1% (455)	37.7% (153)	
6.1–12.0	31.7% (752)	36.8% (326)	29.8% (322)	25.6% (104)	
12.1–18.0	9.8% (233)	10.9% (97)	9.5 % (103)	8.1% (33)	
Age at diagnosis, years: Mean (SD)	2.3 (1.6)	2.4 (1.7)	2.3 (1.5)	2.2 (1.6)	3.4*
Disability severity					53.2***
Very severe	20.4% (485)	20.1% (178)	20.8% (225)	20.2% (82)	
Severe	25.5% (605)	28.9% (256)	25.3% (274)	18.5% (75)	
Moderate	21.6% (512)	24.0% (212)	21.9% (237)	15.5% (63)	
Mild	12.7% (302)	11.1% (98)	12.7% (137)	16.5% (67)	
Unrated	19.8% (469)	15.9% (141)	19.3% (209)	29.3% (119)	
Disability types					136.9***
Physical disability	5.1% (120)	2.9% (26)	4.9% (53)	10.1% (41)	
Vision, hearing, & speech disability	13.0% (308)	5.6% (50)	14.9% (161)	23.9% (97)	
Intellectual disability	15.8% (375)	17.1% (151)	14.2% (154)	17.2% (70)	
Mental disability	48.0% (1138)	53.8% (476)	47.8% (517)	35.7% (145)	
Multiple disabilities	18.2% (432)	20.6% (182)	18.2% (197)	13.1% (53)	
Socio-familial characteristics					
Primary Caregiver					13.6***
Father	19.3% (458)	15.7% (139)	20.6% (223)	21.1% (86)	
Mother	80.7% (1915)	84.3% (746)	79.4% (859)	76.2% (309)	
Parental marital status					3.3
Married	93.3% (2214)	92.8% (821)	93.0% (1006)	95.3% (387)	
Divorced/ separated/ widowed	6.1% (145)	6.7% (59)	6.4% (69)	4.2% (17)	
Never married	0.6% (14)	0.6% (5)	0.6% (7)	0.5% (2)	
Educational attainment, primary caregiver					10.4
Middle school and below	8.2% (194)	10.2% (90)	6.2% (67)	9.1% (37)	
High school	18.7% (444)	19.4% (172)	18.2% (197)	18.5% (75)	
Junior college	33.3% (791)	32.2% (285)	34.6% (374)	32.5% (132)	

(*continued on next page*)

Table 1 (*continued*)

Variables	Total sample $N =$ 2373	Caregiver's perceived discrimination			
		Class 1: Severe $n = 885$	Class 2: Moderate $n = 1082$	Class 3: Low $n = 406$	χ^2/*F*-test[a]
College and above	39.8% (944)	38.1% (338)	40.0% (444)	39.9% (162)	
Parental employment					32.5***
Both parents working	28.6% (265)	23.8% (101)	28.7% (125)	38.4% (39)	
One parent working, Mother	5.1% (120)	4.7% (42)	5.0% (54)	5.9% (24)	
One parent working, Father	55.2% (1310)	60.0% (531)	54.7% (592)	46.1% (187)	
Both unemployed	11.2% (678)	11.4% (211)	11.6% (311)	9.6% (156)	
Monthly household income (RMB)					32.5**
< ¥5000	18.0% (427)	22.1% (196)	15.9% (172)	14.5% (59)	
¥5000–9999	42.0% (997)	43.1% (381)	42.1% (456)	39.4% (160)	
¥10,000–19,999	25.9% (615)	22.1% (196)	28.1% (304)	28.3% (115)	
¥20,000–29,999	7.3% (173)	6.4% (57)	7.1% (77)	9.6% (39)	
¥30,000–49,000	4.7% (111)	4.0% (35)	5.0% (54)	5.4% (22)	
≥ ¥50,000	2.1% (50)	2.3% (20)	1.8% (19)	2.7% (11)	
Basic living allowance	3.5% (84)	3.5% (31)	3.5% (38)	3.7% (15)	0.03
Migrant resident (by household registration)	8.6% (204)	9.4% (83)	7.9% (85)	9.1% (37)	1.6
Place of residence					1.8
Central urban	63.5% (1489)	64.2% (559)	62.2% (667)	65.6% (263)	
Peripheral urban	36.5% (856)	35.8% (312)	37.8% (406)	34.4% (138)	

Notes.

[*] $p < .05$.

[**] $p <. 01$.

[***] $p < .001$ (2-tailed tests).

[a] $\chi^2$for the categorical variables and Analysis of variance *F*-test for the continuous variable.

of CWD (33.7%) were working outside the family, in contrast to the high female labor force participation rate of 75.5% in Shenzhen (Bureau of Statistics of Shenzhen Municipality, 2017). More than half of families (60.0%) had a monthly income below ¥10,000, and in particular, 18.0% had a monthly family income below ¥5000, which was lower than the average monthly income for individuals in Shenzhen (¥7103– ¥12,963) and only slightly higher than the city's minimum living standard of ¥3900 per month for a household of three in 2021 (Bureau of Statistics of Shenzhen Municipality, 2022). The majority of the caregivers held a local household registration (91.4%), while just under one-tenth (8.6%) were migrant residents. The percentage of participants' households receiving a minimum living allowance from the government was 3.5%, more than 20 times greater than the ratio in Shenzhen among all residents in 2021 (0.17%; $n = 2988$) (Bureau of Statistics of Shenzhen Municipality, 2022). Most families lived in the central urban areas of Shenzhen (74.2%).

3.2. *Perceived discrimination by latent class analysis*

Overall, the mean score of perceived discrimination was 13.3 ± 3.9, with a median score of 13 (inter-quartile: 11–16). About 8% of the caregivers (8.3%, $n = 196$) strongly endorsed (score = 5) all four discrimination experiences on the scale. Of the item-wise responses, 64.1% ($n = 1521$) of the caregivers agreed at least somewhat (score ≥3) with the personal discrimination experience "Because of my child's disability, I often suffer from all kinds of exclusion"), and 75.5% ($n = 1792$) agreed with the statement "Because of my child's disability, people often look at me differently"). More than 80% of the caregivers (83.8%, $n = 1989$) indicated at least some agreement (score ≥3) with the group discrimination experience described as "Discrimination against children with disabilities is serious," and 71.0% ($n = 1685$) endorsed the statement "The problem of children with disabilities is rooted in social exclusion."

