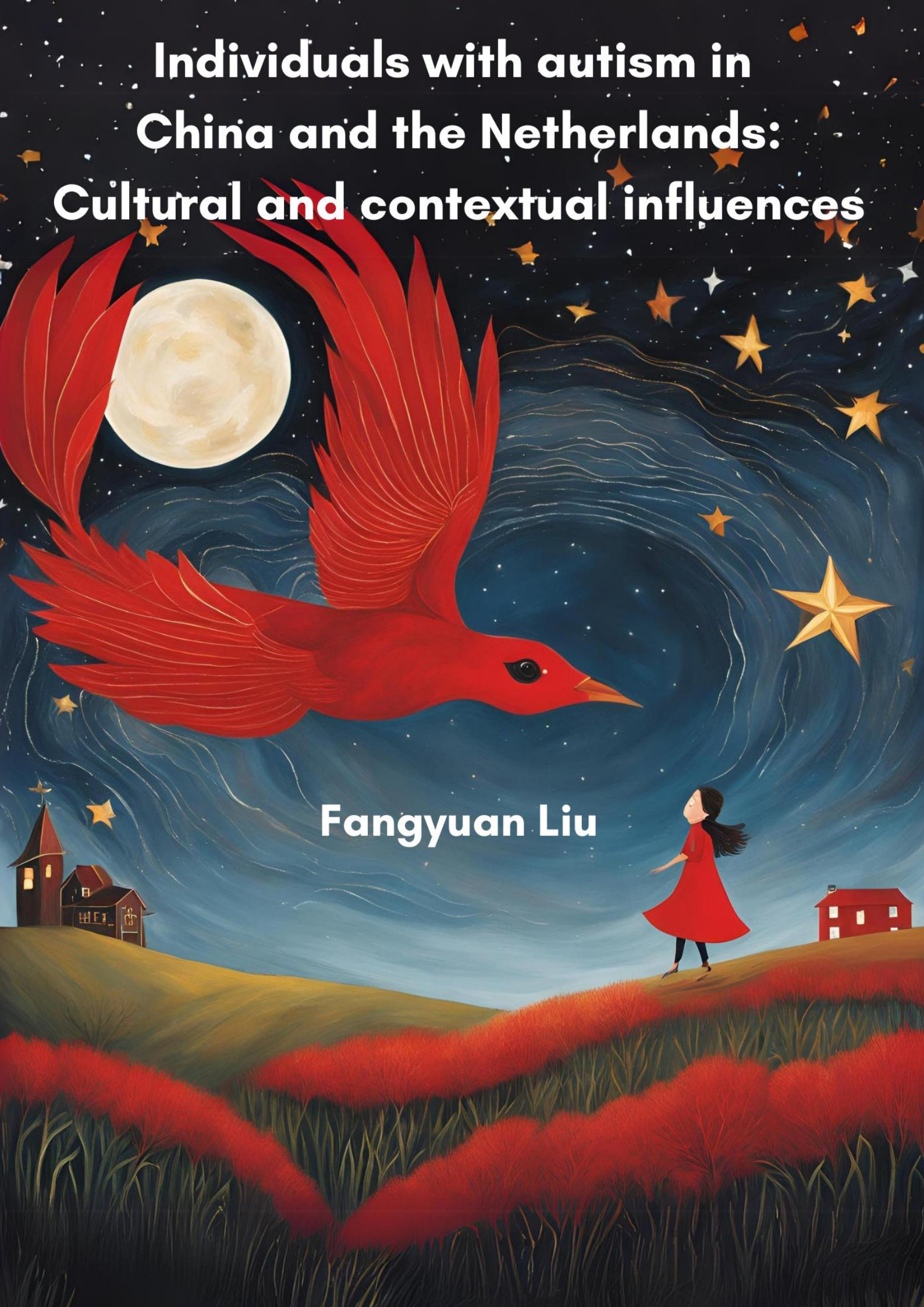


Individuals with autism in China and the Netherlands: Cultural and contextual influences

Fangyuan Liu



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VRIJE UNIVERSITEIT

**Individuals with autism in China and the Netherlands:
Cultural and contextual influences**

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Chapter 1 : General Introduction

Autism

Definition and prevalence

Autism spectrum disorders (from hereon ‘Autism’) are characterized by difficulties in social interaction and communication, and unusually repetitive and restricted behaviours and interests (American Psychiatric Association, 2013). Autism research is globally unbalanced, with a predominant focus on populations from Western, educated, industrialized, rich, and democratic (WEIRD) countries, despite less than 20% of the world's population living in these regions (World Bank, 2022) (Durkin et al., 2015). Such a skewed research concentration might introduce biases in our understanding of screening and diagnosing of autism and support services for individuals with autism, potentially limiting our understanding of autism in non-WEIRD countries (de Leeuw et al., 2020; Durkin et al., 2015; Freeth et al., 2013; Rice & Lee, 2017). In many non-WEIRD countries, including low- and middle-income countries (LMIC), it is likely that relatively many individuals with autism and (above) average intellectual abilities remain undiagnosed. This disparity is reflected in prevalence rates, such as the 34/10000 autism prevalence in South-East Asia, which is lower than the prevalence rate of 63.5/10000 in Europe (Zeidan et al., 2022). Additionally, limited access to professional support or specialized education in LMICs can exacerbate challenges faced by individuals with autism and their families, influencing their long-term well-being. These imbalances suggest that there is a need to expand our research focus and better represent the diverse experiences of individuals with autism across cultures and contexts (de Leeuw et al., 2020; de Vries et al., 2020; Divan et al., 2021).

China, as a non-WEIRD country with an estimated 10 million autistic people living in China alone (Zhou et al., 2020), represents an enormously growing population of individuals with autism. In Chinese, “autism” is commonly referred to in two terms: “guduzheng”, translating to “alone syndrome”, and “zibizheng”, translating to “self-isolation syndrome”.

Another term, carrying a more romanticized expression, describes individuals with autism as "children from the stars" (Wang et al., 2019). This phrase implies that children with autism, like stars, shine brightly in the dark sky, giving autistic children a special status. Yet, the prevalence rate of autism in Chinese children is reported to be 0.7% (Zhou et al., 2020), which is lower than the 1-2% global prevalence rate of autism (Zeidan et al., 2022). Zhou et al. (2020) found that 43.4% of Chinese children with autism who attended regular schools had not received an official diagnosis prior to the start of the study. The difference in reported prevalence rates between China and the global rate highlights the critical role of cultural and contextual influences in understanding and addressing autism.

Cultural and contextual influences

Various cultural and contextual factors may contribute to underdiagnosis of autism in China, such as limited public and parental knowledge of autism (Luo et al., 2022; Robison, 2019), insufficient numbers of autism experts who are mainly located in major cities (Wu & Pan, 2019), the concealment of possible autistic symptoms due to social discrimination (Clark et al., 2019), financial constraints to accessing psychiatric care (Huang et al., 2013), and a lack of autism awareness and/or expertise in professionals to accurately diagnose autism (Au-Yeung et al., 2019). Cultural and contextual factors play a crucial role in shaping the understanding of autism, autism diagnosis, and well-being of autistic individuals and their families, with these influences varying significantly across different regions and societies, such as in China.

Cultural influences

Culture encompasses, values, social norms, language, rituals, traditions, beliefs, behaviours, food, dress, music, relationships and other customs shared and/or learned by a group of people (Birukou et al., 2013; Rathje, 2009). What is considered "typical" behaviour

varies from one cultural and contextual setting to another, and the threshold at which behaviour is classified as a disorder can be influenced by cultural norms and values (de Leeuw et al., 2020; Freeth et al., 2013; Norbury & Sparks, 2013).

Western, educated, industrialized, rich, and democratic (WEIRD) cultures tend to have an individualistic social orientation, emphasizing independent self and autonomy and encouraging individuals to differentiate themselves from others and focus on personal achievement and uniqueness (Henrich et al., 2010; Vignoles et al., 2016). Nowadays in Western European/American countries, autism is recognized as a broad spectrum, covering a vast range of manifestations. The spectrum refers to varying degrees of autistic traits and different types of exhibited behaviours (e.g., aloof social behavior vs active social behavior). Furthermore, the intellectual abilities of autistic individuals range from profound intellectual disabilities to highly able and fully fluent (Lord et al., 2018). In these Western high-income countries, a wide range of people, including older adults with average to high intellectual abilities are diagnosed with autism (Begeer et al., 2013; Brugha et al., 2016; Christensen & Zubler, 2020). The Netherlands, as one of WEIRD cultures and a Western European individualistic country, have a long history of autism awareness as well as active self-advocacy movements for autistic individuals, promoting their empowerment and creating a inclusive society for people with autism (Szlamka et al., 2022).

China, as a non-WEIRD country in East Asia, shares with Eastern Asian cultures prioritizing adherence to social norms and collective harmony (Grossmann & Varnum, 2010; Sedikides et al., 2015). In Eastern Asian cultures, uniqueness may be perceived negatively, as it may threaten the collectivist social relationships and interpersonal harmony within the community (Vignoles et al., 2016). For example, in China, despite increasing awareness (Huang et al., 2013), negative portrayals of autism persist in media (Clark et al., 2019; Tang & Bie, 2016). Non-conforming autistic behaviours may be perceived negatively in Eastern Asian

cultural context (Mak & Kwok, 2010; Zhou et al., 2020). In China, mostly children who show classic autistic behaviors (such as limited functional communication) and intellectual disabilities are diagnosed. Due to a general lack of public awareness of autism and stigma concerning mental health diagnoses (Yu et al., 2020), Chinese psychiatrists are reluctant to assign an autism diagnosis to individuals exhibiting high functionality and less severe symptoms (Huang et al., 2013), viewing the diagnostic categories themselves as a source of discrimination.

Stigma

Stigma toward individuals with autism and their families is a global issue, across cultures and contexts (Kim et al., 2022; Someki et al., 2018; Yu et al., 2020). The stigma of mental illness is the negative stereotyping and discrimination toward people with mental illness (Corrigan & Watson, 2002; Hinshaw, 2009). Stigmatization of autism can hinder diagnosis and reduce access to social supports or opportunities, such as jobs, for individuals with autism (Brohan et al., 2010; Johnson & Joshi, 2016). Individuals with autism and their families in Eastern Asian cultures may experience a higher degree of stigma and discrimination compared to Western American/European cultural context (de Vries et al., 2020; Kim et al., 2022; Someki et al., 2018). Stigma can also be internalized, which means that people come to internalize negative stereotypes, bias, and discrimination toward oneself (Boyd et al., 2014; Hammer & Toland, 2017). Internalized stigma contributes to poor mental health and community integration among autistic individuals (Botha & Frost, 2018; Mitchell et al., 2021).

Contextual influences

The availability, accessibility, affordability, and acceptability of autism support services across countries may serve as socio-economic contextual factors resulting in different help-seeking strategies and differences in the quality and quantity of assistance received and provided by clinical professionals (de Leeuw et al., 2020). High-income Western European countries, such as the Netherlands, have a long history of autism care and research, as well as advocacy and rights-oriented empowerment of individuals with autism and their families, relatively improving the public image of autism as well as achieving service development (Boshoff et al., 2016; Szlamka et al., 2022; Waltz et al., 2015). The Netherlands have a well-developed welfare system nationwide. This welfare system ensures the provision of formal support services in education and healthcare. Consequently, individuals with autism and their families have relatively available and affordable access to resources, potentially alleviating parenting stress and improving the well-being of individuals with autism and their families. Additionally, this enhanced healthcare system promotes an inclusive environment for autistic individuals (van Kessel et al., 2019).

Limited social support and knowledge about autism has been related to lower empowerment of individuals with autism and their caregivers (Hahler & Elsabbagh, 2014; Lord et al., 2022; Wakimizu et al., 2011). Despite policies and guidelines aimed at supporting individuals with autism in China (Fisher et al., 2010; Xiao, 2023), challenges persist, such as disparities in service and educational provision between urban and rural areas (Divan et al., 2021; Wang et al., 2019), a shortage of healthcare and educational professionals trained to offer high-quality specialized care and a lack of individualized educational plans or interventions (Li & Qi, 2023; Sun, Allison, Auyeung, Matthews, et al., 2013; Wu & Pan, 2019). Limited access to services affects not only the caregivers, but also the developmental opportunities for autistic individuals. When no suitable public-school option can be found, families either keep their child

at home and try their best to educate them or pay out of pocket for special education or interventions (Sun, Allison, Auyeung, Matthews, et al., 2013).

Overall, cultural attitudes and stigma, along with disparities in the availability, accessibility, affordability, and acceptability of support services across countries may shape the interpretation of autistic traits, and well-being outcomes of individuals with autism and their families. Therefore, cross-cultural research on autism is crucial for understanding how perceptions of autism vary globally, and for improving the well-being of autistic individuals and their families by fostering inclusive and supportive environments worldwide.

Interpretation and Screening of Autism

Developmental delays can be detected earlier through strengthening of developmental monitoring systems, an approach supported by the World Health Organization (WHO, 2012). It is essential to develop culturally appropriate tools for observation, screening, and diagnosis to monitor developmental concerns or specifically screen for autism (de Leeuw et al., 2020). In China, unlike in Western countries, systematic observation of the child in multiple settings (e.g., school, home and community) is not common. Instead, hospital referrals for autism were mostly initiated by parents rather than being flagged by developmental checkup clinics or through concerns raised at school (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013).

The endorsement of autism symptoms and the rating of their severity by parents can be influenced by cultural contexts. For example, Japanese caregivers compared to American caregivers may interpret a lack of interest in other children as modesty or shyness rather than an autism symptom (Carruthers et al., 2018; Inada et al., 2011). A lack of eye contact is often considered an indicator of nonverbal communication issues in Western cultural contexts, while in Chinese cultural context, avoiding eye contact with adults is seen as respectful, but atypical

eye contact could indicate autism (Bernier et al., 2010; Wang et al., 2019). These findings suggest potential cultural differences in the recognition and interpretation of certain autism characteristics, particularly when relying on reports from parents. These differences raise concerns about the reliability and validity of screening measures across cultures, because behaviours viewed as signs of autism in one culture might not hold the same significance in another. Currently, there is a lack of systematic cross-cultural comparative studies on autism based on parent report. While some studies (Carruthers et al., 2018; Chung et al., 2012) have begun to address this, more research is needed to fully understand how cultural differences impact parents' perceptions of autistic traits.

Well-being of individuals with autism and their families

Parenting stress

The behaviours and needs of autistic children can place considerable demands on their primary caregiver (Falk et al., 2014; Kuusikko-Gauffin et al., 2013; Stein et al., 2011). Caring for a child with autism can be particularly challenging due to the child's sometimes non-conforming and unpredictable behaviours/emotional problems (Estes et al., 2013; McStay et al., 2014), the high co-occurring psychiatric conditions of autism with intellectual disabilities and other psychopathology (Lai et al., 2019), as well as burden of time management and financial concerns (Bonis, 2016; Vohra et al., 2014; Zablotsky et al., 2014; Zhao et al., 2023). These cumulative challenges can leave caregivers of autistic children distressed and isolated, leading to increased parenting stress, negatively affecting their overall well-being (Masfield et al., 2020; Shorey et al., 2020), marital satisfaction (Ilias et al., 2017), parenting quality and in turn affecting the behaviour problems and developmental outcome of their children (Tharner et al., 2012).

Cultural and contextual backgrounds may shape parenting experiences and stress levels (de Leeuw et al., 2020). Caregivers in Western cultures, which emphasize individualism, are more likely to foster autonomy in their children and employ problem-focused coping strategies to seek professional resources and support that confront and modify parenting stressors (French & Kennedy, 2018; Xue et al., 2014). Parents from Eastern Asian cultures, which emphasize collective harmony, may more likely utilise familial supports and engage in community sharing information and obtaining emotional support from other parents in a similar situation (Chun et al., 2006; McCabe, 2007). Eastern Asian cultures also place a high value on parental obligations (Ashton-James et al., 2013; Chua, 2011) and parents tend to adopt a self-sacrificing approach by altering their personal lives for the well-being of their children (Huang & Zhou, 2016; McCabe, 2008). Currently, the responsibility for education services largely falls on the parents, and they serve as caregivers, educators, and trainers (Wang et al., 2023; Zhao & Fu, 2022; Zhou & Yi, 2014). While this approach fosters strong family bonds and community support, it also presents significant challenges. Parents often face lots of challenges including the lack of trained professionals, limited social support, and high economic burden for training and intervention services (Liao et al., 2022; Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013). Additionally, stigma and lack of professional support in Eastern Asian countries may lead to parents' avoidance coping strategies, with an inclination towards concealing their child's condition and preventing them from seeking support (Lai et al., 2015; Su et al., 2018), further increasing parenting stress (Chan & Lam, 2018; Mak & Kwok, 2010).

To date, there have been many studies on parenting stress in caregivers of autistic children in both western and European countries (de Maat et al., 2021; McStay et al., 2014; Rivas et al., 2020), and in Eastern Asian countries (Hu et al., 2019; Ilias et al., 2017; Ng et al., 2021; Wang et al., 2022). However, there have been few comparative studies which have examined well-being among caregivers of autistic children and parenting stress across different

cultural and contextual backgrounds (DeLambo et al., 2011; Giannotti et al., 2021; Smith et al., 2021). Given the strong impact of cultural and contextual backgrounds, it is necessary to expand research to the well-being of caregivers of children with autism across different cultural contexts. Taking this approach can help improve the tailored support for families navigating the complexities of raising a child with autism.

Objective and subjective outcomes of autistic adults

Our understanding of the experiences of autistic adults lags far behind our understanding of autistic children (Ayres et al., 2018). Moreover, studies on autistic adults are mostly based in Western high-income countries like the U.S. and European countries (Sáez-Suanes & Álvarez-Couto, 2021; Scheeren et al., 2022), revealing challenges autistic adults face in independent living, finding employment, and maintaining relationships (Mason et al., 2021; Sáez-Suanes & Álvarez-Couto, 2021; Scheeren & Geurts, 2015). Nowadays, autism research in China has primarily focused on four key areas: etiology, diagnostics, intervention, and education provision for children with autism (Luo et al., 2022; Sullivan & Wang, 2019; Sun, Allison, Auyeung, Matthews, et al., 2013; Wang et al., 2019). However, autism research with a focus beyond early childhood is scarce, and objective and subjective outcomes of autistic adults with or without high support needs remain largely unknown in China. Such a gap highlights the critical need for increased study of the experiences and wellbeing of autistic adults, both in China and in comparison with autistic adults in Western high-income countries.

Autistic adults in China and Western European countries, such as the Netherlands, may experience different levels of well-being and community integration due to different cultural and social systems. In the Netherlands, emphasizing independence, autonomy, and advocacy in autistic adults (Waltz et al., 2015), 86% of Dutch autistic adults, who were mostly late-

diagnosed adults with average to high intellectual abilities, showed a fair to very good level of objective psychosocial functioning (Scheeren et al., 2022). For autistic individuals, the societal infrastructure, including the health care and social support system, is effective to foster independent living through education, employment opportunities, and living accommodations (Forti et al., 2014; Maddox & Gaus, 2019). The social welfare system also provides safety nets for those who may not be able to fully support themselves financially (<https://www.autismeurope.org/>). Despite the existing support systems, a significant number of children with autism in the Netherlands continue to face substantial challenges in both special and mainstream schools. Additionally, many adults with autism encounter issues with unemployment or underemployment, along with difficulties in securing suitable housing. (Mason et al., 2021). Additionally, independent living and employment may also bring challenges such as increased stress, anxiety, and sensory overload (Baldwin & Costley, 2016; Bishop-Fitzpatrick et al., 2016). In China, options for employment and daytime activities are limited (Hua, 2017). Also, the costs of living and purchasing a house is high in urban cities, and financial constraints and care facilities are scarce in rural cities (Xiao, 2023). Most parents actively care for autistic adults and live together with their adult children (Fisher & Jing, 2008). The strong family support system may be a source of comfort and stability for autistic adults, potentially mitigating some of the challenges posed by inadequate professional support services and societal stigma (Ghosh & Magana, 2009; Xue et al., 2014).

Given that more than 10 million individuals are identified as autistic in China (Zhou et al., 2020) and over 90% of families with an autistic child struggle with various challenges such as high levels of stress, financial burdens, limited access to adequate healthcare and educational services, and a lack of professional support in China (Clark et al., 2019; Huang et al., 2013), research on the well-being of Chinese individuals with autism and their families is particularly

important. A nuanced approach to autism support, considering the cultural, societal, and individual factors that influence well-being and community integration is needed.

Aim of this dissertation

This dissertation aims to expand our understanding on experiences of both parents of autistic children and autistic adults in China and the Netherlands. The first aim is to examine the reliability and validity of a parent-report screening tool, the Autism Spectrum Quotient-Short (AQ-Short), in samples of children with autism in these two countries and to compare children's parent-reported autistic traits across both countries (chapter 2). Secondly, we want to compare parenting experiences in China and the Netherlands, particularly in terms of the levels of parenting stress related to the care for autistic children (chapter 3). The third aim is to examine the life satisfaction of autistic adults in China and how well they integrate into their community (independent living, employment, friendship and life satisfaction ratings), and compare these results with an adult sample from the Netherlands (Chapters 4 + 5). The final goal is to investigate the impact of demographic factors (e.g. age and sex of autistic individuals), socioeconomic status (income level), and autism-related internalized stigma on experiences of parents of autistic children and autistic adults across the aforementioned chapters (Chapters 2 + 3 + 4 + 5).

Differences in interpretations of autistic traits across cultural and contextual settings may impede the generalizability of screening tools developed within Western contexts to Eastern settings, potentially affecting diagnostic prevalence. A systematic comparison of autistic traits between children from Chinese and Western countries remains limited. In Chapter 2, we examined the factor structures of the parent-report version of the AQ-Short, a screening tool targeting the core dimensions of autism and a suitable screener for autistic traits in large

samples (Murray et al., 2014; Rentergem et al., 2019). Participants in this study were parents of autistic children between 2 and 17 years old from China and the Netherlands. We included 327 Chinese and 694 Dutch participants. The first aim of the study is to investigate whether the AQ-Short is a meaningful instrument that can be used as a parent report measure across different cultures. The second aim is to examine whether any categories of autistic behaviours (i.e. social behaviour difficulties and a fascination for numbers/patterns) were more or less prevalent across countries. The third aim is to examine whether demographic factors (age and sex), and socioeconomic status (income level) have similar impacts on parent-reported autistic traits within both samples.

Caregivers of children with autism often experience higher parenting stress than those of typically developing children (Barroso et al., 2018). Cultural background and societal context may also influence the levels of stress experienced by those caregivers. While some studies show Asian parents of autistic children may experience higher levels of stress compared to their European or American counterparts, findings of similar stress levels have also been reported. In Chapter 3, hierarchical multiple regression analyses were conducted to examine the varying levels of parenting stress experienced by caregivers of children with autism in China and the Netherlands. 95 Chinese caregivers and 118 Dutch caregivers of autistic children aged 2 to 16 years participated in this study. Furthermore, we compared country differences in parenting stress of autistic children and examined possible contextual factors (such as socioeconomic status) and amount of worries about the Covid-19 pandemic.

A notable research gap exists regarding one of the cohorts of autistic adults, specifically the estimated 10 million individuals with autism residing in China (Zhou et al., 2020). In the last two chapters, our focus shifts to the degree of community integration and life satisfaction of autistic adults and we compare their objective and subjective outcomes between two distinct cultural contexts. In Chapter 4, we investigated the extent and factors influencing community

integration (employment, independent living, friendship) and life satisfaction among young autistic adults with high support needs, through caregiver reports. Caregivers of young adults aged 18-30, with 99 from China and 109 from the Netherlands, participated in this study.

Furthermore, limited public awareness and varying cultural acceptance may potentially lead to autism-related internalized stigma and a reluctance among autistic adults to seek professional assistance, and further affect the overall outcomes of autistic adults. The final chapter extends this inquiry to the self-reported experiences of 36 Chinese and 29 Dutch autistic adults, aiming to further investigate potential variations in community integration and life satisfaction and the role of self-stigma in potential group differences. Together, these chapters not only compare the experiences and challenges across two different countries but also highlight how diverse cultural and contextual factors shape the well-being of individuals with autism and their families.

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Chapter 2: Exploring cultural differences in autistic traits: A factor analytic study of children with autism in China and the Netherlands

Liu, F., Scheeren, A. M., Grove, R., Hoekstra, R. A., Wang, K., Guo, D., ... & Begeer, S. (2022). Exploring cultural differences in autistic traits: a factor analytic study of children with autism in China and the Netherlands. *Journal of Autism and Developmental Disorders*, 52(11), 4750-4762.