To further identify the patterns of perceived discrimination, an LPA with a three-class solution was established as the optimal model, based on prespecified fit indices (see Supplementary Table S1). The BLRT test of the three-class model was statistically significant, with entropies above 0.80. The AIC and BIC values decreased with increases in class numbers. Fig. 2 shows the distribution and conditional means of each item of the perceived discrimination scale in the three-class model. In the three-class model, the average latent class probabilities for most likely latent class membership (0.96, 0.92, and 0.89) demonstrate reasonable classification and good distinction (see Supplementary Table S2).

Given the conditional means of items in each class, we defined Class 1 ($n = 885$) as the "severe perceived discrimination group," accounting for more than one-third of the sample (37.3%). This group was characterized by the caregivers' endorsement of all four social discrimination experiences in their daily life, with their responses ranging from "agree" to "strongly agree" across the four scale items. Class 2 ($n = 1082$) was labeled the "moderate perceived discrimination group" and represented just under half of the sample (45.6%). Caregivers in this group, on average, indicated some agreement with the study's designated social discrimination experiences, with their responses ranging from "disagree" to "agree" across the four scale items, thus suggesting some exposure to social discrimination. Class 3 ($n = 406$) was defined as the "low perceived discrimination group" and comprised approximately one-sixth of the sample (17.1%). This group was identified by the caregivers disagreeing with all four of the social discrimination experiences that were described, with their responses ranging from "strongly disagree" to "somewhat agree" across the four scale items, thus implying a minimum level of having experienced social discrimination associated with their CWD.

3.3. *Associations between different latent classes on perceived discrimination and child- and socio-familial characteristics*

Differences in the children's characteristics and the socio-familial characteristics across the latent classes are presented in Table 1. In terms of the children's characteristics, there were significant differences in their age ($F = 14.5$, $p < 0.001$), their age at diagnosis ($F = 3.4$, $p < 0.05$), the severity of their disability ($\chi^2 = 53.2$, $p < 0.001$), and their types of disability ($\chi^2 = 136.9$, $p < 0.001$). Specifically, children of caregivers in the severe-perceived-discrimination group were the oldest in biological age (mean = 7.1 ± 3.7 years) and age at diagnosis (mean = 2.4 ± 1.7 years), had the highest percentages of severe disability (28.9%) or moderate disability (24.0%), and had the greatest rates of multiple disabilities (20.6%) and mental disability (53.8%), compared with the moderate-perceived-discrimination group and the low-perceived-discrimination group. The three latent classes of perceived discrimination also differed significantly in their socio-familial characteristics, including the caregiver's relationship to the child ($\chi^2 = 13.6$, $p < 0.001$), caregiver's educational attainment ($\chi^2 = 18.0$, $p < 0.05$), parental employment ($\chi^2 = 32.5$, $p < 0.001$), and monthly family income ($\chi^2 = 32.5$, $p < 0.01$). Compared with the two other groups, Class 1, the severe-perceived-discrimination group, had the highest proportion of caregivers who were mothers (84.3 %), of those who had only a middle school or below education (10.2%) or a high school degree

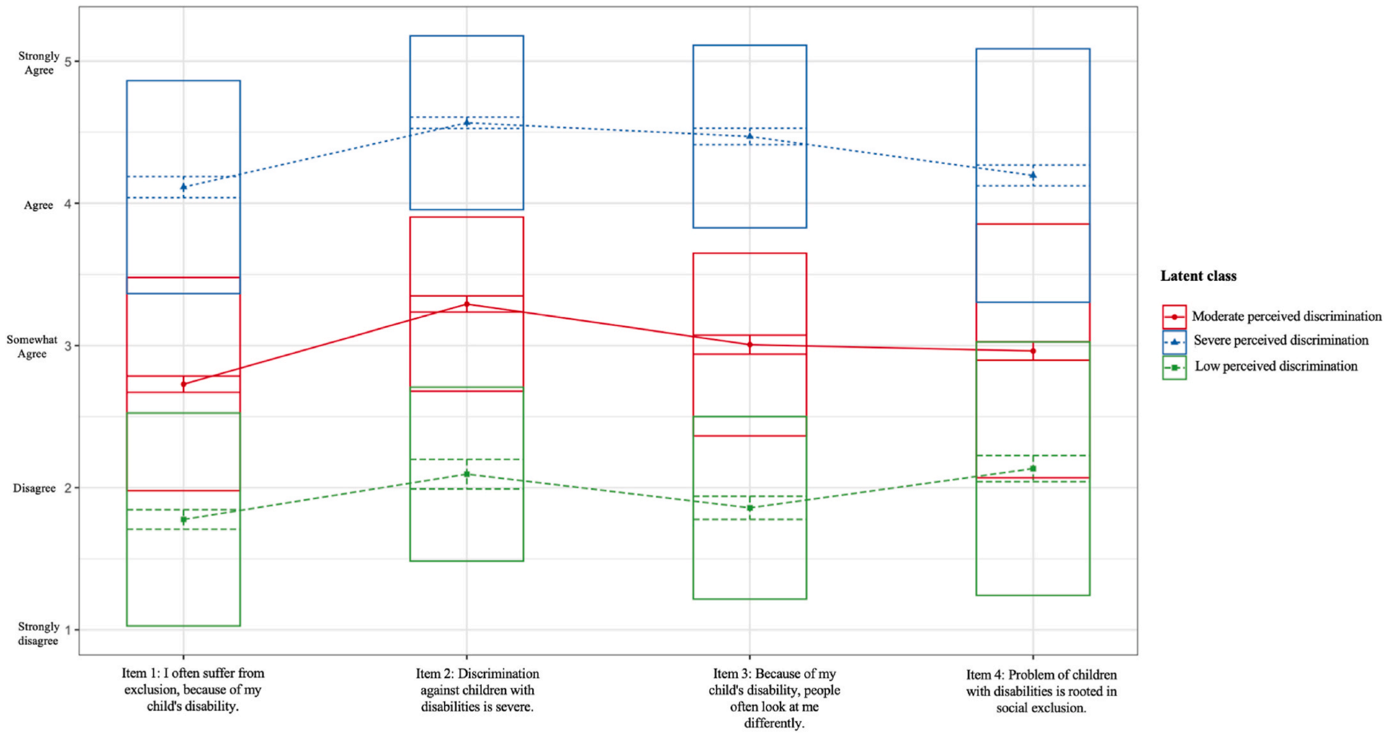

Fig. 2. The three classes of caregiver's perceived discrimination, based on the best-fitting three-class model.

(19.4%), and of families in which only the father was employed (60.0%) and the monthly family income was below ¥5000 (22.1%).

In the final multinomial logistic regression analysis, four of the variables that were retained in the model were significantly associated with membership in one of the three perceived discrimination groups (See Table 2). Those variables were the severity of the children's disability ($\chi^2 = 29.0$, $p < 0.001$), the disability type ($\chi^2 = 109.0$, $p < 0.001$), the caregiver's relationship with the child ($\chi^2 = 13.0$, $p < 0.01$),

Table 2
Estimated effects of selected variables on caregiver's perceived discrimination, using a multinomial logistic regression model.

Variables	Caregiver's perceived discrimination[a]						Likelihood ratio tests
	Moderate			Severe			
	B	AOR (95% CI)	p	B	AOR (95% CI)	p	χ^2
Disability severity							29.0***
Mild (ref.[b])	–	–	–	–	–	–	
Very severe	0.3	1.3(0.9–2.0)	0.209	0.6	1.8(1.1–2.9)	0.012	
Severe	0.4	1.5(1.9–2.3)	0.043	0.7	2.0(1.3–3.0)	0.002	
Moderate	0.5	1.6(1.1–2.4)	0.024	0.7	2.0(1.3–3.0)	0.002	
Unrated	−0.2	0.8(0.6–1.2)	0.397	−0.1	0.9(0.6–1.4)	0.737	
Disability type							109.0***
Physical disability (ref.)	–	–	–	–	–	–	
Hearing & speech	0.2	1.2(0.7–2.0)	0.452	−0.4	0.7(0.4–1.3)	0.257	
Intellectual disability	0.4	1.5(0.9–2.5)	0.114	1.1	3.0(1.7–5.4)	0.000	
Mental disability	0.9	2.3(1.5–3.7)	0.000	1.4	4.2(2.5–7.3)	0.000	
Multiple disabilities	0.9	2.3(1.4–4.0)	0.002	1.4	3.9(2.2–7.2)	0.000	
Primary caregiver							13.0**
Father (ref.)	–	–	–	–	–	–	
Mother	0.2	1.2(0.9–1.6)	0.222	0.2	1.7(1.2–2.4)	0.001	
Parental employment							26.4***
Both parents working (ref.)	–	–	–	–	–	–	
One parent working, Mother	0.1	1.1(0.6–1.8)	0.842	0.2	1.2(0.7–2.2)	0.449	
One parent working, Father	0.5	1.6(1.2–2.0)	0.001	0.7	2.1(1.7–2.8)	0.000	
Both parents unemployed	0.5	1.6(1.1–2.5)	0.028	0.6	1.9(1.2–2.9)	0.007	
Model fit							
χ^2 (df = 24)	206.8		0.000				
Pseudo R-square[c]	0.10						

Notes: Beta coefficients (B), Adjusted Odds Ratios (AOR), Confidence Interval (CI).

** $p < .01$.

*** $p < .001$ (2-tailed tests).

[a] The reference group is low perceived discrimination.

[b] Ref = Reference group.

[c] Nagelkerke Pseudo R-squared reported.

and parental employment ($\chi^2 = 26.4$, $p < 0.001$). Overall, the inclusion of the four predictor variables significantly improved the fit of the regression model containing only the intercept [$\chi^2(24, N = 2373) = 206.8$, Nagelkerke $R^2 = 0.10$, $p < 0.001$]. The multinomial logistic regression model utilized a low perceived discrimination class as the reference group. Our results indicated that the CWD of caregivers in the severe-perceived-discrimination group were about two times more likely to be moderately disabled (AOR = 2.0, $p < 0.01$), severely disabled (AOR = 2.0, $p < 0.01$), or very severely disabled (AOR = 1.8, $p < 0.05$), than to be mildly disabled. The CWD of caregivers in the severe perceived discrimination group were also 3.9 times more likely to be multiple disabled ($p < 0.001$), 4.2 times more likely to be mentally disabled ($p < 0.001$), and three times more likely to be intellectually disabled ($p < 0.001$) than physically disabled. Moreover, the caregivers in the severe-perceived-discrimination group were 1.7 times more likely to be mothers ($p < 0.01$) than were those in the low-perceived-discrimination group. The families of the severe-perceived-discrimination group were roughly two times more likely to have only the father working (AOR = 2.1, $p < 0.01$) and both parents unemployed (AOR = 1.9, $p < 0.01$) than were the families of the other two groups.

The combined effect of the caregiver's relationship with the child and parental employment was significantly associated with membership in the three perceived discrimination groups ($\chi^2 = 52.8$, $p < 0.001$), suggesting a significant interaction effect for these two variables (see Table 3). Using the low-perceived-discrimination group as the reference group, the severe-perceived-discrimination group was significantly more likely to have both parents unemployed if the mother was the caregiver (AOR = 3.6, $p < 0.001$), while the odds of having both parents unemployed when the father was the caregiver stayed marginally significant (AOR = 2.3, $p = 0.051$). We identified similar gender patterns in the case of dual-earner households—in those families, mother caregivers were 1.7 times more likely ($p < 0.05$) to report severe discrimination than the father caregivers were. These results suggest that regardless of whether both of the parents were unemployed or working, the caregivers were at higher risk of suffering from severe discrimination if they were the mothers.

Moreover, a family in the severe-perceived-discrimination group was 3.3 times more likely to have the mother as the caregiver and the father as the single-earner of the family ($p < 0.001$), implying that full-time working mothers were at higher risk of suffering from severe discrimination in the single-earner households. However, when the father was the caregiver, the father was not at significantly greater risk of suffering from severe perceived discrimination if the mother was the single-earner of the family (AOR = 1.2, $p = 0.656$). These results indicate that the effects of household labor divisions on the caregiver's perceived discrimination differed between mother and father caregivers.