Abstract

Autism spectrum disorders (ASD) are diagnosed globally, but recognition, interpretation and reporting may vary across cultures. To compare autism across cultures it is important to investigate whether the tools used are conceptually equivalent across cultures. This study evaluated the factor structure of the parent-reported Autism Spectrum Quotient Short Form (AQ-Short) in autistic children from China ($n = 327$; 3 to 17 years) and the Netherlands ($n = 694$; 6 to 16 years). Confirmatory factor analysis (CFA) did not support the two-factor hierarchical model previously identified. Exploratory factor analysis (EFA) indicated culturally variant factor structures between China and the Netherlands, which may hamper cross-cultural comparisons. Several items loaded onto different factors in the two samples, indicating substantial variation in parent-reported autistic traits between China and the Netherlands.

Keywords

Culture, autistic traits, children, autism spectrum disorder, autism spectrum quotient

Introduction

Autism spectrum disorders (ASD) are characterized by deficits in social interaction and communication, and unusually repetitive and restricted behaviors and interests (American Psychiatric Association, 2013). Reliable instruments are needed to quantify autistic traits and screen for high-risk children, thereby improving early detection of autism and promoting better emotional and behavioral outcomes (Saito et al., 2017; de Leeuw et al., 2020). However, the majority of screening tools for autistic traits have been developed in Western high-income countries, typically in Western Europe and North America (Durkin et al., 2015; West et al., 2016). Our knowledge of measurements of autistic traits may thus be culturally and contextually biased (Durkin et al., 2015). In this study, we compare a popular parent-report screening tool for ASD between children with ASD from Eastern (Chinese) and Western (The Netherlands) cultures.

If the recognition, interpretation and reporting of children's autistic traits are not consistent across cultures, as suggested by a recent review (de Leeuw et al., 2020), this restricts the usability of autism screening tools developed in Western cultures in other countries (Norbury & Sparks, 2013). Even though there is a growing number of studies attempting to develop or adapt screening instruments for use in Eastern cultures, outcomes are not always optimal. For instance, translated screening instruments showed low sensitivity (.48) in identifying children with ASD in Japan (Kamio et al., 2014), and had low to moderate internal consistencies in China (.21-.69) (Zhang et al., 2018). There is preliminary evidence suggesting subtle differences in autistic traits across Eastern and Western countries (de Leeuw et al., 2020; Freeth et al., 2014; Norbury & Sparks, 2013). For example, disinterest toward other children, which is an important indicator of autism in the original screening tools developed in the United States (Robins et al., 2001), is not reported by Japanese caregivers as an autism symptom of their children with ASD (Inada et al., 2011). As Japanese people generally are more introverted

than westerners (Wakabayashi, Baron-Cohen, & Wheelwright, 2006), Japanese caregivers may interpret a lack of interest in other children as modesty or shyness rather than an autistic trait. Therefore, assessment tools that have been developed and standardized in the West may not be reliable or valid if applied in other non-Western cultures (Henrich et al., 2010). In line with this, a lack of culturally adapted screening tools may further contribute to the discrepancies in prevalence estimates (Pang et al., 2018). China, with a population of almost 1.4 billion and an increasing prevalence of ASD, represents an enormously growing population of individuals with ASD. Yet, the prevalence rate of autism in Chinese children is reported to be 0.7% (Zhou et al., 2020), which is lower than the 1-2% prevalence rates among Western children (Xu et al., 2018; Baron-Cohen et al., 2009). Thus, further research is needed to evaluate whether autism screening tools are culturally appropriate and whether they are valid across different countries and cultures. So far, there have been no systematic comparisons of children's autistic traits from Chinese and Western samples.

Besides the role of culture, socioeconomic status (SES) and demographic (sex and age) information may also impact on the recognition, interpretation and reporting of autistic traits. Parents from low SES families (e.g. lower maternal education) within the United States tend to over-report symptoms associated with ASD (Khowaja et al., 2014; Scarpa et al., 2013) and exhibit lower consistency in screening outcomes when compared to families with higher maternal education levels (Khowaja et al., 2014). This high false-positive rate might be due to the limited awareness of early childhood development and behaviors in families with low SES (Bishop-Fitzpatrick & Kind, 2017; Colbert, Webber, & Graham, 2017; Ratto et al., 2016) or lack of internal consistency and accuracy in screening tools across low SES groups (Scarpa et al., 2013). Whether the effects of SES on parental report of children's autistic traits is the same in different cultural contexts is still unknown. Within ASD, males outnumber females with a sex ratio of 4.3:1 (Maenner, 2020). Previous studies found that boys with ASD are prone to

isolation and thus less social (Hiller et al., 2015) and have more stereotyped and repetitive behaviors than girls (Hiller et al., 2015; Sun et al., 2019; Szatmari et al., 2012). Moreover, although ASD is generally considered a ‘life-long’ condition, the severity of core symptoms seems to increase or decrease as children grow older (Fountain et al., 2012; Louwerse et al., 2015; Scheeren et al., 2019). Increased insight into the effects of SES, sex and age on autistic traits in children with ASD will promote screening and diagnostic accuracy.

Worldwide, the most frequently used questionnaire for autism is the Autism-spectrum Quotient (AQ; Baron-Cohen et al., 2001), which is a 50-item self-report or parent-report measure. The parent-report children’s version of the AQ (AQ-Child) aims to quantify autistic traits in children 4-11 years old across five theoretical domains (Social skills, Attention to detail, Attention switching, Communication and Imagination) (Auyeung et al., 2007; Baron-Cohen et al., 2001). The factor structure of the parent-report AQ-Child varies according to different studies (Auyeung et al., 2007; Gomez et al., 2018; Sun et al., 2019). Auyeung et al. (2007) found a 4-factor model (Mind-reading, Attention to detail, Social Skills and Imagination), with 47 items based on 1225 typically developing UK children. A Chinese study reported a 5-factor model (Socialness, Social communicative competence, Imagination, Patterns and Attention Switching), with 30 items in a sample of 1020 typically developing children (Sun et al., 2019). However, they reported a low alpha coefficient (.588) for the Attention Switching domain, suggesting weak internal consistency of this subscale. Finally, Gomez et al. (2018) found a 4-factor model with 32 items reflecting Mind-reading, Social Skills, Attention to details and Imagination in 404 Australian children with a diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD). These inconsistent factor structures raise the concern that the construct validity and latent structure of the AQ-Child may differ across samples, countries and cultures. These studies have all been conducted in samples that are typically developing or had additional

diagnoses such as ADHD. Therefore, there is a need for evaluating the structure of this parent report measure within a sample of children with ASD.

A popular, shortened version, the Autism Spectrum Quotient-Short Form (AQ-Short, Hoekstra et al., 2011), includes 28 items targeting the core dimensions of autism and is suitable for quick assessment of autistic traits in large samples (Murray et al., 2013; Rentergem et al., 2019). Previous research has supported a two-factor structure, including a social behavior factor and a numbers and patterns factor, of the self-report AQ-Short in adults with ASD (Grove et al., 2016; Kuenssberg et al., 2014; Murray et al., 2013). While these results indicate that the AQ-Short is a valid and useful autism screening instrument in adults with ASD, the AQ-Short has not been tested as a parent report measure of autistic traits in children with ASD. As mentioned above, previous research evaluating the factor structure of the AQ-Child suggests a large degree of variability across samples and cultures. The reliability and validity of the parent-report AQ in samples of children with ASD needs more investigation. Moreover, underlying differences in the interpretation and reporting of autistic traits in different countries may affect the generalizability of Western screening tools in Eastern cultures. Clearly, there remains a need for structural validation studies to investigate whether the AQ-Short can be adapted as a parent report measure for use across cultures.

The current study's objectives are threefold: (a) examine the factor structure of the parent-report version of the AQ-Short for children with ASD in China and the Netherlands; (b) compare autistic traits between children with ASD in China and the Netherlands; (c) explore the role of SES, children's gender and age on parent-reported autistic traits in China and the Netherlands. As specified in our preregistered analysis plan (<https://osf.io/7xpkj/>), we expect that 1. the underlying factor structures of the AQ-Short for each population are similar; 2. more autistic traits will be reported for the Chinese compared to the Dutch participants; and 3. boys will be reported to score higher than girls on autistic traits in both countries.

Method

Study sample

The current study included parent-reported data on children with ASD from China ($n = 327$, 85% boys, 3 to 17 years) and the Netherlands ($n = 694$, 78% boys, 6 to 16 years). The Chinese sample ($n=327$) was recruited through the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR), the national autism organization in charge of providing services for ASD in China. Members of the CAPPDR service centers from all over China invited their patients and families to participate in our study. This data collection was conducted online in late 2018. Children diagnosed with ASD or receiving an ASD subsidy from the government were included in the final sample. Data of Dutch children with ASD ($n=694$) were collected via the Netherlands Autism Register (NAR, <https://www.netherlandsautismeregister.nl/english/>), an online database that collects information from individuals with ASD and their families. The NAR data have been collected in annual waves since 2013 and cover various domains including general demographics, clinical diagnosis, co-occurring psychiatric conditions, and autistic traits. All participants had a formal ASD diagnosis, the sample did not include control participants.

Measurements

Background information of the children and the parents was collected using structured questions on demographics (age, sex) and socioeconomic status (parents' employment status and family income). Parents reported their employment status in three categories: employed, unemployed and other. Income data were available for 309 Chinese and 143 Dutch parents. Chinese parents reported their monthly income, whereas Dutch parents selected one of eight

predefined yearly income levels. Since the two countries differ in absolute income, the categorization of income levels was based on country-specific percentiles (low: below 30th percentile; middle: 30th-70th percentile; high: above 70th percentile) of the data from the National Bureau of Statistics of China (2019) and Statistic Netherlands (CBS; 2019) separately. We categorized family income into low (China: 0-¥3590 a month, €0-€5532 a year; Netherlands: €0-€30000), middle (China: ¥3590 - ¥9118 a month, €5532- €14052 a year; Netherlands: €30000-€70000), and high income (China: above ¥9118, above €14052 a year; Netherlands: >€70000).

The Autism Spectrum Quotient-Short

The parent-report version of the Autism Spectrum Quotient Short Form (AQ-Short) is based on the adult self-report version (Hoekstra et al., 2010), which includes 28 items comprising two higher-order factors assessing ‘social behavior difficulties’ and ‘a fascination for numbers/patterns’. The higher order social behavior factor consists of Social Skills, Routine, Switching and Imagination. Each statement can be answered on a 4-point Likert scale (1=definitely agree; 2=slightly agree; 3=slightly disagree; 4=definitely disagree). The scoring is reversed for items in which an “agree” response is characteristic for autism (13 out of 28 items). Scores on the AQ-Short range from 28 to 112, with higher scores indicating greater endorsement of autistic traits. The AQ-Short has good sensitivity and specificity in distinguishing individuals with ASD from controls and has been shown to correlate highly with the original 50-item version of the measure (Hoekstra et al., 2011). The AQ-Short has previously been translated into Dutch (Hoekstra et al., 2008). The translation of the Chinese version of the AQ-Short was done by three experts, which followed the forward and backward procedure (Hall et al., 2017). For the parent-report version of the AQ-Short, the first-person perspective (“I”) of the items was changed into a third-person perspective (“He/She”).

Community Involvement

This study was not designed with community involvement, but the content and formulation of the NAR (Dutch) survey was developed together with a panel of individuals with ASD and their parents. The NAR also has several team members with ASD.

Statistical Analysis

Confirmatory Factor Analysis

Before conducting group comparisons, we first needed to make sure the factor structure of the parent-report AQ-Short was comparable between China and the Netherlands. The data was first cleaned, coded, and analyzed using SPSS version 22.0 for Windows (SPSS Inc., Chicago, IL). Following the factor structure identified in adult samples in Hoekstra et al. (2010), a two-factor hierarchical model was implemented in which the social skills, routine, switching, and imagination factors were predicted to load on a higher-order social behavior factor. The numbers and patterns items were predicted to load on a separate factor. This model was estimated in the Chinese and Dutch samples separately. Confirmatory factor analyses (CFAs) on the parent-report AQ-Short were conducted using *MPlus* version 7 (Muthén & Muthén, 2012). To compare the relative fit of the models, approximation fit indices including the comparative fit index (CFI; Hu & Bentler, 1998) and Tucker-Lewis index (TLI; Tucker and Lewis, 1973) and the root mean square error of approximation (RMSEA; Steiger and Lind, 1980) were calculated. For CFI and TLI, values above 0.90 indicate a reasonable model fit, with values above 0.95 indicating a good fit to the data (Hu & Bentler, 1999; Marsh et al., 2004). For RMSEA, values below 0.06 indicate a good fit to the data (Browne and Cudeck, 1993).

Exploratory Factor Analysis

EFA analyses were conducted to further explore the underlying relationships among the items. For these analyses, WLSMV estimation with promax (i.e., oblique) rotation was applied. Norris and Lecavalier (2010) suggest that a scree plot, model fit indices, content and interpretability of the factors, salience of item loadings, items with cross-loadings, and the number of salient items in the factors should be used to ascertain the number of factors to be retained. Items with a factor loading of less than 0.32 and/or items with strong cross-loadings (loaded ≥ 0.40 on more than one factor) were dropped (Tabachnick & Fidell, 2007). Only factors with three or more strongly loading items were considered solid and justifiable factors (Costello & Osborne, 2005).

Internal Consistency and Relationships between factors

Cronbach's alpha and correlations among the latent factors were estimated to measure the internal consistency and the correlations between the identified factors of the EFA model for the Chinese and the Dutch samples separately.

Group Comparison

Differences in demographics and SES characteristics across countries were evaluated using χ^2 tests (for categorical variables) and t-tests (for continuous variables). The impact of demographic variables (age and sex) and SES were evaluated per country. All statistical tests were two-tailed with an alpha of .05. Where appropriate, these were corrected for multiple testing using the false discovery rate (FDR) procedure (Benjamini & Hochberg, 1995). Where

applicable, effect sizes were calculated (Cohen, 2013). Preregistration of this study can be found at Open Science Framework (<https://osf.io/7xpkj/>).

Results

Table 1 presents the primary participant demographic characteristics in the Chinese and Dutch samples. The Dutch sample had a less skewed girl to boy ratio (1:3.5 compared to 1:5.5), was significantly older ($t=-16.95$, $p<.001$, $d=-1.17$). A smaller proportion of the Netherlands sample reported having a low-income (17.5%) compared to the Chinese sample (40.5%). In both countries, most fathers were employed, but more Dutch mothers (65.4%) were employed compared to Chinese mothers (56.9%).

Table 1 The Demographic Variables between China and the Netherlands

Variables	China		The Netherlands		Statistics
	N	% / SD	n	% / SD	
Total N	327	100.0	694	100.0	
Sex					$\chi^2 = 6.87, p < .01$
Male	277	84.7%	539	77.7%	
Female	50	15.3%	155	22.3%	
Mean age	8.59	2.97	11.81	2.54	$t = -16.95, p < .001$
Father's employment status					$\chi^2 = 2.02, p > .05$
Employed	292	89.3%	600	86.5%	
Unemployed	33	10.1%	91	13.1%	
Not reported	2	0.6%	3	0.4%	
Mother's employment status					$\chi^2 = 79.21, p < .001$
Employed	137	41.9%	454	65.4%	
Unemployed	186	56.9%	199	28.7%	
Not reported	4	1.2%	41	5.9%	
Family income level					
Low income	125	40.5%	25	17.5%	
Middle income	132	42.7%	83	58.0%	
High income	52	16.8%	35	24.5%	

Factor Analysis of the AQ-Short in China and the Netherlands

Confirmatory factor analyses were performed for the Chinese and Dutch samples separately. The fit indices for the Chinese AQ-Short model were: $\chi^2 = 1378.68$, $df = 345$, $p < .001$; RMSEA = .096; CFI = .770; TLI = .748. The fit indices for the Dutch CFA model were: $\chi^2 = 1327.69$, $df = 345$, $p < .001$; RMSEA = .064; CFI = .876; TLI = .864. Only the RMSEA value in the Dutch sample indicated a good model fit. The CFI, TLI values indicated moderate to poor model fit for both the Chinese and Dutch samples. Thus, there was little support for the two-factor model previously identified for the self-report adult AQ-Short. We therefore used exploratory factor analysis (EFA) to ascertain an alternate better fitting model separately for the AQ-Short in China and the Netherlands, using the same sample.

Chinese EFA results

The scree plot for the Chinese sample suggested three or four factors. Both 3- and 4-factor models showed good fit, as indicated by RMSEA, CFI, and TLI values (see fit indices in supplementary Table S1). However, the second factor of the 4-factor model only contained one item. Taken together, the scree plot, fit values, and the number of salient items supported a 3-factor model. Item 6 “When s/he reads a story, s/he can easily imagine what the characters might look like” and item 11 “S/he finds making up stories easy” were dropped due to high cross-loadings on two factors ($>.40$). Item 17 “It does not upset him/her if his/her daily routine is disturbed” was dropped

based on a low factor loading ($< .32$). Corresponding to the original AQ-Short factor model, we labeled factors 1, 2, 3 as Numbers and Patterns, Social Skills, and Mind-Reading, respectively. Final factor loadings of the 3-factor model (25 items) for the Chinese sample are presented in Table 2. Correlations among the latent factors for the Chinese sample are shown in Table 3.

Table 2 Chinese AQ-Short fit indices: RMSEA=0.051 CFI=0.952 TLI=0.937

Item	Content	Factor loadings			Original subscale
Factor 1 Number/Patterns		1	2	3	
5	S/he usually notices car numbers or similar strings of information	0.906*	0.150*	-0.024	Number/Patterns
7	S/he is fascinated by dates	0.825*	-0.001	-0.002	Number/Patterns
10	S/he would rather go to a library than a birthday party	0.471*	-0.141*	0.239*	Social Skills
13	S/he is fascinated by numbers	0.872*	0.017	0.042	Number/Patterns
16	S/he notices patterns in things all the time	0.424*	-0.175*	0.173*	Number/Patterns
22	S/he likes to collect information about categories of things (e.g. types of cars, types of bird, types of train)	0.476*	-0.114*	0.241*	Number/Patterns
Factor 2 Social Skills					
1	S/he prefers to do things with others rather than on her/his own	-0.105	0.445*	-0.041	Social Skills
2	S/he prefers to do thing the same way over and over again	0.187*	0.437*	0.312*	Routine
3	If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind	-0.296*	0.402*	0.063	Imagination
4	S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things	0.325*	0.467*	0.262*	Switching
8	In a social group, s/he can easily keep track of several different people's conversations	-0.136*	0.557*	0.086	Switching
9	S/he finds social situations easy	0.013	0.744*	-0.084	Social Skills
12	S/he is drawn more strongly to people than to things	0.046	0.670*	0.032	Social Skills
18	S/he finds it easy to go back and forth between different activities	-0.138*	0.679*	0.008	Switching
19	S/he enjoys doing things spontaneously	-0.045	0.688*	-0.075	Routine
20	S/he find it easy to work out what someone is thinking or feeling just by looking at their face	-0.062	0.594*	-0.001	Imagination
21	If there is an interruption, s/he can switch back to what s/he was doing very quickly	-0.04	0.544*	-0.153*	Switching
24	S/he enjoys social occasions	0.125*	0.837*	-0.125*	Social Skills
26	New situations make him/her anxious	0.066	0.327*	0.144*	Routine
27	S/he enjoys meeting new people	-0.001	0.746*	-0.051	Social Skills
28	S/he finds it very easy to play games with children that involve pretending	-0.136*	0.691*	0.025	Imagination
Factor 3 Mind Reading					
14	When s/he is read a story, s/he finds it difficult to work out the characters' intentions or feelings	0.002	0.101	0.687*	Imagination
15	S/he finds it hard to make new friends	-0.037	0.344*	0.692*	Social Skills
23	S/he finds it difficult to imagine what it would be like to be someone else	0.210*	0.001	0.504*	Imagination
25	S/he finds it difficult to work out people's intentions	0.01	0.299*	0.551*	Imagination
Items omitted from the Chinese AQ-Short					
6	When s/he is read a story, s/he can easily imagine what the characters might look like				
11	S/he finds making up stories easy				
17	It does not upset him/her if his/her daily routine is disturbed				

Table 3 Chinese Geomin Factor Correlations

	1	2	3
1 Number/Patterns	1		
2 Social Skills	-0.194*	1	
3 Mind reading	0.049	0.193*	1

*significant at 5% level

Dutch EFA results

The scree plot for the Dutch sample suggested four or five factors. Only the 4- and 5-factor models showed a good fit in the RMSEA value and the CFI and TLI values (see fit indices in Supplementary Table S2). The fourth factor “Attention Switching” and the fifth factor “Imagination” in the 5-factor model together made up the third factor in the 4-factor model. Even though in the 4-factor model, an “Attention Switching” factor and an “Imagination” factor were effectively combined into one factor, this combined factor was neither conceptually congruent with the theme of their designated factor, nor resembled any factors in the original AQ-Short models (Hoekstra et al., 2010). The five-factor Dutch model was conceptually comparable to the original AQ-Short, although the original two-factor hierarchical model previously identified in adult self-report samples was not replicated in this sample. Thus, the five-factor model was deemed the optimal model. Item 8 “In a social group, s/he can easily keep track of several different people's conversations” was eliminated based on a low factor loading ($< .32$) and item 19 “S/he enjoys doing things spontaneously” was eliminated based on

high cross-loadings on two factors ($>.40$). Corresponding to the AQ-Short, we labeled factors 1, 2, 3, 4, and 5 as Imagination, Numbers and Patterns, Social Skills, Attention Switching, and Mind-reading. Final factor loadings of the 5-factor model (26 items) for the Dutch sample are presented in Table 4. Correlations among the latent factors measuring the internal relatedness of the EFA model for the Dutch sample are shown in Table 5.

Table 4 Dutch AQ-Short fit indices: RMSEA=0.043; CFI=0.963 TLI=0.941

Item	Content	Factor loadings					Original subscale
Factor 1 Imagination		1	2	3	4	5	
3	If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind	0.682*	0.004	0.044	0.052	-0.075	Imagination
6	When s/he is read a story, s/he can easily imagine what the characters might look like	0.834*	0.014	-0.038	0.027	0.084	Imagination
11	S/he finds making up stories easy	0.615*	0.021	0.123*	-0.205*	0.044	Imagination
28	S/he finds it very easy to play games with children that involve pretending	0.418*	-0.017	0.206*	0.056	0.024	Imagination
Factor 2 Number/Patterns							
5	S/he usually notices car numbers or similar strings of information	0.066	0.649*	-0.073	0.183*	0.029	Number/Patterns
7	S/he is fascinated by dates	0.001	0.905*	-0.007	-0.026	-0.041	Number/Patterns
13	S/he is fascinated by numbers	0.103*	0.880*	0.018	-0.094	-0.006	Number/Patterns
16	S/he notices patterns in things all the time	-0.072	0.505*	0.051	0.289*	-0.093	Number/Patterns
22	S/he likes to collect information about categories of things (e.g. types of cars, types of bird, types of train)	-0.198*	0.482*	0.053	0.202*	0.077	Number/Patterns
Factor 3 Social Skills							
1	S/he prefers to do things with others rather than on her/his own	0.029	0.024	0.426*	-0.116*	0.037	Social Skills
9	S/he finds social situations easy	0.023	-0.065	0.591*	0.066	0.184*	Social Skills
10	S/he would rather go to a library than a birthday party	-0.136*	0.092*	0.591*	0.014	-0.006	Social Skills
12	S/he is drawn more strongly to people than to things	0.083	0.121*	0.456*	0.041	0.099	Social Skills
15	S/he finds it hard to make new friends	0.006	0.107*	0.534*	-0.128*	0.191*	Social Skills
24	S/he enjoys social occasions	-0.037	-0.042	0.797*	0.048	-0.077	Social Skills
27	S/he enjoys meeting new people	0.073	-0.035	0.743*	0.013	-0.06	Social Skills
Factor 4 Attention Switching							
2	S/he prefers to do thing the same way over and over again	0.015	0.189*	0.016	0.414*	0.123*	Routine
4	S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things	-0.248*	0.136*	-0.025	0.424*	0.175*	Switching

Table 4 (Continued)

Item	Content	Factor Loadings					Original subscale
17	It does not upset him/her if his/her daily routine is disturbed	0.064	0.034	0.01	0.539*	0.06	Routine
18	S/he finds it easy to go back and forth between different activities	0.05	-0.064	0.044	0.708*	-0.051	Switching
21	If there is an interruption, s/he can switch back to what s/he was doing very quickly	0.089	-0.053	0.024	0.580*	0.019	Switching
26	New situations make him/her anxious	-0.011	0.081	0.248*	0.373*	0.067	Routine
Factor 5 Mind Reading							
14	When s/he is read a story, s/he finds it difficult to work out the characters' intentions or feelings	0.297*	0.107*	-0.103*	0.083	0.439*	Imagination
20	S/he find it easy to work out what someone is thinking or feeling just by looking at their face	0.097	-0.175*	0.066	0.263*	0.392*	Imagination
23	S/he finds it difficult to imagine what it would be like to be someone else	0.074	0.019	0.046	0.032	0.544*	Imagination
25	S/he finds it difficult to work out people's intentions	-0.057	-0.05	0.028	-0.024	0.866*	Imagination
Items omitted from the Dutch AQ-Short							
8	In a social group, s/he can easily keep track of several different people's conversations						
19	S/he enjoys doing things spontaneously						

Table 5 Dutch Geomin Factor Correlations

	1	2	3	4	5
1 Imagination	1				
2 Number/Patterns	0.084*	1			
3 Social skills	0.244*	0.108*	1		
4 Attention switching	0.302*	0.118*	0.401*	1	
5 Mind reading	0.350*	0.171*	0.274*	0.430*	1

*significant at 5% level

Internal Consistency and Relationship between factors in the EFA models

Cronbach's alpha scores $> .70$ indicate good internal consistency (Streiner, 2003). However, when dealing with subscales derived from a single questionnaire, values around .60 are considered acceptable (Nunnally, 1975). In the Chinese sample, Cronbach's α for the total AQ-Short, Numbers and Patterns, Social Skills and Mind-reading subscales were 0.77, 0.78, 0.84, and 0.65, respectively. For the Dutch sample, Cronbach's α for total AQ-Short, Imagination, Numbers and Patterns, Social Skills, Attention Switching and Mind-reading were 0.82, 0.71, 0.76, 0.75, 0.64, and 0.62, respectively.