4. Discussion

4.1. The pervasiveness of perceived discrimination among caregivers of Chinese children with disabilities

Drawing upon regionally representative data, the present study investigated the perceived discrimination experienced by 2373 caregivers of CWD recruited from 166 rehabilitation organizations in Shenzhen, China. The results reveal that discrimination experiences, involving both discrimination toward CWD as a group and discrimination toward the children's caregivers, are prevalent in contemporary urban China. Over two-thirds of the caregivers in the study agreed that social exclusion and discrimination exist toward CWD. More strikingly, more than half the caregivers had encountered discrimination themselves because of their child's disability, including social exclusion and a demeaning "non-disabled gaze"(Loja et al., 2013). Taking the personal- and group-level discrimination altogether, more than one-third of the caregivers indicated severe perceived discrimination, characterized as the caregiver endorsing all four possible discrimination experiences.

Our findings provide empirical evidence corroborate the pervasiveness of social discrimination perceived and experienced by caregivers of CWD (Ali et al., 2013; Green et al., 2005; Mak and Kwok, 2010; Manago et al., 2017; Vadivelan et al., 2020). Narratives revolving around how caregivers were challenged by their CWD being mistreated, discriminated against, and segregated in the community, and how they themselves were confronted by overt social exclusion and discrimination due to socio-structural constraints, have been well-documented across different regions of the world (Broady et al., 2017; Chiu et al., 2013; Ilias et al., 2019; Kinnear et al., 2016; Zuurmond et al., 2022). For instance, caregivers in the US have reported experiencing stigmatizing reactions of others toward their CWD, being marginalized by families and communities, and bearing the blame of others for bringing such children into the world (Green, 2003). In Tanzania—a low-income African country—caregivers of children with mental and intellectual disabilities have articulated concerns about the vulnerability of their children being subjected to not only judgmental labeling and social rejection but also to physical and sexual abuse (Ambikile and Outwater, 2012).

The high prevalence of caregivers' experiences with discrimination reported in the present study is particularly alarming, considering the decades of efforts that China has spent in promoting policy changes and improving social welfare for people with disabilities, after the United Nations Convention on the Rights of Persons with Disabilities entered into enforcement in 2008, such as the establishment of a national rehabilitation service system (Zhao and Zhang, 2017; Huang, 2019). In a study that surveyed caregivers of children with mental disability across six middle- and high-income countries in Latin America, the rate of respondents who reported being discriminated against by others for

Table 3
Combined effect of the caregiver's relationship with the child and parental employment on the caregiver's perceived discrimination.

Variable 1	Variable 2	Caregiver's perceived discrimination[a]				Interaction
		Moderate		Severe		
		AOR (95%CI)	p	AOR (95%CI)	p	χ^2
Primary caregiver	Parental working					52.8[***]
Father	Both parents working (ref.)	–	–	–	–	
	One parent working, Mother	1.3(0.7–2.8)	0.420	1.2(0.5–2.7)	0.656	
	One parent working, Father	2.2(1.2–4.0)	0.010	2.6(1.4–5.0)	0.003	
	Both parents unemployed	2.8(1.3–59)	0.006	2.3(1.0–5.1)	0.051	
Mother	Both parents working	1.5(1.0–2.3)	0.078	1.7(1.0–2.7)	0.048	
	One parent working, Mother	2.0(0.8–4.9)	0.130	3.5(1.4–8.8)	0.006	
	One parent working, Father	2.2(1.4–3.4)	0.000	3.3(2.1–5.3)	0.000	
	Both parents unemployed	2.1(1.2–3.9)	0.013	3.6(1.9–6.8)	0.000	

Notes: Children's disability severity and disability type were adjusted in the model; Beta coefficients (B), Adjusted Odds Ratios (AOR), Confidence Interval (CI), Chi-square (χ^2).

[***] $p < .001$ (2-tailed tests).

[a] The reference group is low perceived discrimination.

having a child with a mental disability was about half of the percentage reported in our study (Paula et al., 2020). The prevalence rate of perceived discrimination in our findings is also higher than that in a previous study in a low-income African country, in which fewer than half of the caregivers of children with mental or intellectual disability in Ethiopia were concerned about being treated differently and being socially excluded (Tilahun et al., 2016). Traditional Chinese cultural values of family and parenting are likely to contribute to perpetuating the common experiences of social judgment and discrimination reported in our study by the caregivers of CWD (Liu and Fisher, 2023; Yang, 2015). Having a CWD in the family can be treated as a poor reflection of the family's morality and can devalue the family's social standing (Ng et al., 2014; Lauber and Rössler, 2007). Our results reveal that although progress has been made in the Chinese social welfare systems for people with disabilities, the sociocultural attitudes toward CWD and their families are entrenched and slow to change. Thus, improvement in social awareness, understanding, and acceptance in the community and society should be prioritized by both practitioners and policymakers, so that societal discourses that devalue CWD and their families can be altered and ultimately replaced.

4.2. Child and socio-familial characteristics contributing to caregivers' perceived discrimination

Notably, the present study was among the first that has examined the child-level and socio-familial-level socio-determinants of perceived discrimination among caregivers of CWD. Existing studies on disability discrimination have indicated the importance of disentangling the diverse characteristics of disabilities, such as the visibility of and types of impairment, in order to understand the social construction of disability stigmatization and discrimination (Deal, 2003; Gray, 2002). Expanding upon earlier work, our study found differing impacts from children's disability-related characteristics on their caregivers' perceptions of discrimination. More specifically, parents with children with a severe or moderate disability, and with mental disability or multiple disabilities, were found to be more likely to report severe perceived discrimination. This might be because those disability characteristics have been linked to stigma associated with highly visible signs of physical disability and mental disability, which could heighten the ableist stereotypes and treatments toward CWD and their families (Kaushik et al., 2016; Niedbalski, 2023; Ysasi et al., 2018). Because children with autism recently accounted for a significant proportion of children with mental disability in China (Leng et al., 2023), and most of the rehabilitation organizations were founded by Chinese parents of people with autism (McCabe, 2008), many of CWD from rehabilitation organizations in this study were likely to be children with autism. Our findings are in line with previous research which found that caregivers of people with autism reported experiencing higher affiliate stigma than did caregivers of children with other developmental disabilities, such as physical and intellectual disabilities (Werner et al., 2023). Existing studies in the Chinese context also have indicated that children with mental disability experience high levels of discrimination and social exclusion, such as denial of educational opportunities and inability to access health and social care services, which may in turn exacerbate the associative discrimination perceived by their caregivers (Li et al., 2020; Liu and Fisher, 2023; Zhao and Fu, 2022).

At the socio-familial level, we found the caregiver's gender to be predictive of the social discrimination they perceived. In line with prior studies, mothers were at greater risk of severe discrimination than fathers, suggesting that disability, as a social concept, is experienced divergently by mother and father caregivers (Singh et al., 2016; Vadivelan et al., 2020). On one hand, the greater risk of the mothers might reflect the widely held belief driven by the social ideologies of mothering and gender norms: the well-being of children is inextricably linked to the conduct of mothers (Caplan, 1998). While the parents in our study did not differ in their experiences of social exclusion in general, the mothers scored significantly higher than the fathers did in the experience of receiving a demeaning "non-disabled gaze". In parallel, previous studies also suggested that mothers more often than fathers are the subjects of scrutiny and surveillance by professionals, academicians, and the broader public in general (Frederick, 2017; Ryan and Runswick-Cole, 2008). The Chinese cultural belief that regards birthing a CWD as past sin might further cast a shadow over the mother's social standing in China's patrilineal society (Wu, 2020). On the other hand, the mothers' higher risk of severe perceived discrimination might also be attributable to their greater tendency to identify with the caregiver role. In a cultural norm of intensive mothering, the moral imperative that mothers should care for their children and be responsible for their fate is more intensified than fathers (Shearn and Todd, 2000). Therefore, the tendency to embody the caregiver role and represent their CWD is more often observed among mothers than fathers (Lin et al., 2012). Such an inclination by the mothers can be exemplified in a personal narrative reported in a prior study: "I feel as if I am the one who is disabled" (Scott, 2010). As a result of embodied motherhood, one important moral obligation of good mothering practices is to advocate for CWD in an unjust society (Chang, 2009; Tabatabai, 2020). Correspondingly, mothers in our sample scored significantly higher than the fathers in the endorsement of social exclusion and discrimination toward their children, implying that mothers might be more sensitive to the negative treatment that their CWD experience.

The intersectionality between the caregiver's gender and parental employment status in our results further revealed the greater vulnerability of the mothers to social discrimination, compared with the fathers. In households where the parents held similar employment status, caregivers were at greater risk of severe discrimination if they were the mothers. Of note, the risk was the greatest for mother caregivers in the non-employed households, suggesting that the intersection of women's gender and the status of unemployment exposes caregivers of CWD to the greatest marginalization in society. Moreover, the effects of household labor divisions on the caregiver's perceived discrimination differed as a function of the caregiver's gender. The relative risk of severe discrimination differed between full-time mother and full-time father caregivers in single-earner households compared to caregivers from dual-earner families. Because effect of the household income was insignificant in the regression model with other predictors, it indicates that full-time mother caregivers from single-earner households were associated with a greater risk of severe discrimination for reasons other than lower economic power. This result is not surprising, because women's unemployment is well-documented to compromise their social standing within the family in urban China through their loss of economic independence (Attané, 2012; Du and Dong, 2009; Zheng et al., 2021). Empirical studies have suggested that women's role as a co-breadwinner is essential for urban Chinese marriages, and that women's unemployment will generate negative responses from their spouses, thus leading to increased marital tension (Hu et al., 2010). Outside the family, women's employment has carried political and ideological meaning since the socialist transformation in China, connoting that women's participation in the paid labor market is not only a right but also a duty. As housewives became a scorned social label and an unresolved historical problem in Chinese society, unemployed women have experienced a loss of self-esteem and a sense of stigmatization, humiliation, and social injustices (Zheng, 2003). In addition, our results suggest that the burden of caring for a child with special needs can complicate a woman's employment decisions and conditions. Despite the fact that the women caregivers in our sample were generally well-educated, with the percentage that had attained a junior college or higher education being more than twice that of the general population in Shenzhen, their labor force participation rate was only half of the rate for women in Shenzhen. The low labor participation rate of the mothers in our study might also explain why families of CWD are inclined to fall on the low end of Shenzhen's income spectrum. Household incomes below the city's minimum living standard were overly represented in our sample (i.e., 20 times greater than Shenzhen's general population), thus indicating the creation of a vicious spiral of disability and poverty.

Unexpectedly, the risk of severe discrimination was not greater for father caregivers when the mothers were the sole breadwinners in the family. Staying at home and undertaking caregiving tasks are at odds with the normative notion of masculinity and the widely circulating cultural narratives of fatherhood in a patriarchal society. Nevertheless, father caregivers in our study did not report a greater risk of being socially discriminated against when they assumed an unconventional role in the family. In fact, in accord with our finding, a study conducted in Spain observed that instead of being devalued, men gained social recognition when they assumed the family's caregiver role (Del Río--Lozano et al., 2013). They found that the fathers' sacrifice of personal careers to take on caregiving were considered honorable sacrifices because the men dared to venture into unorthodox practices that were not inherent to their masculine nature. The contrasting results of social discrimination between father and mother caregivers in families in which their spouses were the sole breadwinners are evidence of gender-biased double standards and systemic gender inequality embedded in Chinese society. Unequal power relationships between the genders are also implied by the fact that father caregivers in families with wives as the sole breadwinners only constitute a minimum percentage of our sample (2.7%), while mother caregivers from parallel family contexts represent almost half of the sample. This finding coincides with a rich body of research suggesting that a traditional parental labor division is universally common in families with CWD (Cidav et al., 2012; Di Giulio et al., 2014).