Overall, the relations between factors in the Chinese and Dutch EFA models ranged from very weak to moderate (.05 to .43). Against expectation, a negative modest correlation (-.19) was found between the Social Skills and Numbers and Patterns factors in the Chinese sample, indicating that increased attention to numbers and patterns was associated with better social skills.

Impact of age, sex, and socioeconomic status (SES) based on country-dependent analysis

Due to different factor structures in the Chinese and Dutch sample, it was not possible to compare the AQ-Short total and factor scores between countries. However, we were able to examine the impact of demographic variables *within* both countries.

There were no significant sex differences in total AQ-Short scores within both the Chinese and Dutch samples. Dutch boys were reported to score significantly higher than girls on the Numbers and patterns factor ($t = 4.60, p < .001, d = 0.430$; males = 11.40 [SD=3.63], females = 9.90 [SD= 3.34]). No other sex differences across the AQ-Short subscale scores were found within the Dutch sample. There were no significant sex differences found in any of the subscales within the Chinese sample.

In the Chinese sample, older children had lower total AQ-Short scores and lower Numbers and Patterns scores than young children ($r = -.16, p = .04$; $r = -.14, p = .043$). Similarly, older Dutch children had lower total AQ-Short scores ($r = -.10, p = .042$), Attention switching scores ($r = -.13, p = .01$) and Numbers and patterns scores ($r = -.20, p < .001$). The specific results of sex and age differences in both countries are shown in supplementary Table S3.

Within the Chinese sample, parents who were unemployed reported fewer autistic traits (AQ-Short total) and better social-skills for their child compared with employed Chinese mothers ($F = 4.82, p = .04, \eta^2 = .029$; $F=6.668, p = .01, \eta^2 = .040$). Chinese parents in the low income bracket also reported fewer autistic traits and better mind-reading skills in their children with ASD ($F = 4.41, p = .04, \eta^2 = .028$; $F = 9.58, p < .001, \eta^2 = .059$) than children of parents with middle and high income levels (see supplementary Table S4). In the Dutch sample, parents who were unemployed reported worse mind-reading skills for their child compared with those who were employed ($F = 5.59, p = .03, \eta^2 = .016$). There was no relationship between AQ-Short subscale scores and income level in the Dutch sample (see supplementary Table S5).

Item comparison between China and the Netherlands

To get a deeper understanding of potential cross-cultural differences on the AQ-Short in children with ASD, the nonparametric Mann-Whitney U test ($p < .05$) was used to test for cross-cultural differences at an item level (see supplementary Table S6). Out of the 23 ‘Social behaviors’ items based on the original AQ-Short factor structure, there was a higher endorsement on 9 items (39%), lower endorsement on 7 items (30%) and no significant difference on the other 7 items (30%) for the Chinese sample compared with Dutch participants. Out of 5 ‘Numbers and patterns’ items based on the original AQ-Short factor structure, the Chinese sample showed a higher endorsement of 1 item (20%), lower endorsement on 3 items (60%) and no significant difference on the other 1 items (20%). We also checked potential sex differences on item level across countries. Out of the 28 items, boys showed higher endorsement on 4 numbers and patterns items (80%, out of 5 items) and 3 social behaviors items (13%, out of 23 items), lower endorsement on 5 social behaviors items (22%, out of 23 items) and no significant differences on the other 16 items compared with girls. No cross-cultural sex differences on the AQ-Short item scores were found.

Discussion

This study examined and compared the factor structure of the parent-reported AQ-Short for children with ASD from China and the Netherlands. Initial CFA models

showed that the AQ-Short child version did not map onto the two-factor hierarchical model previously identified in typically developing adults (Hoekstra et al., 2010) and adults with ASD (Grove et al., 2016). Subsequent exploratory factor analyses supported a three-factor model in the Chinese sample (Numbers and Patterns, Social Skills, and Mind-reading) and a five-factor model in the Dutch sample (Imagination, Numbers and Patterns, Attention Switching, Social Skills, and Mind-reading). SES, sex and age influences on AQ-Short scores were observed. Older children tended to receive lower AQ-Short scores in both countries. Chinese children from low SES families also tended to receive lower AQ scores.

Even though the EFA results showed a different factor structure for the Chinese and Dutch parent-reported AQ-Short, the Social Skills factor, Numbers and Patterns factor, and Mindreading factor emerged in both models, suggesting that the same types of behaviors tended to group together in different cultures. Consistent with the original adult AQ-Short (Hoekstra et al., 2010), a Social Skills factor and a Number and Patterns factor was found. However, the items loading on the Social Skills factor in the Chinese model included a combination of items loading on separate factors in the Dutch model (Social Skills, Attention Switching, and Imagination), indicating that certain behaviors group together differently across cultures. Specifically, Social Skills, Attention Switching and Imagination factors appear more closely linked in children with ASD in China than in the Netherlands.

How parents interpret and report on their child's behavior is likely influenced by culture (Norbury & Sparks, 2013; de Leeuw et al., 2020). Certain AQ-Short items

may therefore be interpreted differently in Eastern and Western cultures. For example, item 18 “S/he finds it easy to go back and forth between different activities”, is part of attention switching in the Netherlands, but loaded on the social skills factor in China. Possibly, in China, social skills depend more strongly on the ability to switch between activities and contexts, so as to preserve group harmony. There is also a special term, Ren Qing (人情), for social favors exchanged in the form of money, information, or affection. Item 20 “S/he finds it difficult to work out other’s thinking and feeling by looking at their face” loaded onto the Social Skills factor in the Chinese sample, but in the Dutch sample, it loaded onto the Mind-reading factor. The concept of Mind-reading, describing difficulty in perspective-taking (Baron-Cohen et al., 1985), emerged as Communication/Mindreading in Austin (2005) ’s 3-factor model (Social skills, Attention to details/patterns and Mindreading/Communication). Perspective taking may depend less on the ability to decipher someone’s facial expression in China, but more so on the understanding and incorporation of the entire social context. This would be in line with earlier study findings that Asian participants attended to the whole social context when interpreting facial expressions, while American participants focused exclusively on faces (e.g., Masuda et al., 2008). Moreover, Chinese parents tended to endorse social behavior items slightly more compared to Dutch parents based on the original AQ-Short factor structure. Dutch parents more likely endorsed number and pattern items compared to Chinese parents. In sum, there may be subtle cross-cultural differences in how parents reflect on their children’s social behaviors.

Of further note is the modest negative correlation between Numbers and Patterns and Social Skills in the Chinese sample. This negative correlation has also been reported in previous studies using the AQ (Kloosterman et al., 2011; Lau et al., 2013; Ward et al., 2021). The items assessing interests in numbers and patterns may not be a good measure of autistic traits in Chinese children, as also indicated by the large proportion of Chinese parents that reported to “strongly disagree” on all of the Numbers and Patterns items (see supplementary Figure S1). Thus, a large number of Chinese parents in this sample disagreed that their child with ASD showed a particular interest in numbers and patterns. In the Dutch sample, items 5, 7 and 13 of the Numbers and patterns factor also showed an inverse distribution. An alternative explanation of these seemingly counterintuitive results is to conceive autism as a multi-dimensional spectrum rather than a linear one. Consistent with a two-dimensional spectrum, Kitazoe et al. (2017) performed a cluster analysis of the AQ on a Japanese sample and found that participants scoring high on total AQ could be divided into two groups: one with low scores on the Attention to detail subscale but high scores on the other four subscales and the other with high scores on all five subscales. Thus, it is conceivable that some individuals with ASD may have less interest in details.

Parent-reported AQ-Short factor scores generally were the same for boys and girls in the present study, conflicting with some previous findings on sex differences in the social behavior factor of the self-report AQ-Short in adults with ASD (Hoekstra et al., 2011; Grove et al., 2016). The discrepancy between these findings and other previous adult AQ-Short studies may be a) because women with ASD may experience

more problems or are more aware of their autistic traits than men with ASD (Lai et al., 2011), or b) parents may not recognize all autistic traits of their daughters, perhaps because girls are better at camouflaging (Jorgenson et al., 2020; Lai et al., 2016). The compensatory camouflaging may help girls receive a more similar levels of parent-reported autistic traits compared to boys. However, boys were reported to have more interest in numbers and patterns than girls in the Dutch sample, which is consistent with previous research (Grove et al., 2016; Hattier et al., 2011). The comparison between boys and girls at the item level across countries also indicated subtle biases. Boys with ASD showed a higher endorsement of the Numbers and patterns items. In both samples, parents reported fewer autistic traits and less interest in numbers and patterns for older children, suggesting that autistic symptoms and special interests may decrease with age (Waizbard-Bartov et al., 2020). However, parents of older children may also be more used to their child's difficulties and thus underreport, despite their child potentially experiencing the same level of autistic traits as younger children. It should be noted that the reported correlations are very small. However, Bujang & Baharum (2016) found that the correlation coefficient of 0.1 can be considered important when the lowest minimum sample size is 782. The findings from these groups should be interpreted with care.

SES was associated with parent-reported autistic traits. Unemployed Chinese mothers reported fewer autistic traits and better social skills for their child than employed Chinese mothers. Unemployed Dutch mothers reported worse mindreading skills for their child than employed Dutch mothers. Furthermore, low-income Chinese

families reported fewer autistic traits than middle and high-income families, which is inconsistent with previous research in Western countries showing that low SES families were more likely to endorse autistic traits (Khowaja et al., 2014; Scarpa et al., 2013). This inconsistency might be because low-income families in China are less willing to report autistic traits due to stigma and misconceptions of autism (Su et al., 2019; Sun et al., 2013). Alternatively, low-income families in China may have lower awareness and may not recognize these autistic traits in their children (de Leeuw et al., 2020). No association with family income level was found in the Dutch sample. Larger income inequality differences (using the World Bank's Gini coefficient) and higher poverty levels in China may have resulted in more pronounced effects of SES in China compared to the Netherlands. In addition, the relatively low number of low-income families in the Dutch sample resulted in poor statistical power to detect an effect. More studies are needed to investigate the effects of SES on parent reported autistic traits. This is particularly important as autism may be underdiagnosed in low-income families in some cultural contexts (Durkin et al., 2015) and previous studies have suggested screening accuracy may be lower in low-income families (Gurthie et al., 2019).

Limitations

The current findings should be interpreted with caution. First, as participants' intellectual ability was not formally assessed, any between-country differences may also be due to differences in cognitive ability levels. Second, the AQ-Child includes

items related to children's subjective, internal states, including imagination and mindreading, which parents may find difficult to report on. While previous studies showed adequate concurrent validity, good internal consistency and good test-retest reliability of the Mind-reading and/or Imagination subscales (Sun et al., 2019; Gomez et al., 2018), it would be worthwhile for future studies to examine differences in validity of the imagination/mindreading subscales and the social behavior subscales. Furthermore, study recruitment was not the same in both countries. Chinese participants were recruited via various services for children with ASD around China and most of these participants were identified at a younger age. In contrast, Dutch data were collected through an online volunteer register, including children with ASD who were not necessarily under treatment or assessment in clinics. Behavior of children receiving services may be rated differently than those who are not under treatment in clinics. Moreover, as only children with autism were examined, it is uncertain whether the factor structure differences are specific to Chinese children with autism or reflect more general cross-cultural differences. For a better understanding of cross-cultural differences, it would be worthwhile to examine which items of the AQ-Short best discriminate between clinical and non-clinical groups across cultures. As such, this study's outcome should be taken into consideration as preliminary.

Conclusion

In summary, the factor structure of the parent-reported AQ-Short was substantially different between China and the Netherlands, suggesting that interpretation and reporting of autism symptoms may be culture-dependent. Differences in item-factor loadings indicate variation in the reporting of autistic traits between parents from China and the Netherlands, and this may hamper cross-cultural comparisons. This indicates that the Chinese version of the AQ-Short may assess slightly different autistic traits than the Western version. It would be worthwhile for future research to interview Chinese parents of children with ASD from low-income families to better explore how they recognize, interpret and report their child's autistic traits. This study is the first to test the factor structure of the parent-report AQ-Short across cultures. While our findings require replication in wider samples, including children without ASD, we were able to show that the items of the AQ-Short generally detect autistic traits equivalently in boys and girls with ASD. Autistic traits and special interests may decrease with age, and this decrease may be similar across countries. However, longitudinal studies are needed to further examine the trajectories of autism severity change during childhood. Furthermore, low SES Chinese families reported fewer autistic traits, making them vulnerable for under-detection, which was not the case in our Dutch participants. The under-reporting of autistic traits in low SES families deserves further research to address culture-specific disparities in autism diagnoses and service access.

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Chapter 3: Parenting stress among Chinese and Dutch caregivers of children with autism

Liu, F., Begeer, S., Hoekstra, R. A., Bai, Q., Wang, C., & Scheeren, A. M. (2023). Brief report: Parenting stress among Chinese and Dutch caregivers of children with autism. *Research in Autism Spectrum Disorders*, 107, 102224.

Abstract

Parenting stress is higher in caregivers of autistic compared to typically developing children. Culture and context may impact parenting stress. Some studies suggest that Asian caregivers with autistic children experience more stress compared to European/American caregivers although similar levels have also been reported. Child and caregiver factors (age, gender, income and educational level) may affect parenting stress differently in Asian and European countries. We compared parenting stress levels between caregivers of autistic children from China and the Netherlands, and examined the impact of caregiver factors (age, income, educational level) and child factors (gender) on parenting stress in both countries, and exploring the association with caregivers' worries about COVID-19. We used the 11-item Parenting Distress Subscale (PD) of the Nijmegen Parenting Stress Index (NPSI-PD) to compare parenting stress between two groups: 95 Chinese caregivers (76 boys; 19 girls) and 118 Dutch caregivers of autistic children (93 boys; 25 girls) aged 2-16 years. Controlling for child's gender, caregivers' age, income, educational level and COVID-19-related concerns. Chinese caregivers of autistic children reported higher parenting stress levels than Dutch caregivers, despite fewer COVID-19 worries. Younger caregivers reported more parenting stress in both countries. Culture and context may play a role in the parenting stress of caregivers with an autistic child. Factors influencing parenting stress in different socio-cultural settings are an important issue that requires further study.

Key words

Autism spectrum disorders, parenting stress, caregivers, culture, China, the Netherlands

Introduction

All caregivers experience some degree of parenting stress (Reitman et al., 2002; Tharner et al., 2012). Due to the developmental, behavioral and social challenges associated with autism (Barroso et al., 2018), caregivers of children with Autism (Autism Spectrum Disorder) generally experience higher than average levels of stress, with negative effects on well-being (Shorey et al., 2020), marital satisfaction (Ilias et al., 2017), parenting quality and children's development (Tharner et al., 2012).

Some studies have suggested that Eastern Asian caregivers of autistic children experience more stress than their Western European counterparts (DeLambo et al., 2011; Giannotti et al., 2021), though similar stress levels were also reported (Smith et al., 2021). Eastern Asian countries (e.g., China) emphasize interdependence and in-group (family, community, and society) norms compared to Western European countries (e.g., the Netherlands), where individualism and independence are valued more (Meyer, 2010). Chinese caregivers tend to value their own needs less and fear the non-conformity of their autistic child (McCabe, 2007). This promotes self-sacrificing behavior and social isolation, which negatively impact caregivers' well-being (Smith et al., 2021). Knowledge about autism may be lower in the Chinese community (Yu et al., 2020), and stigmatization and discrimination may be higher (Chan & Lam, 2018; Mak & Kwok, 2010).

In addition, the availability, accessibility, affordability, and acceptability of support services differ between the high-income countries (e.g., the Netherlands) and low and middle-income countries (e.g., China). The Netherlands has adequate formal support services in education and healthcare, along with sufficient financial support for families with special needs nationwide (van Kessel et al., 2019). While, China has a scarcity of child psychiatrists (Wu & Pan, 2019), limited government financial support and professional support is concentrated in large cities (Sun et al., 2013). When comparing country differences in parenting stress of

autistic children, contextual backgrounds, such as socioeconomic status (SES) and stressful situation (e.g. Covid-19 worries) need to be taken into account.

Previous findings suggesting that the level of parenting stress may differ across cultures were based on small samples of autistic children (Giannotti et al., 2021) or a narrow focus on racial and ethnic variations within a single country (DeLambo et al., 2011). In addition, older age (Smith et al., 2008), female gender of the child (Mandell & Salzer, 2007), and higher parental education and income level (Athari et al., 2013) are associated with lower parenting stress, while the effects of socioeconomic status (SES) and parent's age vary across countries (DeLambo et al., 2011; Jiar & Xi, 2012). Therefore, in this study, we will examine child and caregiver factors of parenting stress in China and the Netherlands.

In this pre-registered study (<https://osf.io/p8zyd/>), we will (a) compare parenting stress levels between caregivers of autistic children from Eastern Asian (China) and Western European countries (the Netherlands) using the abbreviated Parenting Stress Index (Brock et al., 1992), and (b) examine the impact of caregiver (age, income, educational level) and child (gender) factors on parenting stress in both countries. As we collected the data during the COVID-19 pandemic, we will also explore whether caregivers' worries about COVID-19 are associated with parenting stress. We expect that caregivers of autistic children in China experience higher levels of parenting stress than Dutch caregivers.

Method

Study sample

Participants were 99 Chinese caregivers (caregivers of 79 boys and 20 girls), and 197 Dutch caregivers (caregivers of 160 boys and 37 girls) of children with autism diagnosed according to DSM-IV or DSM-5 criteria. In China, researchers of the Autism Research Center,

Nankai University, Tianjin City, invited caregivers with autistic children to participate in our study via an online survey between December 2020 and March 2021. Tianjin City, one of the four provincial cities in China with a population of approximately 13.63 million (https://www.tj.gov.cn/sq/tjgb/202303/t20230317_6142972.html?eqid=9508506200004f30000000564893326), plays a leading role in providing autism rehabilitation service. It has established more than 100 service centers for autism, 64 of which are designated rehabilitation institutions (out of 2304) by the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR), indicating a well-organized distribution of rehabilitation facilities and high capacity and quality of professional service (source: <https://www.cappdr.org/>). To ensure a representative sample and wider geographical coverage, the survey was distributed to caregivers across multiple provinces in China, such as Zhejiang, Guangdong and Jiangsu.

The Dutch data were collected via the Netherlands Autism Register. The Dutch data were collected between June and August 2020. In both China and the Netherlands, data were collected after the first wave of the COVID-19 virus, when governmental restrictions had loosened up (e.g., schools, restaurants, and public transportation were reopened). The average numbers of reported deaths from COVID-19 per week were below 5 in both countries.

Measurements

The 11-item Parenting Distress Subscale (PD) of the Nijmegen Parenting Stress Index (De Brock et al., 1992), a modified Dutch version of the Parenting Stress Index-Short Form (Abidin, 1983; McStay et al., 2014) includes questions like: “Being a parent of this child is harder than I thought”. Answers range from 1 (totally disagree) to 6 (totally agree), resulting in a total stress score, with higher scores representing more stress. The translation of the Chinese version of the 11-item NPSI-PD was done by three researchers, following the forward and

backward procedure (Hall et al., 2017). The Cronbach's alpha reliability of the NPSI was between .92 and .95 (De Brock et al., 1992). High internal consistency was found in this study in both the Chinese (Cronbach's alpha = 0.84) and Dutch (Cronbach's alpha = 0.90) samples.

Caregivers' educational level was categorized into the low, middle and high level of education based on the Chinese and Dutch educational system separately. Primary school and special school were categorized into low level of education, secondary school were categorized into middle level of education, and university (Bachelor, Master, Doctoral) were categorized into high level of education in both countries.

Family income was categorized into low (China: 0-¥4000 a month, €0-€6252 a year; Netherlands: €0-€30000), middle (China: ¥4000 - ¥10000 a month, €6252- €15629 a year; Netherlands: €30000-€70000), and high income (China: above ¥10000, above €15629 a year; Netherlands: >€70000) based on country-specific percentiles (low: below 30th percentile; middle: 30th-70th percentile; high: above 70th percentile) of the National Bureau of Statistics of China (2020) and Statistics Netherlands (CBS; 2020) separately.

COVID-19-related worries were assessed by self-reported worries about 1) the COVID-19 pandemic, 2) getting sick, and 3) someone close getting sick. The first item "how worried have you been about the COVID-19 crisis in recent weeks?" was rated on a 10-point scale ranging from "not worried" (rated as 1) to "extremely worried" (rated as 10). Two items asking worries about "getting sick yourself" and "someone close to you getting sick" were each rated on a 5-point scale, ranging from "never" (rated as 1) to "always or almost always" (rated as 5). The score from the latter two items were multiplied by two, resulting in a standardized rating out of 10 for each. By summing up the scores from all three items, a maximum total score of 30 was achievable. A higher score indicates more COVID-19-related worries. High internal consistency was found in this study in both the Chinese (Cronbach's alpha = 0.83) and Dutch (Cronbach's alpha = 0.82) samples.

Data analysis

Prior to the main cross-country comparison analysis, we tested the factorial validity of the NPSI-PD to investigate whether the questionnaire assesses the same construct in China and the Netherlands. We conducted confirmatory factor analyses (CFAs) on the NPSI-PD using *Mplus* version 7 in Chinese and Dutch samples separately. A hierarchical multiple regression analysis was used to examine predictors of parenting stress, such as caregiver factors (age, income, educational level) and child factors (gender) and COVID-19 worries (step 1), followed by country (step 2) and the interaction terms between caregiver/child factors and country (step 3).

Based on a power of 0.95 and an alpha level of 0.05, the required total sample size to detect a medium effect ($f = 0.15$) in a multiple regression analysis is 160 participants. This sample size criterion was met (Cohen et al., 2003).

Results

Due to missing values on caregivers' age, family income and educational level, 95 Chinese and 118 Dutch participants (25-57 years) were included in the final analysis (see Table 1 for participant details). Caregivers included in the analysis did not differ from caregivers excluded from the analysis regarding their age, gender, Covid-19 worries, and parenting stress (see supplementary Table S7). Most caregivers in both countries were well educated (middle to higher educational level; 92%) and had middle to higher-level family income (83%). A majority of the respondents were mothers (91%). Children with autism were aged between 2.0 and 16.1 years ($M = 9.64$ years, $SD = 4.24$) in both countries. Chinese children were significantly younger than the Dutch children ($M_{\text{Chinese}} = 6.01$, $M_{\text{Dutch}} = 12.56$, $t = 17.538$, $p < .001$). Dutch

caregivers reported significantly more Covid-19 worries than Chinese caregivers ($t = 3.92$, $p < .001$, $d = .53$).

The scree plots for both the Chinese and Dutch data confirmed the one-factor model of NPSI-PD (see Supplementary Figure S2 and Supplementary Table S9), in line with the original NPSI-PD subscale (De Brock et al., 1992). The CFA results partially confirmed the fit for the one-factor model (See factor analysis details in supplementary materials).

Table 2 shows the results of the hierarchical multiple regression analysis. Pearson correlation coefficients between child/caregiver factors and parenting stress are shown in Supplementary Table S8. As child's age was highly correlated with the country ($r = -.770$, $p < .0$), we excluded child's age in the multiple regression analysis but examined the association with child's age separately in the Chinese and Dutch samples. Within both groups, children's age and parenting stress are not significantly correlated (Chinese: $r = -.025$, $p = .785$; Dutch: $r = .074$, $p = .476$).