Nevertheless, the extent to which fathers are vulnerable to negative sociocultural attitudes toward ableism should not be underestimated. Our study adds to the literature by incorporating the reports of father caregivers of CWD. In line with previous studies, the majority of the fathers reported at least moderate perceived discrimination because of their child's disability (Pelchat et al., 2003; Thackeray and Eatough, 2016). However, the social attitudes toward men's participation in the caregiving duties of CWD remain largely unknown, even though their experiences with caring for a CWD are likely to differ from women's. Future studies are warranted to bring to light the social experiences of father caregivers in different sociocultural contexts and to facilitate the fathers' engagement in caregiving practices.

The findings of the present study carry significant clinical and policy implications. Most importantly, practitioners and policymakers need to raise the awareness concerning the severity of perceived discrimination among Chinese caregivers of CWD, so that the provision of appropriate clinical and institutional support for these populations can be informed. In particular, sensitivity should be exercised in developing both clinical and public health interventions against community and social discrimination to strategically address the vulnerability of caregivers of children with moderate and severe impairments and children with mental and multiple disabilities. Additionally, practitioners, including healthcare professionals and social service providers, can become effective advocators for families of CWD and educators of the community and public to improve social awareness, understanding, and acceptance of not only CWD, but also families of CWD as a whole. Last but not least, meso and macro-levels policies that aim at improving the situation of caregivers with structural disadvantages, including caregivers of women gender and full-time caregivers, should be prioritized as the national agender for improving social welfare for families of CWD, such as providing full-time caretaking subsidies.

4.3. Study limitations and suggestions for future research

The results of the present study need to be interpreted within the context of several limitations. First, our sample comprised families of Chinese CWD who were participating in the programs of qualified and government-subsidized rehabilitation organizations. Children and families without access to these organizations or who had sought help from other organizations were not included. A previous study suggested that the household registration system in China can lead to disparities in access to healthcare for CWD (Leng et al., 2023). However, migrant families of CWD, who accounted for 8.6% of the sample, were not fully represented because 70.0% of the Shenzhen population are migrants. Future studies should include the social experiences of the caregivers who were underrepresented in our study, and should incorporate more socioeconomic diversity.

Second, the present study was conducted in an urban context that was highly developed economically, thus limiting our ability to detect any disparities associated with regional and urbanicity differences. Considering the tremendous gaps in the implementation of social policies and the institutional structure of social services between urban and rural areas in China, future studies of caregivers' experiences with social discrimination should include more families from less-developed areas.

5. Conclusions

This study provides empirical evidence suggesting that the caregivers of CWD experience pervasive social discrimination in contemporary urban China, despite the nation's progress in reforming social policies and enhancing social welfare for people with disabilities. The majority of the caregivers we studied (82.9%) reported at least a moderate level of perceived discrimination, based on the daily experiences of caretaking of their CWD. Our study demonstrates that the social discrimination that is experienced through disablism is complex and multidimensional and depends upon the children's disability characteristics and the caregivers' social characteristics. Sensitivity should be exercised in providing support for caregivers of children with moderate and severe impairments and children with mental and multiple disabilities, because these caregivers bear a greater vulnerability to social discrimination. Practitioners and policymakers should also acknowledge the unequal social experiences of full-time mother caregivers, which are attributable to the intersection between unequal relationships between genders and socioeconomic disparities.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: 1) National Social Science Fund of China: Research on the Innovation and Development of Social Organizations of People with Disabilities under the Background of Healthy China Strategy (22&ZD185); 2) The Interdisciplinary Pre-research Project of Zhejiang University (S20230012).

CRediT authorship contribution statement

Ling Li Leng: Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Shixin Huang:** Writing – review & editing, Writing – original draft, Conceptualization. **Lin Gang Zhou:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization.

Data availability

Data will be made available on request.

Acknowledgement

We would like to thank all parents of children with disabilities for sharing their time and experiences by participating in this study. We also thank the China Disabled Persons' Federation in Shenzhen for contributing to recruiting participants.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2024.116991.

References

Aguerre, I.M., Riley-Powell, A.R., Weldon, C.T., Pajuelo, M.J., Celis Nacimento, R.A., Puente-Arnao, A., Cabrera, L., Oberhelman, R.A., Paz-Soldan, V.A., 2019. "Knocking on doors that don't open": experiences of caregivers of children living with disabilities in Iquitos and Lima, Peru. Disabil. Rehabil. 41 (21), 2538–2547. https://doi.org/10.1080/09638288.2018.1471741.

Ali, A., Scior, K., Ratti, V., Strydom, A., King, M., Hassiotis, A., 2013. Discrimination and other barriers to accessing health care: perspectives of patients with mild and moderate intellectual disability and their carers. PLoS One 8 (8), e70855. https://doi.org/10.1371/journal.pone.0070855.

Attané, I., 2012. Being a woman in China today: a demography of gender. China Perspect. 2012 (2012/4), 5–15.

Ambikile, J.S., Outwater, A., 2012. Challenges of caring for children with mental disorders: experiences and views of caregivers attending the outpatient clinic at Muhimbili National Hospital, Dar es Salaam-Tanzania. Child Adolesc. Psychiatr. Ment. Health 6 (1), 1–11.

Broady, T.R., Stoyles, G.J., Morse, C., 2017. Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. Health Soc. Care Community 25 (1), 224–233.

Chang, H.H., 2009. From housewives to activists: lived experiences of mothers for disability rights in Taiwan. Asian J. Wom. Stud. 15 (3), 34–59. https://doi.org/10.1080/12259276.2009.11666072.

Chiu, M.Y.L., Yang, X., Wong, F.H.T., Li, J.H., Li, J., 2013. Caregiving of children with intellectual disabilities in China — an examination of affiliate stigma and the cultural thesis. J. Intellect. Disabil. Res. 57 (12), 1117–1129. https://doi.org/10.1111/j.1365-2788.2012.01624.x.

Cidav, Z., Marcus, S.C., Mandell, D.S., 2012. Implications of childhood autism for parental employment and earnings. Pediatrics 129 (4), 617–623. https://doi.org/10.1542/peds.2011-2700.

Del Río-Lozano, M., García-Calvente, M.D.M., Marcos-Marcos, J., Entrena-Durán, F., Maroto-Navarro, G., 2013. Gender identity in informal care: impact on health in Spanish caregivers. Qual. Health Res. 23 (11), 1506–1520.