Table 1 Parent and child demographics and characteristics according to cultural background ^a

	Chinese (n=95)		Dutch (n=118)		t / χ^2
	n (%)	M (SD)	n (%)	M (SD)	
Child's gender					.045
Boys	76 (80)		93 (78.8)		
Girls	19 (20)		25 (21.2)		
Child's age (2-16 years)		6.01 (2.70)		12.56 (2.73)	17.538**
Informant					13.246*
Mother	79 (83.2)		115 (97.5)		
Father	16 (16.8)		3 (2.5)		
Caregiver's age		35.99 (4.62)		45.13 (5.28)	13.263**
COVID-19 worries (5-30)		13.59 (6.07)		16.64 (5.30)	3.917**
Primary caregiver educational level					9.957*
Low educational level	10 (10.5)		5 (4.2)		
Middle educational level	17 (17.9)		42 (35.6)		
High educational level	68 (71.6)		71 (60.2)		
Family income level					2.021
Low income level	13 (13.7)		25 (21.2)		
Middle income level	51 (53.7)		58 (49.2)		
High income level	31 (32.6)		35 (29.7)		
Parenting Stress (11-66)		43.36 (8.45)		32.92 (11.69)	-7.56**

SD: standard deviation.

* $p < .01$, ** $p < .001$

a. Final samples included in the hierarchical multiple regression analysis

Table 2 Hierarchical Multiple Regression analyses of demographic variables and country as predictors of parenting stress in ASD

Predictors	b	SEb	β	R ² change
Step 1				.15**
Constant	51.15	6.72		
Child gender	.46	1.85	.02	
Caregivers age	-.58	.11	-.34**	
Family income level	-.99	1.14	-.06	
Caregivers educational level	1.72	1.28	.09	
COVID-19 worries	.48	.13	.24**	
Step 2				.16**
Constant	2.60	9.31		
Child gender	1.54	1.68	.05	
Caregivers age	.05	.14	.03	
Family income level	-.97	1.03	-.06	
Caregivers educational level	1.73	1.16	.09	
COVID-19 worries	.66	.12	.33**	
Country	12.92	1.88	.56**	
Step 3				.03
Constant	-23.50	23.51		
Child gender	7.19	5.13	.25	
Caregivers age	-.11	.41	-.06	
Family income level	-.50	3.13	-.03	
Caregivers educational level	6.21	3.69	.33	
COVID-19 worries	1.49	.39	.75**	
Country	30.06	14.82	1.29*	
Country \times Child gender	-4.15	3.36	-.31	
Country \times Caregivers age	.11	.28	.15	
Country \times family income level	-.28	2.11	-.04	
Country \times educational level	-2.96	2.32	-.42	
Country \times COVID-19 worries	-.56	.24	-.50*	

* $p < 0.05$ ** $p < .001$

At Step 1 of the multiple regression model, 15% of the variance in parenting stress was explained by caregiver factors, child factors and COVID-19 worries, $F(5,212) = 7.37, p < .001$. Younger caregivers ($\beta = -.34, p < .001$) and caregivers with more COVID-19 worries ($\beta = .24, p < .001$) reported more parenting stress. Other demographic factors did not make a significant independent contribution to the variance in parenting stress.

At Step 2, factor Country explained significant variance (15.9%) in parenting stress ($\beta = .56, p < .001$) over and above the other factors, indicating that Chinese caregivers reported higher parenting stress compared to Dutch caregivers when controlling for the other demographic variables ($M_{\text{Chinese}} = 43.36, M_{\text{Dutch}} = 32.92, t = -7.56, p < .001$). The parenting stress levels in Dutch caregivers was similar to those previously reported in Dutch caregivers raising an autistic child using the same measurement ($M = 32.38$) (Clifford et al., 2022). The association between informants' age and parenting stress lost significance after adding Country to the regression model.

In Step 3, adding interaction terms to the model did not add explained variance in parenting stress, but the association between parental COVID-19 worries and parenting stress did vary significantly per country ($\beta = -.50, p = .023$). In both groups of caregivers, there is a small positive association between COVID-19 worries and parenting stress, but this association is significantly stronger in the Dutch sample (see Figure 1).

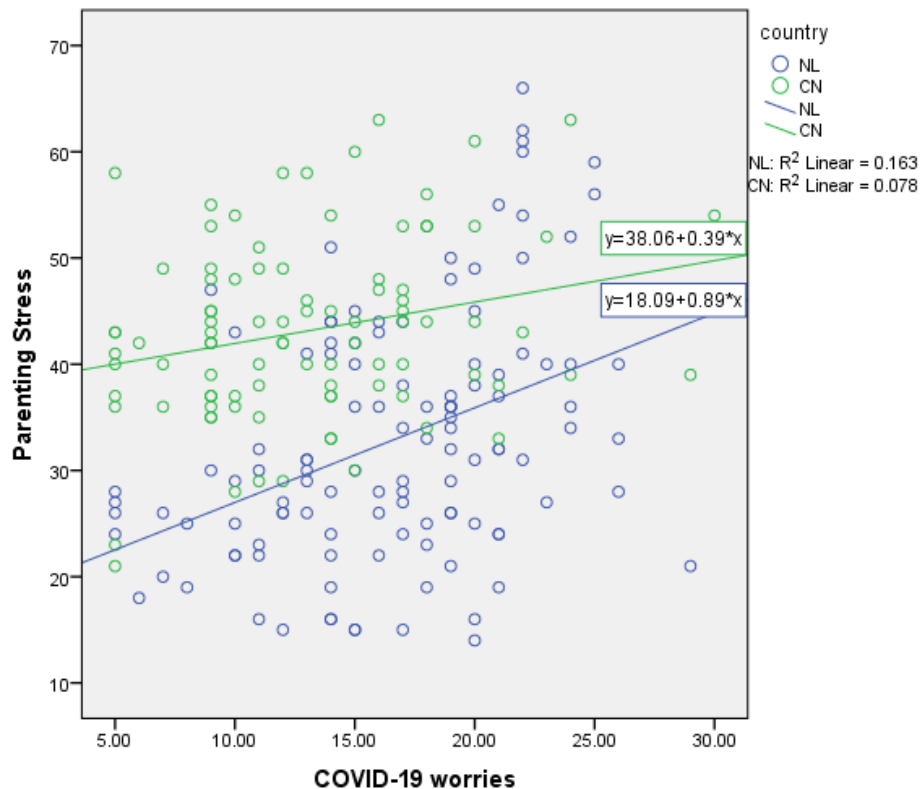


Figure 1 The association between COVID-19 worries and parental stress in both countries

Discussion

The one-factor model of the parenting stress scale was confirmed in China and the Netherlands. Chinese caregivers of autistic children reported significantly higher parenting stress levels than Dutch caregivers. Younger caregivers and caregivers with more COVID-19 worries reported more parenting stress in both countries. Family SES and children's age were not associated with parenting stress.

Consistent with previous studies that reported higher parenting stress in Eastern Asian caregivers compared to Western European caregivers (DeLambo et al., 2011; Giannotti et al., 2021), our findings reveal that Chinese caregivers of autistic children experienced higher levels of parenting stress compared to Dutch caregivers. At least three cultural and contextual factors may account for this finding. First, the focus on family relationships and obligations in Asian

culture may promote self-sacrificing behavior and the social isolation of caregivers, negatively affecting their mental health (Grace et al., 2018). In Western European cultures (e.g., Dutch culture), caregivers may try to seek more external support to help their child live independently (Chun et al., 2006), thereby lowering their parenting stress. Secondly, the Chinese care and support system for autistic individuals may be limited due to restricted access and affordability (de Leeuw et al., 2020; Durkin et al., 2015), lack of experienced and qualified practicing clinicians (Reardon et al., 2017) and low confidence in available interventions (Cauce et al., 2002). External resources, such as formal support services, are an important protective factor against parenting stress (Liao et al., 2022; Zeng et al., 2020). Additionally, China does not have a well-developed social security or welfare system (Huang et al., 2013). Very few families can afford treatment and support for their children with autism on a regular basis. Thirdly, Chinese caregivers may also be burdened with concerns such as loss of face (*mianzi*) due to their autistic child's social and behavioral difficulties. 'Mianzi' (or 'lian' in mandarin Chinese) refers to a person's desire to maintain their social image (Mak & Kwok, 2010; Yabuuchi, 2004).

COVID-19 worries and parenting stress were associated in both countries. The fact that Chinese caregivers reported more parenting stress, but fewer COVID-19 worries than the Dutch caregivers, suggests that the group difference in parenting stress cannot be attributed to generally higher stress levels in all domains.

Consistent with previous findings, younger caregivers reported more parenting stress in both countries (Cheung & Yeung, 2021). It is possible that younger caregivers are in general more inexperienced in life and may exhibit lower levels of confidence in their parenting ability. The "wear and tear" hypothesis suggested that as a child with Autism Spectrum Disorder (ASD) reaches adolescence, the persistent nature of parenting stress may gradually accumulate over time, leading to an elevated sense of burden in caregiving, heightened levels of intrapersonal distress, and increased maladaptive coping strategies appear (Cadman et al., 2012; Rezendes &

Scarpa, 2011). Notably, a large proportion of the caregivers in our study were with children in pre-school and early school ages and most of them were newly diagnosed with autism (50% of Dutch participants and 95% of Chinese participants). Therefore, our findings may reflect that the acute/sub-acute responses of caregivers which could be influenced by their age/maturity. These findings underscore the importance of providing targeted support and resources, such as the utilization of adaptive coping strategies (e.g. cognitive reframing; seeking social support), to younger caregivers who may be facing unique challenges in their caregiving journey.

We found no associations between family SES, children's age and parenting stress, possibly due to a lack of variance in SES. Although the age of a child with autism is a variable that has typically been found to affect parenting stress in a American/ European context (Rivard et al., 2014; Smith et al., 2021), there are some inconsistent findings in an Asian context (DeLambo et al., 2011; Jiar & Xi, 2012). Because autistic children generally tend to be more highly dependent on their caregivers' support compared to their non-autistic peers, the age of the children may not influence their caregivers' stress as much (McStay et al., 2014).

The higher levels of parenting stress in Chinese compared to Dutch caregivers emphasizes the necessity of supporting caregivers of children with autism through tailored interventions that take caregivers' cultural and contextual backgrounds into account. Interventions aimed at stress management and coping skills, reducing self-blame and worries associated with perceptions of competence and parental role burden may be particularly beneficial for (younger) Chinese caregivers (Chan et al., 2018; Hu et al., 2019; Lai et al., 2015). Social support services, including individualized and appropriate educational services, should be contextually adapted, physically available (both in major cities and remote areas), and low-cost access for Chinese families with autism, especially those with lower SES, to reduce the barriers to help-seeking (Divan et al., 2021; Huang et al., 2013). More knowledge of autism and

developing trusting relationships with families is also required to reduce social stigma in the Chinese population (Huang et al., 2019).

Some local governments in China have provided respite care services and enhanced communication between families with autism (Chan et al., 2018; Yu et al., 2016). As a result, they observed considerable improvements in parental mental health (Wang & Hu, 2014). Moreover, the positive association between COVID-19 worries and parenting stress in both countries suggests that caregivers of autistic children may need professional help to reduce parenting stress in particularly stressful situations such as the COVID-19 pandemic. To address the specific challenges posed by the pandemic, various forms of support are necessary, including online support resources, access to child mental health care and information, and empathy from healthcare professionals and other support networks. These measures can be particularly effective in helping caregivers cope with the increased stress and challenges brought about by the pandemic.

Our current research has some limitations, the heterogeneity of our sample in terms of child age, caregivers' age and educational background may limit comparability. Second, low SES caregivers may have limited access to the internet or are difficult to reach for research, and this may particularly be true in China (the proportion of individuals using the internet nationwide is 70% in China and 91% in the Netherlands; World Bank, 2020). Third, we did not collect data about children's severity of autistic traits or co-occurring behavioral problems. This limitation means we can't rule out the possibility that the higher level of parenting stress found in Chinese caregivers is explained by greater symptom severity in their children (Ilias et al., 2018; Ingersoll & Hambrick, 2011; Liu et al., 2021; McStay et al., 2014).

Our results suggest that culture and context play an explanatory role in parenting stress levels of caregivers of autistic children, with Chinese caregivers reporting higher stress levels than Dutch caregivers. Younger caregivers of autistic children in particularly stressful situations

such as the present COVID-19 pandemic may need professional help to reduce parenting stress. The needs of Asian caregivers with autistic children require more careful examination to inform the development of culture-specific support to help buffer parenting stress.

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Chapter 4: Autistic adults in China and the Netherlands: Proxy-reported Community integration and life satisfaction

Liu, F., Begeer, S., Hoekstra, R. A., Wang, C., & Scheeren, A. M. (2024). Autistic adults in China and the Netherlands: Proxy-reported community integration and life satisfaction. *Autism*, 13623613241258182. <https://doi.org/10.1177/13623613241258182>

Abstract

Despite an estimated population of 10 million autistic individuals, there is still a significant lack of research on autistic adults in China. This study aimed to investigate the extent and factors influencing community integration (employment, independent living, friendship) and life satisfaction among young autistic adults in China, and compare them with an autistic adult sample with similar characteristics (58-63% with a reported IQ below 70) from the Netherlands. Data were collected via online surveys to the caregivers of 99 young autistic adults (18-30 years) in China and 109 in the Netherlands, because the autistic adults were not able to fill in the survey independently. Autistic adults in both countries were reported to have limited community integration, as indicated by low rates of employment, limited independent living, and few close friendships. Proxy-reported life satisfaction of autistic adults seemed relatively low in both countries, but even lower in Chinese adults, possibly due to limited awareness and acceptance of autism in China, inadequate or inaccessible support services, higher parenting stress, or general cross-country differences in well-being. In general, the findings indicate a common challenge faced by autistic adults with high support needs in both China and the Netherlands.

Key words Autistic adults, community integration, cultural and contextual, life satisfaction, community participation, quality of life

While there is a growing focus of autism research on adults, (Howlin, 2021) it is striking how little is known about one of the largest populations of autistic adults: the estimated 10 million individuals living with autism in China (Zhou et al., 2020). Studies on autistic adults are mostly based in Western high-income countries like the U.S. and European countries, (Sáez-Suanes & Álvarez-Couto, 2021; Scheeren et al., 2022) generally showing reduced community integration (Mason et al., 2021) and lower life satisfaction (Lord et al., 2020) compared to non-autistic adults. A fundamental question regarding autistic adults in mainland China is the integration within their communities (employment, independent living, and having friends) and their life satisfaction, as well as potential distinctions between Chinese and Western European autistic adults.

Previous research on autism in China indicated limitations in the health, social care and educational services for individuals with autism throughout the country, despite increased attention for more inclusive education (Fisher et al., 2010; Xiao, 2023). Relatively many families with an autistic member experience financial burden and psychological stress (Baker et al., 2020; Clark et al., 2019; Huang et al., 2013; Sun et al., 2013). Studies from China and Japan also suggest that autistic adults experience a lower quality of life (physical health, psychological health, and environment) compared to neuro-typical adults (Kamio et al., 2013; Lin, 2014; Lin & Huang, 2019). The available information on living situations of autistic adults in mainland China is mainly derived from parent reports surveys in locally published books and research. Furthermore, a limited number of parent report studies have indicated that the employment rate among a group of autistic adults in China was below 10%, and 95%

of them lived with their parents (Hua, 2017; Jia, 2022). Most of these adults have what is called ‘high support needs’(Lord et al., 2022), including a constant need for an adult caregiver for assistance, being unable to be left alone, and an inability to independently manage basic daily tasks. Many autistic adults in China have difficulty in communicating their needs and preferences effectively (Zhou et al., 2023). Chinese parents play a central role in the lives of their autistic children (Lei & Kantor, 2021) even after they become adults. In groups with communication difficulties proxy-reports can be employed as an alternative source of information on an individual’s quality of life (Clark et al., 2014; Egilson et al., 2017).

Community integration generally involves three primary areas: employment or other productive activity, independent living, and social engagement (Sander et al., 2010; Scheeren & Geurts, 2015). Many autistic adults face challenges in these domains (Mason et al., 2021; Wickstrom et al., 2021). Cultural and contextual backgrounds may affect community integration of autistic adults across the globe. Western individualistic countries, such as the Netherlands, have a longer history of autism awareness as well as active self-advocacy movements for autistic individuals (Waltz et al., 2015), promoting their empowerment and potentially creating an environment more accepting of neurodiversity (Szlamka et al., 2022). The majority of more recently diagnosed adults with autism in Western countries have average to high intellectual abilities (Brugha et al., 2016; Christensen & Zubler, 2020) and an increasing number of people are diagnosed in adulthood (Begeer et al., 2013; Lai & Baron-Cohen, 2015). In mainland China, autism is generally considered a disorder rather than a form of

neurodiversity. Autistic behaviours may be perceived more strongly as non-conforming in Chinese society (Mak & Kwok, 2010; Zhou et al., 2020). Individuals with high intellectual ability and fewer autism traits are less likely to be recognized as autistic or formally diagnosed (Huang et al., 2013). The majority of individuals with formal autism diagnoses tend to have moderate to severe intellectual disabilities (ID), have limited functional communication and/or are unable to advocate for themselves (Huang et al., 2013), similar to how it was in Western countries about 30 years ago. Chinese families with an autistic member may face a high degree of stigma and discrimination (Chan & Lam, 2018; Mak & Kwok, 2010). Therefore, some Chinese parents may choose to conceal the autism condition of the autistic family member (Luo et al., 2022; Su et al., 2019), contributing to a heavy dependence of Chinese adults with autism on their families (Baker et al., 2020).

Differences in availability, accessibility, affordability, and acceptability of autism support services across countries can also serve as contextual facilitators or barriers for community integration (Chiang & Wineman, 2014; de Leeuw et al., 2020). Table 1 shows the comparative healthcare system as well as the basic socio-economic status of China and the Netherlands. For example, per capita healthcare expenditure in the Netherlands is tenfold that of China. These differences may indicate a more robust mental health care infrastructure and support system in the Netherlands, which may potentially lead to greater community inclusion and more opportunities to live an independent life for autistic individuals. In China, despite policies and guidelines promoting the inclusion of autistic individuals in schools (Fisher et al., 2010; Xiao,

2023), challenges persist, such as financial problems in families with autism, services inequality between urban and rural areas and lack of healthcare and educational professionals (Clark et al., 2019; Li & Qi, 2023; Sun et al., 2013). Some Dutch young autistic adults with high support needs live with their parents but a larger proportion lives in residential care facilities (Barneveld et al., 2014; Scheeren et al., 2021) compared to Chinese adults. In China, especially in urban cities where the cost of living and purchasing a house is high, autistic adults remain living with their parents, as care facilities are scarce and government support for residential care is only provided when there are no family members available (Fisher & Jing, 2008).

Table 1 Comparative information on the background status of China and the Netherlands (Source: World Bank; WHO)

	China	Netherlands
Population	1.4 billion	17 million
Gross Domestic Product (US\$ Billions) in 2021	17,734.1	1,012.9
Gross national income per capita (2021)	\$11880	\$55200
Inflation (annual %) in 2021	1.0%	2.7%
Income share held by lowest 20% (2019)	6.7	8.6
Gini index* (2019)	38.2	29.2
Individuals using the Internet (% of population) in 2021	73	92
Educational attainment, the percentage of 25-64 year-olds who attained a bachelor's or equivalent tertiary education degree, total (%) (cumulative)*	7.8 (2021)	23.6 (2021)
Unemployment, total (% of total labour force) in 2020	5	3.8
Effective social protection coverage for persons with disabilities (%)	32.6	100
Current health expenditure per capita (current US\$)	535.1	5335.3
Psychiatrists working in mental health sector (per 100000 population) in 2015	2.2	20.9
Total number of child psychiatrists per 100000 population	Fewer than 0.4	26.5

*Gini index represents the income inequality or the wealth inequality within a nation. The higher Gini index means higher income inequality.

* https://stats.oecd.org/Index.aspx?datasetcode=EAG_NEAC

To fully understand the outcomes for autistic adults, besides their community integration, we should also take into account their overall well-being, such as happiness and life satisfaction (Lord et al., 2020). Individuals living in wealthier countries tend to report higher life satisfaction compared to individuals in poorer ones (Helliwell et al., 2022), maybe because wealthier countries typically have more beneficial characteristics that contribute to their citizen's life satisfaction, such as political freedom, civil rights, good governance, and low social inequality (Stavrova, 2019). Cultural and contextual dimensions may also play a role, with Eastern Asian countries emphasizing interdependence (Kamio et al., 2013; Krys et al., 2019) and others' evaluation and opinions and Western and European countries, valuing individual freedom, achievement, and the personal pursuit of happiness (Ye et al., 2015). On the other hand, strong family ties and family support could also positively contribute to life satisfaction in Asian countries (Nainee et al., 2021; Napa et al., 2020). In this study, we compared the community integration and life satisfaction of autistic adults between China and the Netherlands to gain insights into the influence of cultural and contextual factors on the outcomes of autistic adults.

In addition to living in different countries, childhood factors have been found to correlate with or predict adult community integration and/or life satisfaction. Positive outcomes (living independently, having a job and having friends) for autistic adults are consistently associated with higher intellectual abilities (Howlin et al., 2013; Mason et al., 2021) and the absence of co-occurring psychiatric conditions (Kraepel et al., 2017; Lin & Huang, 2019). Mixed findings regarding the effects of sex and age on community

integration and general well-being have been found in both Asian and European countries (Howlin et al., 2013; Kamio et al., 2013; Lawson et al., 2020; Lin, 2014; Mason et al., 2018; Scheeren et al., 2022). Variations in sample characteristics, such as age of autism diagnosis and intellectual ability, may explain these differences. The association between different socio-economic status and community integration and life satisfaction in autistic adults remains relatively unexplored. It is important to note that the majority of studies discussed here have focused on self-reporting adults with average to high intellectual abilities, leaving a knowledge gap regarding community integration and life satisfaction of adults with lower intellectual abilities and high support needs (Russell et al., 2019; Scheeren et al., 2023). Given that around 30% of the autism population has an intellectual disability and high support needs (Baio et al., 2018; Zeidan et al., 2022), it is crucial to prioritize understanding the specific challenges faced by this group. A better understanding of the differences in the community integration of autistic adults with high supports needs in China and the Netherlands fits the World Health Organization goals to enhance global social participation for autistic adults (Wickstrom et al., 2021).

We will (a) examine proxy-reported community integration (employment, independent living, friendship) and life satisfaction among young autistic adults in China, and compare them with a sample from the Netherlands, and (b) examine other factors (age, sex, intellectual ability, age of diagnosis, co-occurring psychiatric conditions, use of medicine/intervention, educational level, and income level) associated with community integration and life satisfaction of young autistic adults

from China and the Netherlands. This study focuses on the early adult life stage of 18 to 30 years, because life satisfaction may differ depending on life stage (Henkens et al., 2022) and early adulthood is a period of transition from school life and dependency to social life and independency (living independently, having a job and making friends)(Winpenny et al., 2020).

Methods

Participants and procedure

This study was part of a bigger study on autistic adults with varying intellectual abilities and daily life skills in China and the Netherlands (<https://osf.io/bvxpu/>). Participants were asked to fill in the questionnaire based on their respective roles, either as autistic adults themselves or as a caregiver of an autistic adult. Given the high number of adults who were unable to self-report in China, the study reported here focuses exclusively on caregiver reported data. This study focused on the early adult life stage of 18 to 30 years. We therefore excluded autistic adults aged below 18 years and above 31 years (see Figure S3 in supplementary materials for sample selection process). Participants with missing data on predictors (IQ level and use of intervention and medicine) were excluded from the final analysis. The final sample included 99 Chinese and 109 Dutch adults. There were no significant differences in age, sex, and IQ between the included and excluded participants.

The Chinese participants were recruited via the Autism Research Centre of Nankai University (NKARC), Tianjin, China in the autumn of 2022. NKARC has built a network of over 100 service centres of adults with autism covering all major regions of China. To increase the recruitment of autistic adults, we employed the snowball method through help from leading Chinese psychiatrists, as well as autism researchers and service providers in the autism field. These professionals have connections with autistic adults, groups of autistic adults, or families including autistic adults. The participants were from the eastern side of the Heihe–Tengchong Line, with 94% of China's population resided east of the line (see Figure S4 in supplementary materials for the city distribution of Chinese participants), ranging from first-tier cities (typically with a population of more than millions of people) to fourth-tier cities (typically with a population of hundreds of thousands). Caregivers of autistic adults were invited to participate in our study through an online survey and reported on behalf of the autistic adult. All of the included Chinese adults were diagnosed with autism by clinicians (psychiatrists, psychologists, and pediatricians).

Dutch participants were included via the Netherlands Autism Register (NAR, <https://www.nederlandsautismeregister.nl/english/>), a nationwide autism register that collects information on an annual basis from autistic individuals and their caregiver. All Dutch participants had a formal autism diagnosis according to DSM-IV or DSM 5. The NAR has a diverse distribution of men and women, across all ages, intelligence levels and the entirety of the Netherlands (<https://cijfers.nederlandsautismeregister.nl/index.html>).

Participants were invited to complete the study through an online survey. Participants did not receive payment for their participation. Caregivers consented to participate by reading the informed consent statement and checking a box indicating their agreement. The data collection has been reviewed and approved by the ethics committee of the Vrije Universiteit Amsterdam (VCWE 2020-041R1) and Nankai University (NKUIRB2022127).

Measurements

Outcome measures

Community integration. Following research by Howlin et al. (Howlin et al., 2004) and Scheeren & Geurts, (Scheeren & Geurts, 2015) community integration was measured by employment, independent living, and friendship with hierarchical ratings reflecting different levels of attainment in these areas. The overall community integration rating of an individual was summed up by points on employment scale, independent living, friendship, and leading to a composite score ranging from 0 to 8, making it possible to classify individuals as having very poor (0 points), poor (1-3 points), fair (4-6 points), good (7 points), and very good (8 points) overall community integration; See also Table S10 in supplementary materials with detailed codes column and scale points.

Life satisfaction. Life satisfaction was measured by the 0 to 10 Cantrill Ladder scale: ‘Where would you rate the life of the person with autism generally on a scale from 0 to 10?’, with ‘10’ indicating the best possible life and ‘0’ the worst possible life.

Higher scores indicate higher life satisfaction (Cantril, 1965). This measure has also been used with autistic adults before (Grove et al., 2018; Scheeren et al., 2021). The World Happiness Report data also include Cantrill Ladder data from China and show cross-cultural validity (Helliwell et al., 2022). The Cantrill ladder has been found to be a culturally sensitive measure that can be used internationally (Bartels & Boomsma, 2009).

Demographic variables

Age and age of diagnosis were coded into in years. Sex (1 = male, 0 = female) and Country (1 = China, 0 = Netherlands) were coded into dichotomous variables.

Intellectual ability was reported by the caregiver at a numerical scale, ranging from 1 (IQ below 40 (severe intellectual impairment)) to 7 (IQ above 130 (gifted)), with each number corresponding to a specific IQ range and description. Informants were asked about their IQ test history and asked to select the appropriate IQ level that best described the adults' intellectual ability. If autistic adults had never taken a IQ test or their IQ score was unknown, informants were asked to estimate their intellectual ability and select the corresponding level. In the current study, 81.7% of Chinese IQ reports and 82.6% of Dutch IQ reports were based on a prior IQ test. A high correlation ($r = -0.71$) between proxy-reported IQ and adaptive functioning has been found in previous study, (Werkman et al., 2020) providing initial support for the validity of proxy-reported IQ.

Co-occurring psychiatric conditions was assessed by asking if autistic adults currently had any other psychiatric diagnosis besides autism, such as mental health concerns and other neurodivergent conditions. The options for response were “Yes”, “No”, or “Don’t know”. If the response was “Yes”, a follow-up question was asked to specify the specific diagnosis. Co-occurring psychiatric conditions was coded on a dichotomous scale (0 = Yes, 1 = No).

Use of interventions and medicine was measured by asking if autistic adults have taken any interventions related to autism. The options for response were “Yes”, “No”, or “Don’t know”. “Yes” responses were followed up with a question about the specific intervention and specific medication, including and an indication of the duration and intensity of the intervention followed. Use of interventions and medicine was coded on a nominal scale (0 = no use of intervention and medicine, 1 = receives intervention or medicine, 2 = receives intervention and medicine).

Household income level was categorized into income bands per country, based on country-specific percentiles (low: below 30th percentile; middle: 30th-70th percentile; high: above 70th percentile) of the National Bureau of Statistics of China (2021) and Statistics Netherlands (CBS; 2021) separately. The exact bands were as follows: low (China: 0-¥4110 a month, €0-€6740 a year; Netherlands: €0-€30000 a year), middle (China: ¥4110 - ¥10292 a month, €6740- €16878 a year; Netherlands: €30000-€70000 a year), and high income (China: above ¥10292, above €16878 a year; Netherlands: >€70000 a year). We considered income levels based on household

population for each country separately rather than absolute income over both countries, because some adults may live independently or living in a care facility.

Educational level was categorized into the low, middle and high level of education in each country, based on the Chinese and Dutch educational systems. Primary school and special school were categorized into low level of education, secondary school were categorized into middle level of education, and university (Bachelor, Master, Doctoral) were categorized into high level of education in both countries.

Topics in the online survey were assessed in the following order: sex, age, IQ test, diagnosis of autism, age of diagnosis, co-occurring psychiatric diagnosis, use of medicine/intervention, educational level and household income level. Questions about demographics were followed by questions about employment status, living situation, friendship, and life satisfaction.

Instruments Translation

All of the questions and questionnaires were originally developed and collated in Dutch based on the NAR annual survey. The translation of the questions and questionnaires into Mandarin Chinese was conducted following the forward and backward procedure (Hall et al., 2018). First, all of the items were translated from Dutch into Mandarin Chinese by two Chinese PhD candidates in the Department of psychology at Utrecht University and the University of Amsterdam, who are fluent in

Dutch and obtained at least a B1 Dutch language certificate. To maintain the meaning of words and sentences between Dutch and Mandarin Chinese, a back-translation was conducted by a Dutch translation agency, translating it back into Dutch. The original Dutch and back-translated versions were compared by two native Dutch speakers, co-authors of this paper (AS and SB). Discrepancies were revised to more accurately express the intent of the wording in the original version. The translated Chinese items were checked and adapted by the authors. Therefore, the Mandarin Chinese questions could be considered linguistically equivalent to the original Dutch version.

Data Analysis

We performed hierarchical multiple regression analyses to investigate the predictive value of country (China / Netherlands) on community integration and life satisfaction of autistic adults, by controlling for the impacts of age, sex, intellectual ability, co-occurring psychiatric conditions, and use of medicine/interventions. In each regression model, we first entered age, sex, intellectual ability, co-occurring psychiatric conditions, and use of interventions, followed by country in a second step. Three ordinal logistic regression analyses were also conducted to investigate whether demographic factors and country predicted each component of community integration (employment, independent living, friendship).

Based on a power of 0.95 and an alpha level of 0.05, the required total sample size to detect a medium effect ($f = 0.15$) in a multiple regression analysis including 6 predictors is 146 participants in total (Cohen et al., 2014).

Due to the missing values in the educational level (42 Dutch missing data) and income level (16 Chinese missing data and 38 Dutch missing data), the participants included in the final analysis did not meet the power to detect a medium effect. Therefore, we conducted supplementary analyses by adding either the educational level or income level as an extra predictor in the multiple regression model to explore their impacts on community integration and life satisfaction.

Community involvement

In this study, autistic individuals were not actively involved in the design, but formulation of the NAR (Dutch) survey was developed in collaboration with a panel of autistic individuals and their parents. Every year, the NAR brings together a panel of stakeholders (autistic individuals and parents of children of varied abilities) to discuss and exchange opinions on current research issues, methodology, and dissemination of findings. The NAR also has several autistic team members.

Results

Descriptive Statistics

The complete data consisted of proxy-reported data on 99 Chinese and 109 Dutch autistic adults, aged 18 to 30 years, with no missing data on predictors (IQ level

and use of intervention and medicine (see Table 2 for participant details and statistical details).

The Dutch sample was older and diagnosed later than the Chinese sample, the differences in age ($d = 3.32$) and age of diagnosis ($d = 4.62$) between countries were large in effect size (Cohen, 1988). Most autistic adults in both countries had low educational levels (64.6% in China and 76.1% in the Netherlands) and over half (62.6% of Chinese and 57.8% of Dutch adults) of the samples in both countries were reported to have an IQ below 70. More Dutch adults (41.3%) were reported to have a co-occurring psychiatric diagnosis than Chinese adults (26.3%). Intervention and medicine use were similar across countries, with 62.6% of Chinese and 48.6% of Dutch adults using at least one service (intervention or medicine).

More Chinese adults (51.8%) were reported to have a relatively high household income level compared to Dutch adults counterparts (11.4%). It should be noted that we only asked about the household income. Since a larger proportion of Chinese adults (92.6%) lived with their parents than Dutch adults (50%), their household income included their parents' income. On the other hand, a larger proportion of Dutch adults (41.9%) lived in care facilities compared to Chinese adults (2.1%). Therefore, when an adult was reported to reside in a care facility, their household income was primarily based on their personal income. Consequently, more than half of the Dutch autistic adults included in the study exhibited low household incomes.

Table 2 The Demographic Variables between China and the Netherlands

Variables	China		The Netherlands		Statistics
	N / M	% / SD	N / M	% / SD	
Total N	99	100.0	109	100.0	
Sex					$\chi^2 = 6.87, p < .05$
Male	82	82.8%	73	67.0%	
Female	17	17.2%	36	33.0%	
Mean age	22.68	3.08	24.26	3.51	$t = 3.45, p < .001, d = 3.32$
Mean age of diagnosis	4.80	4.48	6.73	4.67	$t = 2.62, p < .05, d = 4.62$
Proxy-reported IQ level					$\chi^2 = 9.26, p > .05$
IQ below 40	21	21.2%	16	14.7%	
IQ between 40 and 55	20	20.2%	20	18.3%	
IQ between 56 and 70	21	21.2%	27	24.8%	
IQ between 71 and 85	11	11.1%	24	22.0%	
IQ between 86 and 115	19	19.2%	11	10.1%	
IQ between 116 and 130	4	4.0%	8	7.3%	
IQ above 130	3	3.0%	3	2.8%	
Co-occurring psychiatric conditions					$\chi^2 = 5.21, p < .05$
Yes	26	26.3%	45	41.3%	
No	73	73.7%	64	58.7%	
Education level					$\chi^2 = 4.89, p > .05$
Low level of education	64	64.6%	54	76.1%	
Middle level of education	21	21.2%	14	19.7%	
High level of education	14	14.1%	3	4.2%	

Table 2 (Continued)

Household income level					$\chi^2 = 56.82, p < .001$
Low level of income	8	9.6%	51	64.6%	
Middle level of income	32	38.6%	19	24.1%	
High level of income	43	51.8%	9	11.4%	
Employment status					$\chi^2 = 16.84, p < .001$
No structural day time activities	11	11.1%	5	4.6%	
Not any kind of employment	48	48.5%	71	65.1%	
Non-regular employment	13	13.1%	23	21.1%	
Regular paid employment/studying	27	27.3%	10	9.2%	
Living situation					$\chi^2 = 46.54, p < .001$
Living in a care facility ¹	2	2.1%	36	41.9%	
Living with parents or family	87	92.6%	43	50.0%	
Living independently with housing assistance ²	2	2.1%	5	5.8%	
Living independently	3	3.2%	2	2.3%	
Friend relationships					$\chi^2 = 5.29, p > .05$
Hardly any friends	46	46.5%	47	46.5%	
Other friends	48	48.5%	42	48.5%	
Close friends	5	5.1%	15	14.4%	

Table 2 (Continued)

Use of Services³					
No use of services	37	37.4%	56	51.4%	$\chi^2 = 5.99, p = .05$
Receive intervention or medicine	54	54.5%	41	37.6%	
Receive intervention and medicine	8	8.1%	12	11.0%	
Community integration⁴ (Range from 1-8)	3.14	1.44	2.76	1.38	$t = -1.78, p > .05,$ $d = 1.41$
Poor outcome	63	67.0%	65	77.4%	
Fair outcome	29	30.9%	18	21.4%	
Good outcome	1	1.1%	0	0.0%	
Very good outcome	1	1.1%	1	1.2%	
Life satisfaction⁵	5.62	2.23	6.52	1.68	$t = 3.27, p < .001,$ $d = 1.97$

1 Housing assistance entail different kinds of support for independent living, such as help with finances.

2 Care facility entails specialized 24/7 services and care by trained professionals.

3 receiving Intervention and using the medicine during the last year.

4 Total community integration were added by the scores of living situation, friend relationships, and employment status. Dutch participants had 25 missing data and Chinese participants had 5 missing data in this variable

5 Dutch participants had 5 missing data in this variable.

Outcome measures

Most participants did not have any kind of paid or unpaid employment (59.6% in Chinese and 69.7% in Dutch sample) and few of them were reported to have close friends according to their caregiver. Very few Chinese adults (5.3%) and Dutch adults (8.1%) lived independently with or without housing assistance.

Chinese and Dutch adults showed limited, but similar community integration ($d = 1.41$; see Figure S5 in the supplementary material for the score distribution of the overall community integration in each country). Most autistic adults in both countries had a poor community integration according to their caregiver (67% in Chinese sample and 77.4% in Dutch sample) and 30.9% of Chinese adults and 21.4% of Dutch adults had a fair community integration. For the life satisfaction, Dutch adults had higher proxy-reported life satisfaction than Chinese adults, with a large effect size ($d = 1.97$). In both countries, adults' community integration and life satisfaction were modestly, but positively correlated (Netherlands: $r = .280, p < .05$; China: $r = .272, p < .05$). When examining the correlations between life satisfaction and the different facets of community integration in each country, life satisfaction was only significantly correlated with employment status ($r = .249, p < .05$) and friend relationship ($r = .307, p < .05$) in the Chinese sample.

Predictors of community integration and life satisfaction

Based on the hierarchical multiple regression analyses, demographic factors (age, sex, intellectual ability, co-occurring psychiatric conditions and use of

medicine/intervention) explained 28% of the variance in overall community integration at Step 1, $F(5,172) = 13.55$, $p < .001$ (see Table 3). Autistic adults with a higher proxy-reported IQ level ($\beta = .47$, $p < .001$) and younger age ($\beta = -.06$, $p < .05$) were reported to have better community integration. None of the other demographic factors were associated with community integration. Chinese and Dutch adults showed similar impacts on community integration ($R^2 = .01$, $\beta = .33$, $p > .05$). After adding country into the model at Step 2, age lost its association with community integration ($\beta = -.05$, $p > .05$), suggesting that there might be a country-specific effect. A post-hoc regression analysis on community integration in each country separately revealed that younger adults were reported to be more integrated in the community in the Dutch sample ($\beta = -.08$, $p < .05$, see Supplementary Table S11), but not in the Chinese sample ($\beta = -.01$, $p > .05$).

Table 3 Multiple Regression analyses of demographic variables of autistic adults and country as predictors of total community integration in ASD

Predictors	<i>b</i>	<i>SEb</i>	β	R ² change
Step 1				.28**
Constant	2.70	.75		
Sex	.31	.22	.09	
IQ level	.47	.06	.51**	
Age	-.06	.03	-.13*	
Co-occurring psychiatric conditions yes or no	.16	.20	.05	
Use of intervention and medicine	-.22	.15	-.10	
Step 2				.01
Constant	2.33	.78		
Sex	.26	.22	.08	
IQ level	.47	.06	.52**	
Age	-.05	.03	-.11	
Co-occurring psychiatric conditions yes or no	.09	.20	.03	
Use of intervention and medicine	-.25	.15	-.12	
Country	.33	.20	.12	

* $p < 0.05$ ** $p < .005$

At Step 1, demographic factors did not contribute to the variance of the proxy-reported life satisfaction of our participants ($R^2 = .03$, $F(5,197) = 1.34$, $p > .05$). At Step 2, country had a significant impact on life satisfaction, with lower proxy-reported life satisfaction in Chinese adults ($R^2 = .06$, $F(6,196) = 3.41$, $p < .005$) (see Table 4). After adding country into the model, autistic adults without a co-occurring psychiatric diagnosis showed better life satisfaction than those with a co-occurring psychiatric condition ($\beta = .65$, $p < .05$). A post-hoc regression analysis on life satisfaction in each country separately showed that adults without co-occurring psychiatric conditions reportedly had a higher life satisfaction in the Dutch sample only ($\beta = .78$, $p < .05$, see Supplementary Table S12).

Table 4 Multiple Regression analyses of demographic variables of autistic adults and country as predictors of life satisfaction in autistic adults

Predictors	<i>b</i>	<i>SEb</i>	β	R ² change
Step 1				.03
Constant	6.04	1.10		
Sex	-.01	.33	-.00	
IQ level	-.09	.09	-.07	
Age	.01	.04	.01	
Co-occurring psychiatric conditions yes or no	.46	.31	.11	
Use of intervention and medicine	-.29	.23	-.09	
Step 2				.06**
Constant	7.15	1.11		
Sex	.20	.32	.04	
IQ level	-.11	.09	-.09	
Age	-.03	.04	-.05	
Co-occurring psychiatric conditions yes or no	.65	.31	.15*	
Use of intervention and medicine	-.15	.23	-.05	
Country	-1.07	.29	-.27**	

* $p < 0.05$ ** $p < .005$

The results are similar when country is entered first (instead of second) into the regression model. Country was not a significant predictor of community integration ($R^2 = .02$, $F(1, 176) = 3.16$, $p > .05$) and was a significant predictor of life satisfaction ($R^2 = .05$, $F(1, 201) = 10.67$, $p < .005$).

The ordinal logistic regression analyses showed that all predictors accounted for a significant amount of variance in employment status (likelihood ratio $\chi^2(7) = 33.14$, $p < .001$), independent living (likelihood ratio $\chi^2(7) = 50.51$, $p < .001$), and friendship (likelihood ratio $\chi^2(7) = 19.60$, $p < .01$). Autistic adults with a higher proxy-reported IQ level were reported to have greater levels of employment, independent living and friendship (see Table S13-15 in supplementary for statistical results). Country only was a significant predictor of the independent living scale, with Dutch participants more likely living in more strongly supported accommodations than Chinese participants ($B = -2.069$, $SE = .445$, Wald $\chi^2 = 21.587$, $df = 1$, $p < .001$, $OR = 0.126$, 95% CI [.053, .302]). This difference was explained by Dutch participants being much more likely to live in residential care facilities (42%, and 50% living with parents) while Chinese participants mostly lived with family (93%).

When only adding educational level into the model, the samples were reduced (99 Chinese and 68 Dutch adults) due to missing educational data. Lower educational levels predicted poorer community integration ($\beta = .62$, $p < .005$). Educational level did not significantly predict life satisfaction ($\beta = 1.02$, $p > .05$). Only adding household income level into the model also reduced the samples (83 Chinese and 77 Dutch adults).

Household income level did not predict community integration ($\beta = .23, p > .05$) and life satisfaction ($\beta = .35, p > .05$) for both samples.

Discussion

In China and the Netherlands, we investigated levels and determinants of community integration (employment, independent living, friendship) and life satisfaction of autistic adults with relatively high support needs. In both countries, community integration was limited, with low rates of employment, limited independent living, and few close friendships according to their caregiver. Chinese autistic adults had lower proxy-reported life satisfaction than their Dutch counterparts. Autistic adults with a higher proxy-reported IQ level were reported to have better community integration. Only in the Dutch sample, younger adults were more integrated into the community than older adults, and adults without co-occurring psychiatric conditions tended to have better life satisfaction. Sex, household income level and use of intervention/medication did not predict community integration or life satisfaction in both samples.

In our study, the majority of both Chinese (67%) and Dutch (77%) participants showed poor community integration, as indicated by low rates of employment, limited independent living, and few close friendships. The employment rates (40.4% Chinese and 30.3% Dutch adults had some form of (un)paid employment) align with previous studies involving participants with intellectual disabilities (31-48%) (Billstedt et al., 2011; Cameron et al., 2022; Farley et al., 2018). These findings highlight that young

autistic adults with relatively high support needs in high-income developed countries appear to face similar challenges to those in middle-income developing countries. Barriers such as negative attitudes (Wei et al., 2018) and limited accessibility to appropriate services (Malik-Soni et al., 2022; Sun et al., 2013) can hinder the integration of autistic individuals into mainstream settings in both high- and low-income countries. For example, in China, despite the initiation of social inclusion training programs for autistic individuals by service organizations and special schools (Li & Qi, 2023; Xiao, 2023), the provision of effective social inclusion services for autistic adults is hindered by financial constraints (Clark et al., 2019), particularly for individuals with lower socioeconomic status, as well as limited funding for the recruitment and training of professionals and the development of well-designed training programs (Li & Qi, 2023). This limitation in service delivery results in restricted access and diminished quality of support for autistic individuals, potentially impeding their community integration. Similarly, in high-income countries, despite a potentially higher availability of support services, challenges may arise due to long waiting lists, inadequate funding, or difficulties in navigating complex service systems (Malik-Soni et al., 2022). Community integration could be improved by promoting awareness and understanding of autism, challenging negative attitudes and stereotypes, improving accessibility to appropriate services, and providing tailored support for individuals with high support needs.

Even though average community integration level was comparable in both countries, a notable difference was identified in living situation. 92.6% of Chinese

adults resided with their families, while around half (50%) of the Dutch adults lived with their families. Around 42% of Dutch adults lived in a care facility. This result indicates that Chinese parents tend to take care of their adult autistic child, whereas care for autistic adults with high support needs appears more institutionalized in the Netherlands. In 2021, mainland China witnessed a notable rise in the total number of autism rehabilitation institutions designated by the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR), reaching 2304 establishments (source: <https://www.cappdr.org/>). However, there is an obvious exclusion of children above the age of seven (Li & Qi, 2023). Among these institutions, 60% of these institutions primarily cater to children aged eight and below, while only 17% of the services were directed towards children aged 9 to 14. This data underscores a substantial gap in support for older autistic adults in these institutions. To address this issue, it is essential for autism rehabilitation institutions to expand their services more to older autistic adults and ensure that all age groups within the autism spectrum receive the appropriate care and support they need.

Chinese autistic adults were reported to have significantly lower life satisfaction (5.62) compared to Dutch adults (6.52). The difference in life satisfaction may be attributed to three possible factors. Firstly, China has a less comprehensive system of support services for adults on the autism spectrum compared to the Netherlands, including lower per capita healthcare expenditure, lower effective social protection coverage and a shortage of psychiatrists and child psychiatrists (Table 1). These inadequate services limit access to professional and financial support, (Xiang et al.,

2018) possibly leading to lower life satisfaction. Secondly, limited public knowledge about autism in China (Yu et al., 2020) may contribute to stigma experienced by families with autistic adults, which can negatively impact the caregivers and lower the autistic individuals' sense of social inclusion and happiness (Ma et al., 2023; Wei et al., 2018). The Netherlands demonstrates a longer history of Dutch autism self-advocacy (Waltz et al., 2015) and organizations such as the Dutch Autism Society (NVA, founded in 1978) dedicated to the inclusion and support of autistic individuals. This may contribute to reduced stigma and improved life satisfaction in Dutch autistic individuals. Thirdly, heightened parenting stress among Chinese compared to Dutch caregivers may also have resulted in lower perceived life satisfaction of their child. A more comprehensive understanding of the experiences and life satisfaction of autistic adults in different countries is needed for the development of targeted interventions and policies to improve their quality of life.

Our study found that Chinese autistic adults were reported to have lower life satisfaction compared to Dutch autistic adults, consistent with the World Happiness Report's observation that European countries generally have higher average life satisfaction than China (for example, the Netherlands with an average score of 7.40, in contrast to China's average score of 5.82) (Helliwell et al., 2022). Our findings need to be understood within the broader context of country-level differences in life satisfaction. In both countries, the life satisfaction of autistic adults with relatively high support needs was lower on average than the life satisfaction of the general population. This

highlights the significance of prioritizing mental health support and interventions aimed at enhancing the life satisfaction of autistic adults with high support needs worldwide.

When examining predictors of life satisfaction, demographic factors only explained 3% variance in proxy-reported life satisfaction. It is important to recognize that life satisfaction is a complex and multi-dimensional construct that may not be fully explained by demographic characteristics alone. Our study primarily relied on yes/no responses and basic information about employment and living arrangements, which likely do not capture the full complexity of individuals' experiences. Only within the Dutch sample, co-occurring psychiatric conditions predicted lower life satisfaction, consistent with previous findings (Kraepel et al., 2017; Lin & Huang, 2019; Scheeren et al., 2022). However, in our Chinese sample, the prevalence of co-occurring psychiatric conditions (26.3%) was surprisingly low compared to both the Dutch sample (41.3%) as well as prior adult studies (75%) (Sharma et al., 2018). This limited variability within our Chinese sample likely impeded us from thoroughly investigating the association between co-occurring psychiatric conditions with life satisfaction. The lower report of co-occurring psychiatric conditions may be related to the Chinese tendency to prioritize physical health over mental health (Lin & Cheung, 1999), lack of professional services and trained diagnosticians (Pang et al., 2018), as well as a greater stigma surrounding mental health issues in China (Yin et al., 2020). Future studies should utilize multiple methods of assessment to capture a more accurate representation of mental health issues, for example, incorporating clinical diagnostic assessments and standardized measures of co-occurring psychiatric conditions.