Du, F., Dong, X.Y., 2009. Why do women have longer durations of unemployment than men in post-restructuring urban China? Camb. J. Econ. 33 (2), 233–252.

Feaster, D., Franzen, A., 2021. From stigma to acceptance: intellectual and developmental disabilities in Central China. J. Intellect. Disabil. 25 (4), 507–526. https://doi.org/10.1177/1744629520923264.

Flynn, S., 2021. Convergent identities, compounded risk: intersectionality and parenting capacity assessment for disabled children. Child. Youth Serv. Rev. 129 https://doi.org/10.1016/j.childyouth.2021.106185.

Frederick, A., 2017. Risky mothers and the normalcy Project. Gend. Soc. 31 (1), 74–95. https://doi.org/10.1177/0891243216683914.

Goffman, E., 1963. Stigma: Notes on the Management of Spoiled Identity. Prentice-Hall.

Gray, D.E., 2002. "Everybody just freezes. Everybody is just embarrassed": felt and enacted stigma among parents of children with high functioning autism. Sociol. Health Illness 24 (6), 734–749. https://doi.org/10.1111/1467-9566.00316.

Grech, S., 2019. Disabled families: the impacts of disability and care on family labour and poverty in rural Guatemala. Societies 9 (4). https://doi.org/10.3390/soc9040076.

Green, S.E., 2003. "What do you mean 'what's wrong with her?'": stigma and the lives of families of children with disabilities. Soc. Sci. Med. 57 (8), 1361–1374. https://doi.org/10.1016/S0277-9536(02)00511-7.

Green, S., Davis, C., Karshmer, E., Marsh, P., Straight, B., 2005. Living stigma: the impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. Socio. Inq. 75 (2), 197–215.

Green, S.E., 2007. "We're tired, not sad": benefits and burdens of mothering a child with a disability. Soc. Sci. Med. 64 (1), 150–163. https://doi.org/10.1016/j.socscimed.2006.08.025.

Hengelaar, A.H., Wittenberg, Y., Kwekkeboom, R., Van Hartingsveldt, M., Verdonk, P., 2023. Intersectionality in informal care research: a scoping review. Scand. J. Publ. Health 51 (1), 106–124. https://doi.org/10.1177/14034948211027816.

Hu, X., Zeng, X., Zheng, L., Flatt, C., 2010. How does wives' unemployment affect marriage in reforming urban China? J. Comp. Fam. Stud. 41 (5), 717–734.

Huang, S., Li, X., Dong, D., 2023. Negotiating work and care in Chinese families of children with autism: reframing mothers' narratives through a social-relational lens. Disabil. Soc. 1–22 https://doi.org/10.1080/09687599.2023.2227330.

Huang, S., 2019. Ten years of the CRPD's adoption in China: challenges and opportunities. Disabil. Soc. 34 (6), 1004–1009.

Ilias, K., Cornish, K., Park, M.S.A., Toran, H., Golden, K.J., 2019. Risk and resilience among mothers and fathers of primary school age children with ASD in Malaysia: a qualitative constructive grounded theory approach. Front. Psychol. 9, 2275.

Knight, K., 2013. The changing face of the "good mother": trends in research into families with a child with intellectual disability, and some concerns. Disabil. Soc. 28 (5), 660–673. https://doi.org/10.1080/09687599.2012.732540.

Kröger, T., 2009. Care research and disability studies: nothing in common? Crit. Soc. Pol. 29 (3), 398–420. https://doi.org/10.1177/0261018309105177.

Kwok, S.Y.C.L., Leung, C.L.K., Wong, D.F.K., 2014. Marital satisfaction of Chinese mothers of children with autism and intellectual disabilities in Hong Kong. J. Intellect. Disabil. Res. 58 (12), 1156–1171. https://doi.org/10.1111/jir.12116.

Lauber, C., Rössler, W., 2007. Stigma towards people with mental illness in developing countries in Asia. Int. Rev. Psychiatr. 19 (2), 157–178.

Li, C., Feng, S., Yang, Y., 2020. Report of 2019 national survey of disability household income. Disability Research, 02 75–81 (in Chinese).

Liamputtong, P., Rice, Z.S., 2021. Stigma, discrimination, and social exclusion. In: Handbook of Social Inclusion. Springer International Publishing, pp. 1–17. https://doi.org/10.1007/978-3-030-48277-0_6-1.

Lin, I.F., Fee, H.R., Wu, H.S., 2012. Negative and positive caregiving experiences: a closer look at the intersection of gender and relationship. Fam. Relat. 61 (2), 343–358.

Liu, Y., Fisher, K.R., 2023. Struggle for recognition, rights, and redistribution: understanding the identity of parents of children with autism spectrum disorder in China. Front. Psychol. 13 (January), 1–13. https://doi.org/10.3389/fpsyg.2022.981986.

Loja, E., Costa, M.E., Hughes, B., Menezes, I., 2013. Disability, embodiment and ableism: stories of resistance. Disabil. Soc. 28 (2), 190203.

Lovell, B., A Wetherell, M., 2018. Caregivers' characteristics and family constellation variables as predictors of affiliate stigma in caregivers of children with ASD. Psychiatr. Res. 270, 426–429. https://doi.org/10.1016/j.psychres.2018.09.055.

MacCarthaigh, S., 2020. Beyond biomedicine: challenging conventional conceptualisations of autism spectrum conditions. Disabil. Soc. 35 (1), 52–66. https://doi.org/10.1080/09687599.2019.1605884.

Mak, W.W.S., Cheung, R.Y.M., 2008. Affiliate stigma among caregivers of people with intellectual disability or mental illness. J. Appl. Res. Intellect. Disabil. 21 (6), 532–545. https://doi.org/10.1111/j.1468-3148.2008.00426.x.

Mak, W.W., Kwok, Y.T., 2010. Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. Soc. Sci. Med. 70 (12), 2045–2051.

Manago, B., Davis, J.L., Goar, C., 2017. Discourse in action: parents' use of medical and social models to resist disability stigma. Soc. Sci. Med. 184, 169–177.

McCabe, H., 2008. Two decades of serving children with autism in the People's Republic of China: achievements and challenges of a state-run mental health center. Disabil. Soc. 23 (3), 271–282. https://doi.org/10.1080/09687590801954059.