There are a number of limitations of this study. Firstly, because over half of autistic adults in our samples were reported to have an IQ below 70 and could not independently participate, we used proxy-reported life satisfaction as one outcome measure. This is a limitation, because life satisfaction is inherently a highly personal and subjective experience. Caregiver reports may be influenced by the caregiver's own perspectives and feelings, such as parenting stress, and may therefore not be a valid substitute for self-reports (Knuppel et al., 2018). However, Hong et al (2016) did find strong correlations between adult self-reports and proxy-reports (Hong et al., 2016). Secondly, given our focus on young autistic adults with relatively high support needs, a majority of whom were reported to have intellectual disabilities, participants in the current study are probably not representative for older autistic individuals with low support needs and/or an adult autism diagnosis in both countries. There is likely a large number of undiagnosed individuals (with higher intelligence levels) in China (Zhou et al., 2020) and, in line with other Western countries, a presumed majority of autistic adults in the Netherlands has an average to high intelligence level. Thirdly, despite similar proxy-reported IQ levels, cross-country differences in clinical practices and participant recruitment may have resulted in less comparable samples. For instance, in China, adults and those with relatively few symptoms are less likely to be diagnosed (Huang et al., 2013). Therefore, our Chinese sample, recruited via autism research centre, mainly consisted of individuals with a co-occurring intellectual disability who may have shown more typical autism symptoms from a young age. Conversely, in the Netherlands, recruitment through an online survey allowed for the inclusion of

participants with a broad range of skills, intellectual abilities, and autism symptomatology. This may also explain why the Chinese participants in this study were diagnosed at an earlier age than the Dutch participants. Fourthly, limited by the online survey context, we were unable to directly verify the IQ levels of the autistic adults and solely relied on caregiver reports. Future studies should ideally incorporate standardized IQ measurements.

As this is one of the first English publications on community integration and life satisfaction of autistic adults in mainland China, we call for more research on the outcomes and experiences of autistic adults in Eastern Asian countries, such as China, preferably via self-report. Despite extensive efforts and a nationwide network, recruiting self-reporting autistic adults in China for research purposes proved especially challenging. Many Chinese autistic adults have a co-occurring intellectual disability and receive their autism diagnosis in early childhood. Stigma surrounding autism and mental health issues in general may discourage adults seeking a diagnosis or openly identifying as autistic (Huang et al., 2013; Ma et al., 2023). This is further compounded by a general lack of awareness and expertise in diagnosing autism in adults, particularly among those who exhibit adequate social functioning (Huang et al., 2013). Additionally, given the lack of subsidy and financial support for neurodiverse adults in China, it is generally not beneficial to be diagnosed autistic. Enhancing public awareness of autism and collaborating with local autism organizations and support groups are pivotal steps towards building trust and fostering increased engagement in research within the autistic community.

In our study, autistic adults in both countries showed low rates of employment, limited independent living, and few close friendships, suggesting that common, but culturally sensitive and tailored interventions could be developed. Specific skills necessary for community integration, such as self-care and daily living skills (Kamp-Becker et al., 2010), could be targeted to increase integration and participation. Moreover, we encourage more research on autistic adults with high support needs, in both low- and high-income countries. Using a brief adaptive functioning caregiver-report measure and/ or a brief measure of autistic traits could help provide a more comprehensive understanding of this group. Furthermore, community integration measures often rely on "normative" standards that may not always be desirable or fitting for autistic adults, particularly for those with high support needs (Bishop-Fitzpatrick et al., 2016). Other crucial aspects such as access to meaningful and enjoyable everyday life activities, good physical and mental health, neighbourhood support, supportive family contacts are also important to consider when evaluating the community integration of autistic adults (Howlin, 2021). It is crucial for future research to include direct input from autistic individuals themselves (both with and without high support needs), integrating qualitative and quantitative research methods, to provide deeper insights into their personal experiences of what it means to belong to a community and to learn more about optimal "person-environment fit" (Lai et al., 2020). Also, self-report measures, such as the PROMIS (Vaughan et al., 2020) or Single Item QoL (Williams, 2021), could provide a more direct and accurate assessment of adults' life satisfaction. In order to gather information directly from autistic adults with co-

occurring intellectual disability, the use of technology, such as self-administered electronic interfaces, could be useful (Walton et al., 2022).

In conclusion, this study sheds light on the community integration and life satisfaction of autistic adults in China and compares them with their counterparts in the Netherlands. The findings highlight the shared challenges faced by both Chinese and Dutch autistic adults with high support needs.

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Chapter 5: Self-reported outcomes of autistic adults living in China and the Netherlands: Objective and subjective psychosocial outcomes

Liu, F., Begeer, S., Hoekstra, R. A., Wang, C., & Scheeren, A. M. (2024). Self-Reported Psychosocial Outcomes of Autistic Adults Living in China and The Netherlands. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2024.0073>

Abstract

Despite an estimated population of 10 million autistic individuals in China, little is known about Chinese autistic adults. Cultural and contextual factors may impact objective and subjective psychosocial outcomes of autistic adults. In this descriptive study we aim to compare the psychosocial outcomes of autistic adults between China, an Eastern Asian country, and the Netherlands, a Western European country. Based on self-report online questionnaires we compared objective psychosocial functioning (employment, living situation, friendship), life satisfaction, and internalized autism-related stigma of 36 Chinese (23 males and 13 females) and 29 Dutch (18 males and 11 females) autistic adults. The majority of participants in both countries (Chinese: 66.7%; Dutch: 82.8%) self-reported having an IQ above 70. Chinese and Dutch participants exhibited similar levels of employment, quality of friendships, and life satisfaction ($M_{\text{Chinese}} = 5.81$; $M_{\text{Dutch}} = 6.28$). Chinese autistic adults more often lived with their parents and reported more autism-related internalized stigma than Dutch adults ($M_{\text{Chinese}} = 2.25$; $M_{\text{Dutch}} = 1.79$, $p < .001$). Autism-related internalized stigma was negatively correlated with friendships and life satisfaction across both samples. Heightened internalized stigma among Chinese autistic adults compared to Dutch may reflect cultural differences in attitudes towards autism. Strategies aimed at reducing internalized stigma could help to improve the social connections and life satisfaction of autistic adults within the global autistic community. This cross-country study is a first step in understanding the psychosocial outcomes of autistic adults in China.

Key words

Autistic adults, cultural and contextual, psychosocial outcomes, employment, friendship, living situation, life satisfaction, quality of life

Introduction

Increased attention has been paid to the outcomes of autistic adults in Western, educated, industrialized, rich, and democratic (WEIRD) countries (Howlin, 2021; Steinhausen et al., 2016). However, very few studies have thus far focused on autistic adults in Eastern Asian countries, such as China (Mason et al., 2021; Sáez-Suanes & Álvarez-Couto, 2021). Autism was initially identified in mainland China in 1982 (Hobart, 2008; Kuo-Tai, 1987), almost four decades later than in Western countries (Kanner, 1943). Notably, China is estimated to have approximately 10 million autistic individuals, based on a 0.7% prevalence rate (Zhou et al., 2020). Yet, there is still a striking lack of knowledge regarding the psychosocial outcomes of autistic adults in China.

Cultural and contextual factors, such as societal values, norms, and autism awareness, play an important role in how autism is perceived, understood, and experienced. Western individualistic countries emphasize the independent self and autonomy, and have a longer history of advocating for the rights and empowerment of autistic individuals, creating an environment more accepting of neurodiversity (Szlamka et al., 2022). In these Western countries, a wide range of people, including individuals with average to high intellectual abilities and older adults, are diagnosed with autism (Brugha et al., 2016; Christensen & Zubler, 2020). The Netherlands, a Western European individualistic country, emphasizes accessibility and community-based mental health care (Forti et al., 2014), and provides comprehensive intervention programmes to increase independence and social integration of people with mental

health needs (van der Meer & Wunderink, 2019). There are also self-advocacy movements promoting the rights and empowerment of autistic adults in the Netherlands (Waltz et al., 2015). In a recent study a majority of Dutch autistic adults with (above) average IQ levels showed a fair to very good level of objective psychosocial functioning (based on employment, friendships and independent living) (Scheeren et al., 2022).

Unlike Western individualistic culture, Chinese traditional values prioritize the interdependent self, adherence to societal norms, and group concerns (e.g. collective harmony and family responsibilities) over personal achievements (collectivist culture) (Grossmann & Varnum, 2010; Meyer, 2010). In China, there is limited autism awareness (Yu et al., 2020) and a lack of expertise in diagnosing and supporting autistic adults (with average or high intellectual abilities) (Li & Qi, 2023). It is common that only children with obvious classic autistic symptoms are identified (Huang et al., 2013). In China, autism is mostly considered a disorder rather than a form of neurodiversity. Non-conforming autistic behaviours may be perceived more negatively by the general public in collectivistic culture (Kim et al., 2022; Someki et al., 2018), contributing to public stigma (Chan & Tsui, 2023; Mak & Kwok, 2010). Public stigma can lead to internalized stigma, including internalized negative bias and self-discrimination (Chan & Tsui, 2023; Yanos et al., 2008), resulting in lower self-esteem (Boyd et al., 2014). Consequently, autistic individuals and/or their families might conceal their condition and refrain from advocating for themselves.

Most Chinese autistic adults live with their families, relying on them for care and support (Fisher & Jing, 2008; Wang et al., 2023). This may be because of an

emphasis on parental obligations, filial piety and/or a lack of professional services and affordable housing. Living with parents may also result in extensive family and community support for autistic individuals, in turn fostering their mental health and well-being (Ghosh & Magana, 2009). In the Netherlands, Scheeren et al. (2021) found that 79% of autistic adults with mostly (above) average intellectual abilities live independently (Scheeren et al., 2021). The mental health care system in Western individualistic countries tends to support autistic adults to participate in society, enabling their transition to independent living (Forti et al., 2014; Gotham et al., 2015; Maddox & Gaus, 2019). Given the aforementioned contextual and cultural differences between China and the Netherlands, the psychosocial outcomes of autistic adults from China and the Netherlands may also differ. By comparing China and the Netherlands, we can investigate similarities and differences in outcomes of autistic adults in different cultural and contextual settings.

Although there have been some initiatives to enhance care services for autistic adults in China (Beijing Association for Rehabilitation of Autistic, 2018; Xiao, 2023), our current knowledge of the psychosocial outcomes of autistic adults relies on parent-reports (Jia, 2022). For instance, the report of Jia et al. (2022) suggests that Chinese autistic adults (n=144) show a low (11%) employment rate. Our own previous study (under review), focused on autistic adults with high support needs (99 autistic adults in China and 109 in the Netherlands aged between 18 to 30 years), also revealed low employment rates (27.3%) in Chinese autistic adults. Around 93% resided with their parents. Few of them had close relationships, and their life satisfaction was lower

compared to the general Chinese population. It is important to note that these findings relied solely on parental reports, which may not (fully) align with the experiences of autistic adults themselves.

In the absence of basic knowledge about the outcomes of autistic adults in mainland China, we focused on their life satisfaction and objective psychosocial functioning, including employment or productive activities, living situation, and social engagement (Sander et al., 2010; Scheeren & Geurts, 2015). Many autistic adults, including those with average to high intellectual abilities, continue to struggle in these areas (Mason et al., 2021; Wickstrom et al., 2021). In this descriptive study, we aimed to (a) describe the degree of independent living, employment, friendship and life satisfaction ratings as reported by Chinese autistic adults themselves and a comparable sample of autistic adults from the Netherlands, and (b) investigate potential differences in internalized stigma between both samples and explore whether internalized stigma plays a role in outcome differences. We expected that autistic adults in China would report (1) lower employment, friendship ratings and living situation, (2) lower life satisfaction, and (3) more internalized stigma compared to their counterparts in the Netherlands.

Methods

Procedure

In this study, we focused on autistic adults with the capacity to self-report in China and the Netherlands. This study was part of a bigger study on autistic adults with

varying intellectual abilities and daily life skills in China and the Netherlands (<https://osf.io/m9e5s>).

The Chinese participants were recruited via an online nationwide survey through the Autism Research Centre of Nankai University (NKARC), Tianjin, China. NKARC has built a network of over 100 service centres of adults with autism covering all major regions of China. Autistic adults were invited to self-report on the questionnaire. Chinese data were collected in the Fall of 2022. All of the Chinese participants were diagnosed with autism by clinicians (psychiatrists, psychologists, and paediatricians).

Dutch participants were recruited via the Netherlands Autism Register (NAR, <https://www.nederlandsautismeregister.nl/english/>), a nationwide autism register that collects information from autistic individuals and their parents/caregivers. All Dutch participants had a formal autism diagnosis. Dutch data were collected by the NAR in September 2022. All participants consented to participate by reading the informed consent statement and checking a box indicating their agreement. The data collection has been reviewed and approved by the ethics committee of the Vrije Universiteit Amsterdam (VCWE 2020-041R1) and Nankai University (NKUIRB2022127).

Study sample

In this study, 36 Chinese autistic adults aged 17 to 51 years completed a self-report questionnaire. We then selected 29 Dutch autistic adults from the NAR dataset

who matched the Chinese sample in terms of sex (female/male), self-estimated intellectual ability (below/above an IQ of 70), age and age of autism diagnosis (allowing for a difference of 7 years). Table 1 presents the demographic information.

Table 1 The Demographic Variables between China and the Netherlands

Variables	China		The Netherlands		Statistics
	N / M	% / SD	N / M	% / SD	
Total N	36	100.0	29	100.0	
Sex					$\chi^2 = .02, p > .05$
Male	23	63.9%	18	62.1%	
Female	13	36.1%	11	37.9%	
Mean age	26.43	7.59	28.00	7.35	$t = -.85, p > .05,$ $d = 7.48$
Mean age of diagnosis	10.96	9.38	15.91	9.81	$t = -1.85, p > .05,$ $d = 9.57$
IQ level					$\chi^2 = 2.54, p > .05$
IQ below 70	11	30.6%	4	13.8%	
IQ above 70	24	66.7%	24	82.8%	
Missing	1	2.8%	1	3.4%	

Measurements

Outcome measures

Objective psychosocial functioning. Following Scheeren et al. (2022) we measured employment status, living situation, and friendship, with hierarchical ratings reflecting different degrees of attainment in these areas (see supplementary Table S16). Given expected country differences in living arrangements, we analysed employment, friendships and living situations separately.

Life satisfaction. Life satisfaction was measured by the 0 to 10 Cantrill Ladder scale: ‘Where would you rate your life generally on a scale from 0 to 10?’ with ‘10’ indicating the best possible life and ‘0’ the worst possible life. Higher scores indicate higher life satisfaction (Cantril, 1965).

Internalized stigma. The 10-item version of the internalized stigma of Mental illness (ISMI-10) was used to measure the internalized stigma associated with being autistic. (Ritsher et al., 2003) Each item rated on a 1 (strongly disagree) to 4 (strongly agree) Likert scale. Item 2 and item 9 are reversed scored. The ISMI has been widely used around the world like China and the Netherlands with good reliability and validity (Boyd et al., 2014; van Beukering et al., 2022; Young et al., 2016). The ISMI-10 score is calculated by dividing the sum of item scores by the number of answered items. The ISMI-10 showed adequate internal consistency ($\alpha_{Chinese} = 0.69$, $\alpha_{Dutch} = 0.76$). In this paper, the score was used as a continuous variable for analysis. We interpreted the score based on the 4-category method (Lysaker et al., 2007): minimal to no internalized

stigma (1.00–2.00), mild internalized stigma (2.01–2.50), moderate internalized stigma (2.51–3.00), and severe internalized stigma (3.01–4.00).

Demographic variables

Self-estimated intellectual ability was reported at seven levels, ranging from an IQ below 40 (severe intellectual impairment) to an IQ above 130 (gifted). First, autistic adults were asked whether they had ever taken an official IQ test or whether their IQ had ever been determined by a clinical psychologist or professional. If so, they were asked to select the appropriate IQ level that best described their intellectual ability. If the autistic adult had never taken an IQ test or their IQ score was unknown, they were asked to estimate their intellectual ability and select the corresponding level. Most IQ reports (Chinese: 75%; Dutch: 69%) were based on a prior IQ test. For the analyses, intellectual ability was categorized into below 70 and above 70. Proxy-estimated IQ has been found to correlate highly with adaptive functioning ($r = -0.71$). (Werkman et al., 2020) We also found an overlap between self-estimated IQ and highest educational level (IQ ≤ 70 : 80% low, 20% middle educational level; IQ >70 : 12.5% low, 25% middle, 62.5% high educational level). Both findings provide preliminary support for the validity of the self-estimated IQ measure.

Educational level was categorized into low, middle and high, based on the educational systems in each country. Primary schools and special schools were categorized into low level, secondary schools were categorized into middle level, and

university (Bachelor, Master, Doctoral) were categorized into high level of education in both countries.

Instruments Translation

All of the questions and questionnaires were originally developed in Dutch. The translation into Mandarin Chinese was conducted following a forward and backward procedure (Hall et al., 2017). Initially, the items were translated into Mandarin by two Chinese postdoc proficient in Dutch. Then, a Dutch translation agency back-translated these items into Dutch. This back-translated version was compared with the original by two native Dutch speakers, with discrepancies revised for accuracy. Finally, the Chinese version was reviewed and adjusted by the authors, ensuring it was linguistically equivalent to the Dutch original.

Results

Descriptive Statistics

Chinese autistic adults (23 males and 13 females) and Dutch autistic adults (18 males and 11 females) were included in this study. A majority of autistic adults in both countries self-reported an IQ above 70 (Chinese: 66.7%; Dutch: 82.8%) and over half of the samples in both countries reported middle to high educational levels (Chinese 66.6%; Dutch: 72.4%).

Objective psychosocial functioning, life satisfaction and internalized stigma

Contrary to our hypothesis, a similar majority of participants in both countries (68.5% in China and 75.8% in the Netherlands) were engaged in either regular paid or non-regular paid employment (See details in Table 2). Likewise, most of the autistic adults reported having friends in both countries (66.7 % in Chinese and 82.7% in Dutch sample). The majority of Chinese participants (62.9%) reported living with their parents and no one lived in a healthcare facility. In contrast, a smaller percentage (42.9%) of Dutch participants lived with their parents and 5 Dutch participants (17.9%) lived in a healthcare facility.

Chinese autistic adults reported a similar level of life satisfaction as Dutch adults ($t = -.88, p > .05, d = 1.91$), but a higher level of autism-related internalized stigma than Dutch adults ($t = 4.22, p < .001, d = .44$). See statistical details in Table 2.

Table 2 The Outcome Variables between China and the Netherlands

Variables	China		The Netherlands		Statistics
	N / M	% / SD	N / M	% / SD	
Total N	36	100.0	29	100.0	
Education level					$\chi^2 = .65, p > .05$
Low level of education	12	33.3%	8	27.6%	
Middle level of education	7	19.4%	8	27.6%	
High level of education	17	47.2%	13	44.8%	
Employment status					$\chi^2 = .45, p > .05$
Not any kind of employment	11	31.4%	7	24.1%	
Non-regular employment	6	17.1%	5	17.2%	
Regular paid employment/studying	18	51.4%	17	58.6%	
Living situation					$\chi^2 = 9.28, p < .05$
Living in a healthcare facility	0	0.0%	5	17.9%	
Living with parents or family	22	62.9%	12	42.9%	
Living independently with housing assistance	2	5.7%	0	0.0%	
Living independently	11	31.4%	11	39.1%	
Friend relationships					$\chi^2 = 2.92, p > .05$
Hardly any friends	12	33.3%	5	17.2%	
Other friends	14	38.9%	11	37.9%	
Close friends	10	27.8%	13	44.8%	
Life satisfaction	5.81	2.34	6.28	1.87	$t = -.88, p > .05,$ $d = 1.91$
Internalized stigma	2.25	4.45	1.79	4.28	$t = 4.22, p < .001,$ $d = .44$

Associations with internalized stigma

To detect a medium-sized effect ($f=0.15$) in a linear regression analysis, with 80% power and a 5% significance level, a smallest total sample size of 55 is needed (Cohen, 2013). Therefore we explored the associations between objective and subjective outcomes and internalized stigmas across both samples.

A linear regression analysis across both samples, with internalized stigma as a predictor, life satisfaction as dependent variable, showed that internalized stigma had a significant negative impact on life satisfaction scores ($B = -1.58$, $R^2 = .13$, $F(1, 64) = 9.48$, $p < .005$).

Separate ordinal regression analyses with employment, friendship and living situation as categorical outcomes and internalized stigma as a predictor across both samples revealed that internalized stigma negatively impacted the quality of friendships, $\chi^2(1) = 4.30$, $B = -1.03$, $p < .05$, but was not associated with employment, $\chi^2(1) = 2.81$, $p > .05$, or living situations, $\chi^2(1) = .96$, $p > .05$. Internalized stigma accounted for approximately 5.1% of the variance in friendship quality (Proportional Reduction in Error = .051), suggesting a modest yet significant negative relationship between internalized stigma and friendship.

Discussion

We compared self-reported levels of employment, friendship, living situation and life satisfaction of autistic adults in China and the Netherlands. Against our

expectation, Chinese and Dutch autistic adults reported a similar and fairly high degree of employment and most reported having friends. Life satisfaction ratings were moderate, but similar in both samples. As expected, Chinese autistic adults more often lived with their parents compared to Dutch autistic adults. Also, Chinese autistic adults reported more internalized stigma than Dutch autistic adults. Lower autism-related internalized stigma was linked with closer/more friendship and higher life satisfaction ratings across countries.

In contrast to our hypothesis, autistic adults reported similar and positive objective outcomes in terms of employment and friendships. Previous meta-analyses have reported that in Western countries the psychosocial functioning of autistic adults was on average poor, and a higher IQ appears to promote a better outcome (Howlin, 2021; Mason et al., 2021; Steinhausen et al., 2016). Gotham et al. (2015) and Scheeren et al. (2021) observed better objective psychosocial outcomes for self-reporting adults with high estimated IQ and/or a late autism diagnosis (Gotham et al., 2015; Scheeren et al., 2022). Despite the positive objective outcomes in our current study, participants in both countries generally reported moderate life satisfaction in both countries. Life satisfaction ratings were consistently lower than in the general population in each country, as indicated by the World Happiness Report in 2022 (with average happiness scores of 7.40 in the Netherlands and 5.82 in China) (Helliwell et al., 2022).

The similarity in positive objective outcomes between China and the Netherlands might be due to a majority of autistic adults in both countries with self-estimated IQ above 70 and the relatively high level of educational attainment. Another

explanation for the positive outcomes might be that potential beneficial impacts (e.g., policy commitments to include autistic adults in society and heightened family-based support in China (Fisher et al., 2011) mitigate the negative impacts of more autism-related stigma. For example, in China, there are newly initiated services, policies (Xiao, 2023), like ‘recommendations on strengthening rehabilitation and care services for autistic adults’, and programs promoting the employment of autistic adults, such as a Fujian courier station allowing autistic youth to sort and deliver packages (Li & Qi, 2023). Also, some family-based support may serve as a substitute for professional services to increase objective psychosocial functioning (Sun et al., 2013) and quality of life of autistic adults (Hayes et al., 2023). Supportive policies and family support may improve the inclusivity and well-being of autistic adults.

A high percentage (62.9%) of Chinese adults lived with their parents compared to Dutch adults (42.9%), possibly reflecting cultural differences in traditional family values and stronger family support in China. This finding aligns with observations by McCabe and Wu (2009), who found that even employed autistic adults crucially rely on their mothers’ assistance to meet workplace expectations and to enhance their objective psychosocial functioning (McCabe & Wu, 2009). Other potential reasons why it may be more common for Chinese adults (autistic or non-autistic) to live with their parents and family are filial piety (children are traditionally expected to care for their elders when they grow up), high costs of living, and lack of affordable and adequate housing (Gan & Fong, 2020; Wang et al., 2021). An individual’s living situation may

therefore not accurately reflect their psychosocial functioning and may have different meanings within different cultural contexts.

As expected, Chinese adults reported more autism-related internalized stigma than Dutch adults. The biggest group difference was found in the ISMI-10 item describing social withdrawal in order to protect family or friends from embarrassment (See supplementary Table S17 and Figure S6). This may reflect a cultural pressure on safeguarding social harmony and protecting their family's reputation among Chinese autistic adults, which is in keeping with prior findings that Chinese families with autistic individuals tend to conceal their condition and hide from the public (Chan & Lam, 2018; Mak & Kwok, 2010). Additionally, Chinese autistic adults more often endorsed the statement 'People without autism could not possibly understand me'. This tentatively suggests that the double empathy problem might be bigger in China. The double empathy problem is a theory which posits that the social communication gap between autistic and non-autistic individuals is created and felt by both autistic and non-autistic people (Milton, 2012; Mitchell et al., 2021). Thus, multiple factors, including but not limited to public stigma, may help to explain the higher levels of internalized stigma among Chinese autistic adults compared to their Dutch counterparts.

The strong negative correlations between internalized stigma and life satisfaction and friendship are in line with previous research (Botha & Frost, 2018; Cage et al., 2018; Chan & Tsui, 2023), highlighting the role of internalized stigma in the wellbeing of autistic adults. Internalized stigma can lead to reduced self-esteem, low self-efficacy, and reduced help-seeking behaviours, which negatively impact the

pursuit of friends, work and personal goals, further hampering life satisfaction (Corrigan et al., 2009; Li et al., 2023). Yet, despite a higher level of internalized stigma in the Chinese sample this did not result in a lower life satisfaction rating compared to the Dutch sample. We acknowledge that multiple factors, like social support, income, and access to support services, may influence life satisfaction (Li et al., 2023), so the effect of internalized stigma may be relatively small. Future research ideally includes quantitative and qualitative methods, focusing on social support, autism-specific services and autistic adults' personal needs, to provide deeper insights into the factors influencing objective psychosocial functioning and wellbeing of autistic adults in different countries.

Our study has some limitations. Firstly, we used self-estimated IQ reports (Scheeren et al., 2022), which are informative, but do not reflect objective measures of cognitive ability. Furthermore, the way we measured employment, living situation and friendship may not align with a Chinese context and culture. Thirdly, the relatively small sample sizes may limit our generalizability and stresses the importance of replication in larger samples. For instance, we detected a non-significant, but large country effect ($d = 1.91$) on self-reported life satisfaction, suggesting that an increase in sample size might potentially lead to statistically significant differences. Despite extensive efforts and a nationwide network in China, it proved challenging to recruit self-reporting autistic adults for research purposes due to the unavailability of autistic adults who can and want to self-report.

Given the study limitations and our own study findings, we suggest that future research focuses on what “appropriate psychosocial functioning” and quality of life means to autistic adults in different cultures by doing qualitative research. Future research should also develop suitable, accessible and culturally sensitive measures including person-environment fit indices for autistic adults and their families (Henninger & Taylor, 2013; Lai et al., 2020). This type of research will further contribute to learn more about and better meet the support needs of autistic adults across the globe (Georgiades & Kasari, 2018; Mason et al., 2021). Additionally, given the higher levels of autism-related internalized stigma among Chinese adults, we advocate further research to develop and examine effects of positive, neuro-affirmative approaches to support autistic adults (Han et al., 2023).

This cross-country study is a first step in understanding the psychosocial outcomes of autistic adults in China compared to autistic adults in the Netherlands. Despite obvious cultural and contextual differences, life satisfaction, employment, and friendship levels were surprisingly similar for Chinese and Dutch autistic adults. Heightened internalized stigma among Chinese adults may be caused by societal differences in the acceptance of autism. In both countries, higher internalized stigma was associated with lower levels of objective psychosocial functioning and life satisfaction. More research is needed to further investigate and support objective and subjective psychosocial functioning of autistic adults within the global autistic community.

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Chapter 6: General discussion

This dissertation was set out to address the research gap in cross-cultural understanding of autism through four comparative studies within the distinct cultural contexts of China and the Netherlands. We examined country differences in autistic traits, well-being of individuals and families with autism and the impact of various demographic, socioeconomic, and psychological factors. For autistic adults specifically, we examined community integration and life satisfaction based on proxy- and self-report. In the current chapter, the main findings of this dissertation are presented, limitations of the studies and scientific and clinical implications are addressed to inform the relative stakeholders.

Main findings of the current dissertation

Autism may be interpreted and perceived differently in China and the Netherlands

In Chapter 2, we analyzed how autistic traits are perceived and interpreted in China and the Netherlands by examining the factor structure of the parent-reported AQ-Short, a commonly used questionnaire for screening autistic traits, across both countries. The exploratory factor analyses revealed a three-factor model (Numbers and Patterns, Social Skills, and Mind-reading) for the Chinese sample and a five-factor model (Imagination, Numbers and Patterns, Attention Switching, Social Skills, and Mind-reading) for the Dutch sample. The Social Skills factor, Numbers and Patterns factor,

and Mindreading factor emerged in both factor analyses, suggesting that the same types of behaviours tended to group together in different cultures. However, the items loading on the Social Skills factor in the Chinese model included a combination of items loading on separate factors in the Dutch model (Social Skills, Attention Switching, and Imagination). This variability indicates that certain behaviours group together differently across cultures, possibly highlighting the influence of cultural contexts on how autism-related behaviours are perceived and reported by parents.

We also noted that Numbers and Patterns were negatively correlated with Social Skills in the Chinese sample only, indicating that a strong interest in numbers or patterns might not be seen as indicative of autistic traits in China. These results are consistent with other Asian studies validating screening measures for autism (Chee et al., 2024; Fani et al., 2023; Ward et al., 2021). In China, for instance, a specific interest in patterns or numbers might be seen as a positive indicator of high intelligence or academic success rather than a symptom of autism. This cultural variation in interpretation could impact the assessment and understanding of autism in different cultural and contextual settings, emphasizing the need for culturally appropriate screening tools that are sensitive to the understanding and expressions of autism.

Cultural differences in recognition and interpretations of autistic traits may impede the generalizability of autism screening tools developed within Western contexts to Eastern settings, potentially affecting an accurate identification of autism in China (Stewart & Lee, 2017; Sun, Allison, Auyeung, Matthews, Baron-Cohen, & Brayne, 2013; Wang et al., 2020). Furthermore, public stigma, parental expectations,

and limited knowledge about autism among both the public and healthcare professionals may also contribute to underdiagnosis of autism in China, especially for individuals with high intelligence (Clark et al., 2019; Huang et al., 2013). In China, referrals to healthcare professionals (mainly psychiatrists) for further autism assessments often depend largely on parental observation of atypical cognitive and mental development (such as apparent impairments in functional communication and intellectual disabilities) (Huang et al., 2013; Pang et al., 2018). Parents in China may hesitate to report developmental issues due to fear of shame and guilt associated with having a child with a disability (Jin et al., 2018; Wang et al., 2013; Wang et al., 2011), as a diagnosis of a developmental disability may lead to rejection of public regular educational and employment opportunities due to the stigma. Even if atypical development is recognized, parents may misinterpret serious behavioural challenges of a child with high intelligence as "naughty" or a unique personality rather than recognizing these behaviours as indicators of a disorder (Huang et al., 2013). For healthcare professionals, the lack of formal training in psychiatry and the limited number of professionals (i.e., mostly psychiatrists) with knowledge about autism in normally intelligent individuals, may lead to a missed diagnosis (Wang et al., 2020).

Many adults with normal intellectual abilities remain undiagnosed in China, whereas classic autistic behaviours (such as apparent impairments in functional communication) and intellectual disabilities in children are more easily noticed. In Chapter 5, despite our extensive efforts and nationwide network, recruiting self-reporting autistic adults in China turned out to be especially challenging. According to

the available reports, most Chinese autistic adults have a co-occurring intellectual disability and receive their autism diagnosis in early childhood (Jia, 2022). Even some autistic adults who are aware of their condition may choose to conceal their natural social behaviours and use strategies (masking or camouflaging) to minimize their autistic features in order to fit into the largely neurotypical (non-autistic) social world. A late diagnosis of autism, as well as choosing to conceal autistic behaviours, may be related to poor social and psychological outcomes (Bargiela et al., 2016; Cage & Howes, 2020). The ‘lost generation’ of autistic adults (Lai & Baron-Cohen, 2015) still seems to be very much lost in China. However, in Western high-income countries like the Netherlands, with its relatively high acceptance of autism and well-developed welfare system, an autism diagnosis may promote better identity formation and future planning (Cooper et al., 2023; Overton et al., 2023).

Well-being of individuals and families with autism

Chapter 3 focused on the comparison of parenting stress levels among Chinese and Dutch caregivers of children with autism. The levels of reported parenting stress differed significantly, with Chinese caregivers experiencing higher levels of parenting stress than their Dutch counterparts. The higher levels of parenting stress experienced by Chinese caregivers highlight the distinct cultural and contextual challenges faced by caregivers in China. In China, where the one-child policy was in effect for 35 years and ended in 2021, parents often invest all their hopes into their single child with a focus on achievement (Ashton-James et al., 2013). Discovering that their child has autism,

which is highly stigmatized in Chinese society, can lead to a considerable amount of disappointment and frustration (McCabe, 2008). This diagnosis not only confronts the parents with the unexpected task of managing a complex neurodevelopmental condition but also disrupts established patterns of family functioning and socialization, further adding to parental stress (Huang & Zhou, 2016).

Differences in support services and resources may also impact parenting stress. In the Netherlands, care services for autism span a wide range, including general practitioners and Mental Health Practitioners (GGZ), who play an important role in the healthcare system, and special educational support, such as Special needs education (SO, SBO and VSO) and Expert Centre on Inclusive Education (ECIO). Additionally, many organizations such as the Dutch Autism Association (NVA), Vanuit Autisme Bekeken (VAB), Autminds and Personen uit het Autisme Spectrum (PAS) are dedicated to advocacy, providing accurate information, and facilitating connections among autistic individuals and families facing similar situations.

Mental healthcare in mainland China has been recognized as inadequate (Sullivan & Wang, 2019). Children labeled with disabilities face rejection by public regular schools, despite the ‘Suiban Jiudu’ policy (Huang & Wheeler, 2007), which promotes inclusion in mainstream classrooms. Regular education for children with special needs is still limited because of the lack of individualized educational program/plan created for the students (Huang et al., 2013). Recently, many Chinese parents of children with autism are advocating for inclusive education (Zhang et al., 2022) and Chinese researchers and professionals are promoting early identification and

intervention for children with mental disabilities (Sullivan & Wang, 2019; Wei et al., 2022). NGOs, a major force for supporting children with autism, have also expanded the number and improved the quality of provided services (Li & Qi, 2023). For example, apart from public regular and special schools, there has been a rise in the establishment of rehabilitation institutions designated by the China Association of Persons with Psychiatric Disability and their Relatives (CAPPDR). The CAPPDR is reportedly the largest national autism association in China and is responsible for all autism services. Big cities or economically more developed provinces like Beijing, Shanghai and Guangdong province have a higher concentration of such institutions than rural areas (Wang et al., 2018). Therefore, autistic children may be referred to and receive interventions more in developed cities or provinces.

Despite the existing educational and intervention opportunities mentioned above, many children with autism in China, particularly those with moderate to severe symptoms or challenging behaviours, those from low socioeconomic families, and those residing in remote rural areas, still lack access to treatment or interventions. Chinese parents often face significant financial burdens and high social stigma (Zhao et al., 2023) and therefore teach their autistic children mainly by themselves (Clark et al., 2019; Sun, Allison, Auyeung, Matthews, Murray, et al., 2013). Unlike Western countries, a standardized national policy or strategy for autism is still lacking in mainland China. Instead, different regions have local policies, involving a disability certificate for autism and financial support from the China Disabled Persons' Federation (CDPF), the authority responsible for issuing the disability certificate and

the allowance. However, not all children qualify, especially those without a disability certificate (the certificate was required for some but not all provinces) or attending rehabilitation centers outside their registered residence ('Hu Kou'). Additionally, the allowance is often insufficient to compensate for the costs of education and intervention for children with autism (Pan & Ye, 2015; Xiong et al., 2011). This disparity underscores the urgent need for more available, accessible, and appropriate approaches to autism care in China, addressing both the financial and social barriers faced by families, especially for low socioeconomic families. In conclusion, the findings of Chapter 3 emphasize the need for targeted interventions and policy reforms to alleviate the degree of parenting stress experienced by caregivers of children with autism in China.

In Chapter 4, we showed that Chinese autistic adults with high support needs had lower levels of life satisfaction compared to their Dutch counterparts, as reported by their caregivers. The difference in life satisfaction may be due to the less comprehensive system of support services for adults on the autism spectrum (Baker et al., 2020) and limited public knowledge (Yu et al., 2020) in China, and higher stigma of autism in Eastern Asian countries (Kim et al., 2022; Someki et al., 2018). Another possible reason for this difference may stem from the high levels of parenting stress among caregivers. Stressed caregivers may have a bias toward negative interpretations and may also rate their child's life satisfaction more negatively. Moreover, the emphasis on achievement in Eastern Asian countries may foster excessive competitiveness and conformity (Gao & Lee, 2021; Ng, 2002), likely extending to parenting practices and

resulting in higher academic and achievement expectations among Chinese parents compared to Dutch parents. One of parents' greatest concerns is their children's future independence and ability to support themselves, leading to reports of lower life satisfaction for their autistic adult children (Hua, 2017).

Chinese parents also tend to be protective and actively involved with the lives of their children and try to train their children to fit into neurotypical standards (DeLambo et al., 2011; Jiar & Xi, 2012), potentially amplifying stress and undermining happiness of their autistic child. A Chinese mother residing in the Netherlands noted in an interview with me that Dutch practitioners encourage children to develop at their own pace without pressure for improvement, which she appreciated. However, she observed slow progress in her child's development and worried about her child's readiness for further school education. As a result, she sought interventions from Chinese practitioners, believing that their hands-on approach could accelerate progress and better prepare her child for future challenges. Therefore, varying cultural expectations potentially impact how parents interpret their child's experiences and progress.

Similarities of the outcomes of autistic adults in China and the Netherlands

Despite differences in culture and context, our findings in Chapter 4 and Chapter 5 indicate that both Chinese and Dutch autistic adults with or without high support needs face common challenges and achievements, which go against our expectations.

Specifically, autistic adults with high support needs were reported to have limited community integration in both countries, characterized by low employment rates, restricted independent living, and few close friendships. This result aligned with previous research that in Western high-income countries, autistic adults with high support needs struggle to integrate into their communities (Mason et al., 2021). Moreover, autistic adults who can self-report in both samples showed a comparable and fairly high degree of employment and most reported having friends, alongside similar and moderate levels of life satisfaction. The findings showed that autistic adults with or without high support needs end up with similar overall levels of functioning and well-being in both countries.

Even though most Chinese autistic adults did not live independently, they had similar levels of employment and friendships as the Dutch autistic adults. In mainland China, although there has been a rise in the number of autism rehabilitation institutions (around 2304 establishments in 2021) designated by the CAPPDR, the focus of the services and institutions remains heavily skewed predominantly toward younger children. This leaves a substantial gap in professional and structured support for autistic adults, which may limit their opportunity to integrate into society and achieve a higher quality of life. Moreover, financial constraints, particularly for individuals with lower socioeconomic status, further exacerbate these challenges (Clark et al., 2019). Limited funding also affects the recruitment and training of specialized professionals and the development of effective training programs (Li & Qi, 2023). We also found that Chinese parents tend to take care of their adult autistic child in their own homes,

whereas care for autistic adults appears more institutionalized in the Netherlands. In China, the notable emphasis on family-based support for autistic adults may compensate for the lack of professional services tailored to older individuals.

On the other hand, the Netherlands appears to offer more institutional and professional support structures for autistic adults, such as organizations aimed at support for adults with autism (i.e., PAS and Youz) and educational resources like the Expert Centre on Inclusive Education (ECIO) aimed at enhancing community integration and independence. Yet, challenges for autistic adults in the Netherlands may still arise due to long waiting lists in the mental health care system, inadequate funding, or difficulties in navigating complex service systems (Malik-Soni et al., 2022). Additionally, the pressures of maintaining employment or living independently in a more supportive environment can still lead to increased stress, anxiety, and sensory overload, which may negatively impact their well-being (Baldwin & Costley, 2016; Bishop-Fitzpatrick et al., 2016).

Furthermore, in both countries, higher internalized stigma was associated with lower levels of community integration and life satisfaction (Helliwell et al., 2022). Notably, Chinese adults reported more autism-related internalized stigma than Dutch adults. Group differences were most notable in two items: one related to social withdrawal in order to protect family or friends from embarrassment, and the other indicating a heightened sense of being misunderstood by non-autistic individuals among Chinese autistic adults. This divergence possibly reflects the lack of autism awareness and acceptance in China and a deeply ingrained cultural tendency among

Chinese autistic adults to prioritize maintaining social harmony and safeguarding the dignity of their close relations.

Limitation of the current thesis

Several limitations should be acknowledged. Firstly, it is uncertain whether the different results between countries are specific to individuals with autism or reflect more general country differences. The variations in demographic variables such as sex, age, and socioeconomic status between our autistic Chinese and Dutch samples may influence how autistic traits are interpreted and affect the well-being of individuals with autism. For example, in Chapter 4, younger adults in the Dutch sample were reported to be more integrated into their communities compared to older adults, a pattern not seen in the Chinese sample. Furthermore, the Chinese participants in our study showed more classic autism symptoms and/or intellectual disabilities (children with average or high intellectual abilities may be mostly overlooked). In contrast, the Dutch sample, collected through an online autism research register, includes a diverse mix of individuals across all ages, intellectual abilities, and autism symptomatology. The differences in terms of degree of autistic traits and/or intellectual abilities between both samples might also confound the general country differences, making it challenging to determine if the observed results are specific to autism or reflect broader national characteristics. These differences highlight the importance of considering demographic variations in autism research.

Secondly, we used measurements that are based on Western standards and these may not align with Chinese culture and context. The divergence in language, culture, experience, and response styles may also lead to varied results. In Chapter 2, we found that the Numbers and Patterns factor measured in the parent-report version of the AQ-Short may have a different meaning for Chinese parents than the Western version and this may hamper cross-cultural comparisons. Chapters 4 and 5 apply Western criteria to evaluate level of community integration, including independent living, which may not match well with the contextual background in China, where the financial constraints and limited care facilities may compel many young adults, both with and without autism, to reside with their parents (Gan & Fong, 2020; Wang et al., 2021). Thus, living with family in China may not indicate a level of (in)dependence as it does in the Netherlands. A study on Chinese parents' views revealed that 79% wished government-provided long-term residential options for their children, indicating that adults with disabilities frequently reside with family due to a scarcity of alternatives, rather than by preference (Guo et al., 2014).

A third limitation is the lack of information on contextual factors, autism severity and formal intellectual levels of the autistic individuals. Firstly, our study did not comprehensively examine contextual factors. In Chapter 2, 3 and 4, we examined the impact of socioeconomic status (e.g., educational level and family income level of caregivers) but did not investigate other potential contextual factors such as public stigmatization, experiences with education, healthcare, and social services and unmet needs that could affect autistic people and their families. In Chapter 3, we found a

positive association between COVID-19 worries and parenting stress in both China and the Netherlands but did not dig into how numbers of infections and fatalities in both countries affected parenting stress. Furthermore, in Chapter 5, we managed to test autism-related internalized stigma through self-reports from autistic adults, but we did not evaluate other important contextual factors that could impact the experiences of autistic adults, such as the level of support they receive, their income, and access to support services. Secondly, the absence of detailed information on autism severity and formal cognitive assessments limits our ability to fully understand the country differences in parenting stress and the outcomes of autistic adults.

A fourth limitation of our study is that the informants who filled out the surveys may not represent the wider autistic and autism community. All data were either proxy-report or self-report, but no data were collected from multiple informants, for example, clinician observations and comparisons between self-report and proxy-report were not included. Adding reports from different sources could help reduce biases from single viewpoints and enrich our understanding of autism, including the interpretation of autistic traits, and a more nuanced view of the autistic experience across different cultural and contextual settings. Not having this variety of information is a gap in our research that future studies could address.

Implications and future directions

Differences in cultural interpretations of autistic traits are found in Chapter 2, highlighting a need to develop assessment tools to be culturally appropriate and accurately reflect the experiences and behaviours of individuals within each specific background. It is important to combine universal items that are relevant across all cultures with culture-specific items that capture unique cultural expressions of autism. This hybrid approach can facilitate both meaningful cross-country comparisons and culturally sensitive assessments. Qualitative methods like interviews or focus groups with families, the general public, teacher observation, and clinical assessments can help gather insights into perceptions of autism, including beliefs about its causes and symptoms, as well as feedback on the suitability of assessment tools. This information is crucial for tailoring assessment tools to better suit cultural norms and beliefs. Moreover, there is a need for training of psychiatrists, psychologists, and paediatricians to improve knowledge of autism in diverse cultural backgrounds and avoid misdiagnoses, delays in the identification of autism in children as well as overlooking mild autistic traits in China. Furthermore, low-income Chinese families reported fewer autistic traits, making them vulnerable for under-detection. With China having higher income inequality (World Bank's Gini coefficient: 37.1 in China vs. 26 in the Netherlands in 2020) and higher poverty levels than the Netherlands, socioeconomic status may be a Chinese context-specific factor delaying autism diagnosis and hampering access to services. Professional support and services for autism are centralized in major cities like Beijing, Shanghai, and Guangzhou. There is limited

availability of a systematic framework for identification and diagnosis of autism for the Chinese population residing in poor, remote, and rural areas. A possible solution is the "task-sharing" approach, where specialists train and supervise community-based health-care and education workers to facilitate the experts and intervention. These community-based helpers, who know the local language and culture, can make autism care more accessible to those in remote areas (Divan et al., 2021). Future research could also explore how these non-specialist facilitators can be adapted for Chinese cultural contexts to ensure acceptability, feasibility and effectiveness.

Caregivers in China experienced higher parenting stress compared to their Dutch counterparts, as indicated in Chapter 3. Due to "loss of face concern" Chinese parents tend to shoulder everything themselves or ask for help within the family (e.g. grandparents) rather than seeking help from an external resource (Ng et al., 2021). Supports for autism families can promote the combination of internal family effort (i.e., parents, other family members) and external social support (i.e., professionals, communities/general public, stakeholders/policymakers) to reduce parenting stress in Chinese parents of children with autism. Interventions aimed at stress management and coping skills of parents (e.g. cognitive reframing; seeking social support) to reduce parental role burden may be particularly beneficial for caregivers (Chan et al., 2018; Hu et al., 2019; Lai et al., 2015). Social support services, including individualized and appropriate educational services, should be contextually adapted, physically available (both in major cities and remote areas), and low-cost access for Chinese families with autism, especially for those with lower socioeconomic status, to reduce the barriers to

help-seeking (Divan et al., 2021; Huang et al., 2013). Moreover, as there are few cross-cultural studies on parenting stress between Asian and non-Asian or Western caregivers, more in-depth studies and reviews, considering potential factors of parenting stress (such as autism severity of their children, measurement of stigma), could be done across different cultural contexts to inform the development of culture-specific support interventions.

In Chapter 4 and 5, we found that Chinese and Dutch autistic adults with or without high support needs shared similar outcomes in terms of community integration. These similar outcomes (i.e., low rates of employment, limited independent living, and few close friendships) in autistic adults with high support needs highlight the need for exploring the underlying factors contributing to these shared challenges across different cultural and contextual settings to understand the complex and unique experiences of autistic individuals, especially those with high support needs (Lord et al., 2022). It is also important to develop targeted and effective support for promoting the quality of life of autistic adults.

Additionally, community integration measures often rely on "normative" standards that may not be necessarily important to individuals with autism or overlook crucial aspects of life domains such as access to meaningful and enjoyable everyday life activities appropriate to capacity level; good physical and mental health; neighbourhood support; supportive family contacts, and parental/caregiver warmth. There has been an increased focus on the importance of "person-environment fit" support that matches autistic people's developmental level (either behavioural or

cognitive levels) and individual needs (Henninger & Taylor, 2013; Lai et al., 2020). Creating autism-friendly contexts by supporting families, improving societal awareness, and understanding of autism, reducing stigma, and promoting inclusion in education, the community and at work are needed to optimise the person-environment fit.

Recently, researchers call for redefining what “success” means, highlighting the need for a comprehensive and inclusive definition that captures the diversity of autistic adults across different societal settings (Georgiades & Kasari, 2018; Mason et al., 2021). Success can be defined as something more than the state of employment or living independently. It also includes having a positive view of being autistic, being understood by the public and peers, experiencing fewer sensory issues due to environmental changes, and acknowledging the contributions of autistic people to society. Qualitative studies are further needed to explore the needs of individuals and families with autism in China. Moreover, due to the lack of availability of autistic adults with official autism diagnoses in China, longitudinal research tracking the development and outcomes of individuals with autism since early childhood would be valuable in assessing the potential factors influencing community integration and life satisfaction during development.