Molero, F., Recio, P., Garcia-Ael, C., Fuster, M.J., Sanjuan, P., 2013. Measuring dimensions of perceived discrimination in five stigmatized groups. Soc. Indicat. Res. 114, 901–914.

National Bureau of Statistics, 2006. Results of the second national survey of people with disabilities released. http://www.stats.gov.cn/tjgz/tjdt/200612/t20061205_16908.html.

Oliver, M., Barnes, C., 2010. Disability studies, disabled people and the struggle for inclusion. Br. J. Sociol. Educ. 31 (5), 547–560. https://doi.org/10.1080/01425692.2010.500088.

Pan, L., Ye, J., 2015. Family care of people with intellectual disability in rural China: a magnified responsibility. J. Appl. Res. Intellect. Disabil. 28 (4), 352–366. https://doi.org/10.1111/jar.12167.

Pascoe, E.A., Richman, L.S., 2009. Perceived discrimination and health: a meta-analytic review. Psychol. Bull. 135 (4), 531–554. https://doi.org/10.1037/a0016059.

Paula, C.S., Cukier, S., Cunha, G.R., Irarrázaval, M., Montiel-Nava, C., Garcia, R., et al., 2020. Challenges, priorities, barriers to care, and stigma in families of people with autism: similarities and differences among six Latin American countries. Autism 24 (8), 2228–2242.

Piškur, B., Beurskens, A.J., Jongmans, M.J., Ketelaar, M., Norton, M., Frings, C.A., Hemmingsson, H., Smeets, R.J., 2012. Parents' actions, challenges, and needs while enabling participation of children with a physical disability: a scoping review. BMC Pediatr. 12 (1), 177. https://doi.org/10.1186/1471-2431-12-177.

Recio, P., Molero, F., García-Ael, C., Pérez-Garín, D., 2020. Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: the mediational role of affiliate stigma and social support. Res. Dev. Disabil. 105 (March), 103737 https://doi.org/10.1016/j.ridd.2020.103737.

Ryan, S., Runswick-Cole, K., 2008. Repositioning mothers: mothers, disabled children and disability studies. Disabil. Soc. 23 (3), 199–210. https://doi.org/10.1080/09687590801953937.

Scott, E.K., 2010. "I feel as if I am the one who is disabled:" the emotional impact of changed employment trajectories of mothers caring for children with disabilities. Gend. Soc. 24 (5), 672–696.

Shang, X., Fisher, K.R., 2014. Social support for mothers of children with disabilities in China. J. Soc. Serv. Res. 40 (4), 573–586. https://doi.org/10.1080/01488376.2014.896849.

Shearn, J., Todd, S., 2000. Maternal employment and family responsibilities: the perspectives of mothers of children with intellectual disabilities. J. Appl. Res. Intellect. Disabil. 13 (3), 109–131.

Shorey, S., Ng, E.D., Haugan, G., Law, E., 2020. The parenting experiences and needs of Asian primary caregivers of children with autism: a meta-synthesis. Autism 24 (3), 591–604. https://doi.org/10.1177/1362361319886513.

Singh, A., Mattoo, S.K., Grover, S., 2016. Stigma and its correlates among caregivers of schizophrenia: a study from North India. Psychiatr. Res. 241, 302–308.

Stanton-Chapman, T.L., Schmidt, E.L., 2019. In search of equivalent social participation: what do caregivers of children with disabilities desire regarding inclusive recreational facilities and playgrounds? Journal of International Special Needs Education 22 (2), 66–76. https://doi.org/10.9782/16-00035.

Stone, E.V., 1998. Reforming Disability in China: A Study in Disability and Development. Unpublished Ph.D. dissertation. The University of Leeds.

Stuber, J., Meyer, I., Link, B., 2008. Stigma, prejudice, discrimination and health. Soc. Sci. Med. 67 (3), 351–357. https://doi.org/10.1016/j.socscimed.2008.03.023.

Tabatabai, A., 2020. Mother of a person: neoliberalism and narratives of parenting children with disabilities. Disabil. Soc. 35 (1), 111–131.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., Hoekstra, R.A., 2016. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey. BMC Health Serv. Res. 16 (1) https://doi.org/10.1186/s12913-016-1383-9.

UNICEF, 2021. Seen, Counted, Included: Using Data to Shed Light on the Well-Being of Children with Disabilities.

Vadivelan, K., Sekar, P., Sruthi, S.S., Gopichandran, V., 2020. Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. BMC Publ. Health 20 (1). https://doi.org/10.1186/s12889-020-08808-0.

Werner, S., Freg, D., Sarsour, I.A., 2023. Family stigma and community participation of Arab children and youth with disabilities. J. Child Fam. Stud. 32 (11), 3526–3539. https://doi.org/10.1007/s10826-023-02674-1.

Wu, J., 2020. Mothering special children: negotiating gender, disability, and special education in contemporary China. Harv. Educ. Rev. 90 (1), 26–48.

Yang, X., 2015. No matter how I think, it already hurts: self-stigmatized feelings and face concern of Chinese caregivers of people with intellectual disabilities. J. Intellect. Disabil. 19 (4), 367–380. https://doi.org/10.1177/1744629515577909.

Zheng, W., 2003. Gender, employment and women's resistance. In: Perry, E.J., Selden, M. (Eds.), Chinese Society. Routledge, pp. 176–204.

Zheng, L., Xu, X., Xu, T., Yang, L., Gu, X., Wang, L., 2021. Financial strain and intimate partner violence against married women in postreform China: evidence from Chengdu. J. Interpers Violence 36 (17–18), NP9175–NP9196.

Zhou, T., Wang, Y., Yi, C., 2018. Affiliate stigma and depression in caregivers of children with Autism Spectrum Disorders in China: effects of self-esteem, shame and family functioning. Psychiatr. Res. 264, 260–265. https://doi.org/10.1016/j.psychres.2018.03.071.

Zuurmond, M., Seeley, J., Nyant, G.G., Baltussen, M., Abanga, J., Polack, S., et al., 2022. Exploring caregiver experiences of stigma in Ghana: they insult me because of my child. Disabil. Soc. 37 (5), 827–848.