In both countries, higher internalized stigma was associated with lower levels of community integration and life satisfaction in individuals with autism. Future work can be implemented at several levels to coordinate a multidimensional and collaborative effort aimed at reducing autism-related stigma, including the general public, caregivers and families, individuals with autism, practitioners, service providers, researchers, and

policymakers. Effective anti-stigma campaigns should prioritize direct social contact between people with and without autism instead of emphasizing biological causation, which may unintentionally increase stigma (Thornicroft et al., 2022). Intensive awareness campaigns that share stories of individuals and families who have sought help and found improvement can further change public perceptions (Huang et al., 2019). Moreover, focusing on positive and neuro-affirmative interventions to support autistic adults can help to reduce internalized stigma in autistic individuals, fostering a more inclusive and supportive environment (Han et al., 2023).

A unified approach involving collaboration among government, school, community, healthcare professionals and caregivers is essential. This collaboration should aim to promote a systematic observation of the child through a multidisciplinary team to reduce the underdiagnosis of autism and further create a unified support system that can be embedded in the community and involve respected community leaders and influencers to help reduce stigma. Workshops, seminars, and support groups for families with autism can be initial touchpoints that introduce families to the concepts of care and support. Providing tangible benefits for engagement, such as subsidies for educational support, counselling can be a motivating factor for families to overcome stigma and seek help. Strengthening advocacy efforts and empowering not just caregivers and professionals but also autistic adults themselves is crucial for reducing public and internalized stigma and improving their social inclusion. This includes developing platforms for autistic individuals to voice their needs and preferences and ensuring these inputs inform policy and autism community development.

General conclusion

The current dissertation aimed to address the research gap in cross-cultural understanding of autism, and more specifically, to compare autistic individuals and their families in China and the Netherlands. We found differences in the interpretation and reporting of autistic traits among parents of autistic children between the two countries, which may in turn affect access to services and support. Low SES Chinese families reported fewer autistic traits, making them vulnerable to under-detection, which was not the case in our Dutch participants. Furthermore, Chinese caregivers experienced higher levels of parenting stress and reported lower life satisfaction for their autistic adults. Chinese adults experienced higher levels of internalized stigma compared to Dutch adults. Despite different challenges and different social support systems, autistic adults in both countries tend to have similar outcomes in community integration and life satisfaction.

The study suggests that cultural and contextual backgrounds influence the recognition, interpretation and reporting of autistic traits, as well as the well-being of autistic people and their families. However, certain challenges, such as autism-related internalized stigma, affect all autistic individuals regardless of nationality. These findings highlight the importance of developing support systems that are both culturally sensitive and globally accessible, aiming to reduce misdiagnosis and stigma, enhance

internal and external support for individuals and families with autism, and improve community integration and life satisfaction for autistic adults.

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Summary

Autism spectrum disorders (ASD) are globally prevalent, but cultural and contextual factors may impact the recognition, interpretation, and reporting of autism. Cultural and contextual factors are also crucial in shaping the well-being and community integration of individuals with autism. Despite the growing global interest in autism research, most studies have focused on Western high-income countries, leaving a gap in understanding autism in non-WEIRD countries, including China. With an estimated 10 million autistic individuals in China, it is critical to explore how cultural and contextual factors influence the interpretation of autistic traits, and well-being outcomes of individuals with autism and their families. This dissertation addresses the research gap in cross-cultural understanding of autism, focusing on the experiences of both parents of autistic children and autistic adults in China and the Netherlands.

Early detection of developmental delays can be achieved by strengthening developmental monitoring systems. To effectively monitor developmental concerns and specifically screen for autism, it is essential to develop culturally appropriate tools for observation, screening, and diagnosis. Cultural and contextual factors can influence how parents endorse autism symptoms and rate their severity. In China, hospital referrals for autism were mostly initiated by parents, making it crucial to examine the reliability and validity of the Autism Spectrum Quotient-Short (AQ-Short) as a parent-report screening tool in China and the Netherlands. In Chapter 2, we investigated whether the tools used are conceptually equivalent across China and the Netherlands.

We included 327 Chinese and 694 Dutch parents of autistic children between 2 and 17 years old from China and the Netherlands. The exploratory factor analysis of the AQ-Short revealed culturally variant factor structures between China and the Netherlands, indicating that certain autistic behaviours may group together differently across cultures. This possibly highlights the influence of cultural contexts on how autism-related behaviours are perceived and reported by parents. We noted that ‘Numbers and Patterns’ were negatively correlated with ‘Social Skills’ in the Chinese sample only, indicating that a strong interest in numbers or patterns might not be seen as indicative of autistic traits in China. This cultural variation in interpretation could impact the assessment and understanding of autism in different cultural and contextual settings, emphasizing the need for culturally appropriate screening tools that are sensitive to the understanding and expressions of autism.

The behaviours and needs of autistic children can place considerable demands on their primary caregivers, leading to increased parenting stress and negatively affecting their well-being. These challenges can leave caregivers of autistic children distressed and isolated, impacting their marital satisfaction and parenting quality, which in turn affects the child's behaviour and development. Cultural and contextual backgrounds can shape parenting experiences and stress levels. However, there have been few comparative studies which have examined well-being among caregivers of autistic children and parenting stress across different cultural and contextual backgrounds. Therefore, In Chapter 3, we explored parenting stress in China and the Netherlands to understand how different cultural contexts influence the experiences of

caregivers of autistic children and identify the factors influencing parenting stress. We examined the varying levels of parenting stress experienced by caregivers of children with autism in China and the Netherlands. The study included 95 Chinese caregivers and 118 Dutch caregivers of autistic children aged 2 to 16 years. Chinese caregivers reported higher parenting stress levels than Dutch caregivers. Compared to older caregivers, younger caregivers in both countries reported more parenting stress. Possible cultural and contextual factors that may help to explain a higher level of parenting stress in Chinese caregivers might be high expectations of parental obligation in China, limited access to professional support systems and heightened social stigma. Interventions aimed at stress management and coping skills, reducing self-blame and worries associated with perceptions of competence and parental role burden, may be particularly beneficial and needed for Chinese caregivers raising autistic children, particularly for younger caregivers.

Our understanding of the experiences of autistic adults lags far behind our understanding of autistic children. In China, a notable research gap exists regarding autistic adults, and objective and subjective outcomes of autistic adults with or without high support needs remain largely unknown in China. In the last two chapters, our focus shifts to the degree of community integration and life satisfaction of autistic adults and we compare their objective and subjective outcomes between China and the Netherlands. In Chapter 4, we investigated community integration and life satisfaction of young autistic adults with high support needs in China and the Netherlands, based on caregiver reports. Data were collected from caregivers of 99 young autistic adults in

China and 109 in the Netherlands. The findings indicated that autistic adults in both countries demonstrated limited community integration, with low rates of employment, limited independent living, and few close friendships. Proxy-reported life satisfaction was relatively low in both countries, but even lower among Chinese adults. Lower proxy-reported life satisfaction of Chinese autistic adults is possibly due to limited awareness and acceptance of autism in China, inadequate or inaccessible support services, higher parenting stress, or general cross-country differences in well-being. In Chapter 5, we explored community integration, life satisfaction, and self-stigma among autistic adults in China and the Netherlands, based on self-reports. The study included 36 Chinese and 29 Dutch autistic adults. Chinese and Dutch participants exhibited similar levels of employment, frequency or quality of friendships, and life satisfaction. However, Chinese autistic adults were more likely to live with their parents and reported higher levels of autism-related self-stigma compared to Dutch adults. Higher self-stigma was negatively correlated with friendships and life satisfaction across both samples. These findings highlight the need for strategies to reduce self-stigma and improve the social connections and life satisfaction of autistic adults.

In sum, this dissertation provides basic insights into how cultural and contextual factors may influence the experiences of autistic individuals and their families, emphasizing the need for tailored approaches to autism care and support in different cultural settings.

Appendices

Supplementary materials to Chapter 2/3/4/5

Appendix 1 Supplement to Chapter 2

Table S1 Fit values for the Chinese one- to four-factor models tested in the EFA

Models	χ^2	df	RMSEA (90% CI)	CFI	TLI
One-factor	2179.46	350	0.126 (.121-.132)	0.593	0.560
Two-factor	820.16	323	0.069 (.063-.074)	0.889	0.871
Three-factor	557.56	297	0.052 (.045-.058)	0.942	0.926
Four-factor	495.68	272	0.050 (.043-.057)	0.950	0.931

Table S2 Fit values for the Dutch one- to five-factor models tested in the EFA

Models	χ^2	df	RMSEA (90% CI)	CFI	TLI
One-factor	3861.61	350	0.12 (.117-.124)	0.556	0.521
Two-factor	2153.64	323	0.09 (.087-.094)	0.769	0.729
Three-factor	1326.10	297	0.071 (.067-.075)	0.870	0.834
Four-factor	835.59	272	0.055 (.050-.059)	0.929	0.901
Five-factor	573.76	248	0.044 (.039-.048)	0.959	0.937

Table S3 Demographic information and mean scores on the explored AQ-Short for the Chinese and Dutch sample

Chinese autistic children				
	All	Boys	Girls	t
	(n=327)	(n=277)	(n=50)	
Age	8.57 (0.16)	8.52(0.18)	8.83(0.38)	
Total scores	71.76 (9.42)	71.90 (9.56)	71.02 (8.66)	0.61
Numbers and Patterns	11.92 (4.23)	12.10 (4.35)	10.92 (3.34)	2.19
Social skills	47.48 (7.53)	47.34 (7.63)	48.26 (6.99)	-0.79
Mind reading	12.36 (2.94)	12.45 (2.80)	11.84 (3.62)	1.14
Dutch autistic children				
	All	Boys	Girls	t
	(n=694)	(n=539)	(n=155)	
Age	11.81 (2.54)	11.87 (0.11)	11.62 (0.20)	
Total scores	74.81 (9.83)	75.17 (9.88)	73.55 (9.59)	1.81
Imagination	10.58 (2.88)	10.73 (2.84)	10.08 (2.98)	2.49
Numbers and patterns	11.06 (3.62)	11.40 (3.63)	9.90 (3.34)	4.60**
Social skills	20.44 (3.86)	20.45 (3.93)	20.41 (3.61)	0.10
Attention switching	19.66 (2.91)	19.55 (2.92)	20.03 (2.86)	-1.80
Mind reading	13.06 (2.18)	13.04 (2.19)	13.13 (2.16)	-.45

** $p < .001$

Table S4 AQ-Short scores of Chinese children according to their parents' socioeconomic status

	Socioeconomic status								
	Father's employment status			Mother's employment status			Family income level		
	Employed	Unemployed	Other	Employed	Unemployed	Other	Low	Middle	High
	(n=292)	(n=33)	(n=2)	(n=137)	(n=186)	(n=4)	income (n=125)	income (n=132)	income (n=52)
Total score	71.91 (9.55)	71.06 (8.08)	62.00 (9.90)	73.36 (9.99)* ¹	70.78 (8.82)	63 (6.38)	69.92 (8.90)* ³	72.99 (9.80)	73.50 (9.53)
Numbers and Patterns	11.89 (4.29)	12.21 (3.86)	12.00 (2.83)	11.99 (4.33)	11.82 (4.15)	14.25 (4.86)	11.47 (4.45)	12.29 (4.18)	12.29 (3.90)
Social Skills	47.61 (7.53)	46.79 (7.52)	40.00 (7.07)	48.67 (7.36)* ²	46.84 (7.49)	36.75 (3.69)	46.97 (7.93)	47.85 (7.30)	48.08 (7.24)
Mindreading	12.41 (3.01)	12.06 (2.30)	10.00 (0.00)	12.70 (2.74)	12.12 (3.09)	12 (0.82)	11.48 (3.26)* ⁴	12.86 (2.58)	13.13 (2.71)

* $p < .05$

1 Employed Chinese mothers reported higher total AQ-Short score than unemployed mothers and mothers of other employments status

2 Employed Chinese mothers reported higher scores on Social skills factor than unemployed mothers and mothers of other employment status

3 Parents with low income level reported lower total AQ-Short score than parents with middle and high income level

4 Parents with low income level reported lower scores on Mind-reading factor than parents with middle and high income level

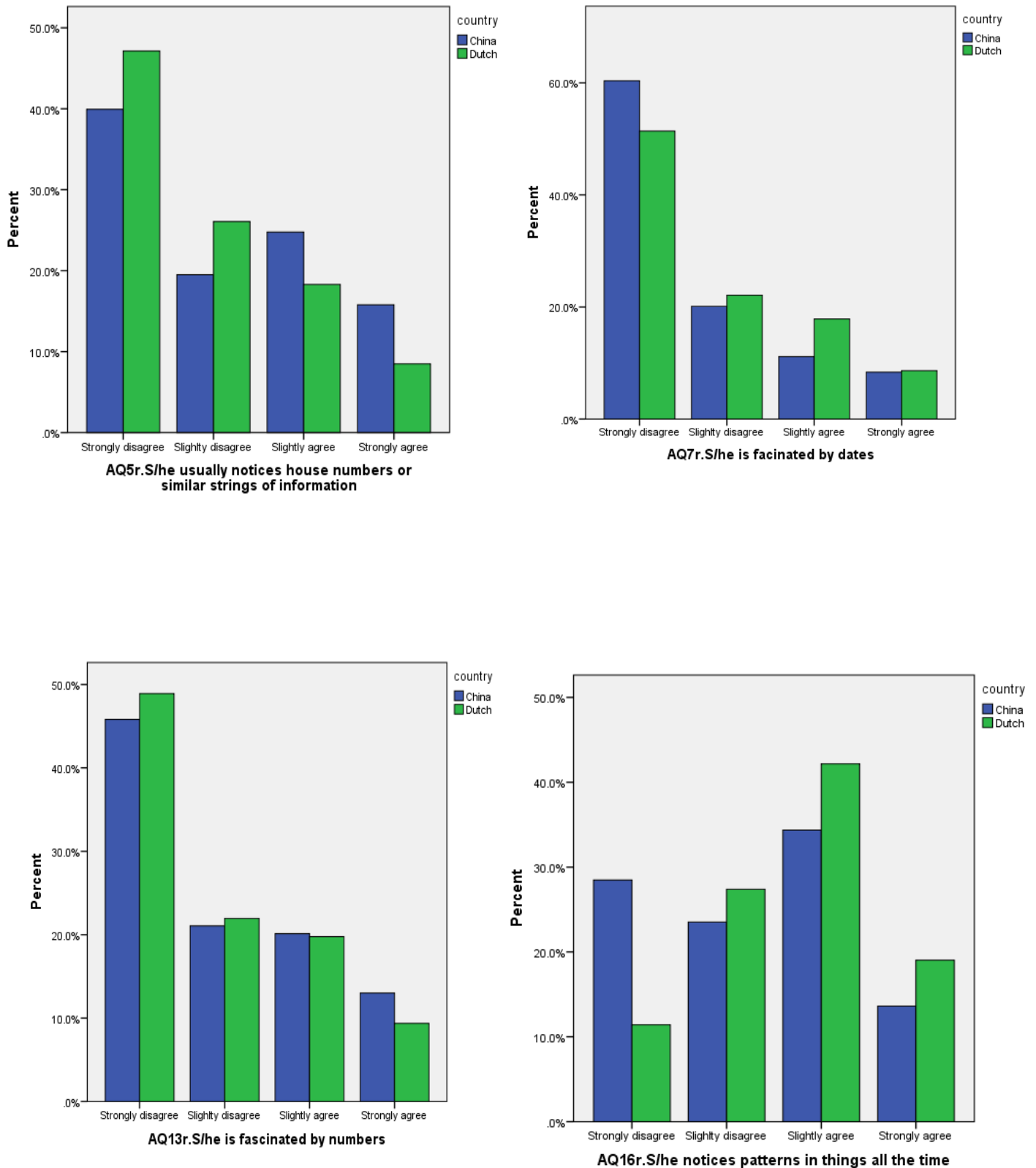
Table S5 AQ-Short scores of Dutch children according to their parents' socioeconomic status

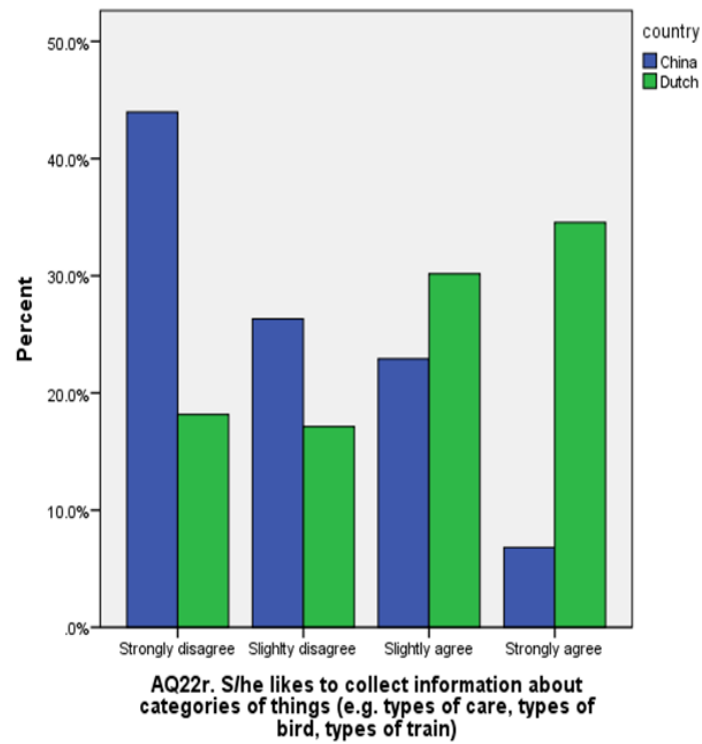
	Socioeconomic status								
	Father's employment status			Mother's employment status			Family income level		
	Employed (n=600)	Unemployed (n=91)	Other (n=3)	Employed (n=454)	Unemployed (n=199)	Other (n=41)	Low income (n=25)	Middle income (n=83)	High income (n=35)
Total score	74.75 (9.83)	74.95 (9.97)	82 (2.65)	74.61 (9.48)	75.54 (10.62)	73.51 (9.72)	73.60 (9.33)	75.02 (10.75)	76.06 (8.74)
Imagination	10.56 (2.86)	10.71 (3.05)	11.67 (2.31)	10.59 (2.85)	10.73 (2.99)	9.78 (2.62)	11.48 (2.62)	10.30 (3.02)	10.14 (3.46)
Numbers and Patterns	11.04 (3.61)	11.16 (3.69)	13.67 (1.15)	11.07 (3.57)	10.98 (3.63)	11.37 (4.13)	10.56 (4.46)	11.39 (3.74)	11.80 (4.34)
Social Skills	20.43 (3.88)	20.44 (3.75)	22.67 (2.31)	20.53 (3.73)	20.29 (4.20)	20.24 (3.48)	19.84 (3.45)	20.25 (4.22)	20.94 (3.71)
Attention Switching	19.67 (2.90)	19.60 (3.02)	20.67 (0.58)	19.53 (2.89)	20.05 (2.92)	19.24 (2.97)	19.32 (3.16)	19.81 (3.22)	20.31 (2.45)
Mind reading	13.06 (2.18)	13.02 (2.23)	13.33 (1.15)	12.89 (2.15)* ¹	13.49 (2.22)	12.88 (2.09)	12.40 (2.66)	13.28 (2.14)	12.86 (2.17)

* $p < .01$ ¹ Employed Dutch mother reported lower scores on Mind reading factor than unemployed Dutch mother

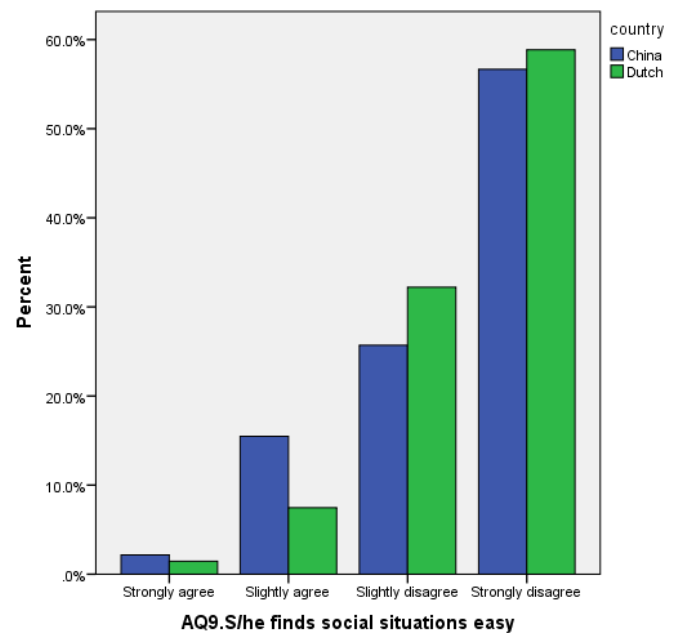
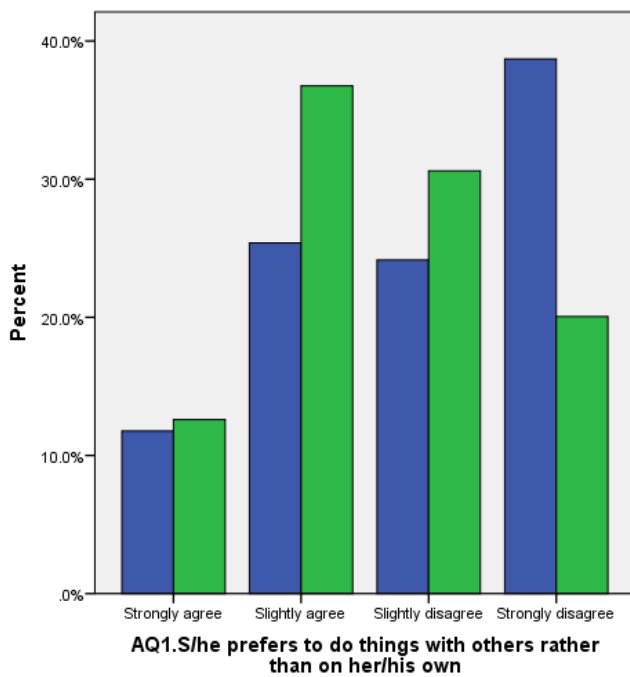
Figure S1 Item distributions of AQ-Short items

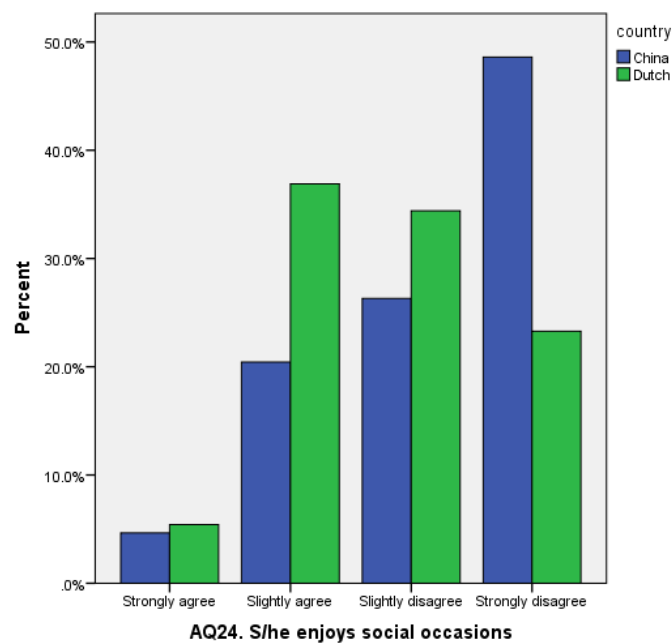
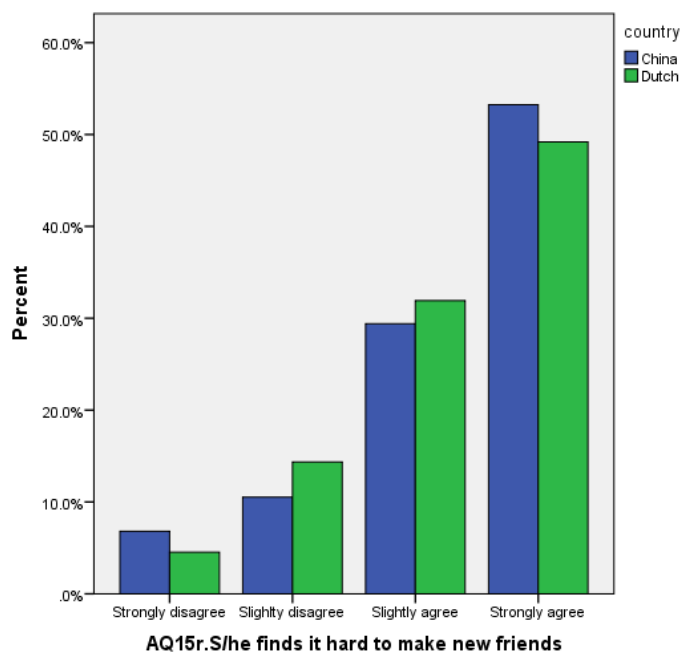
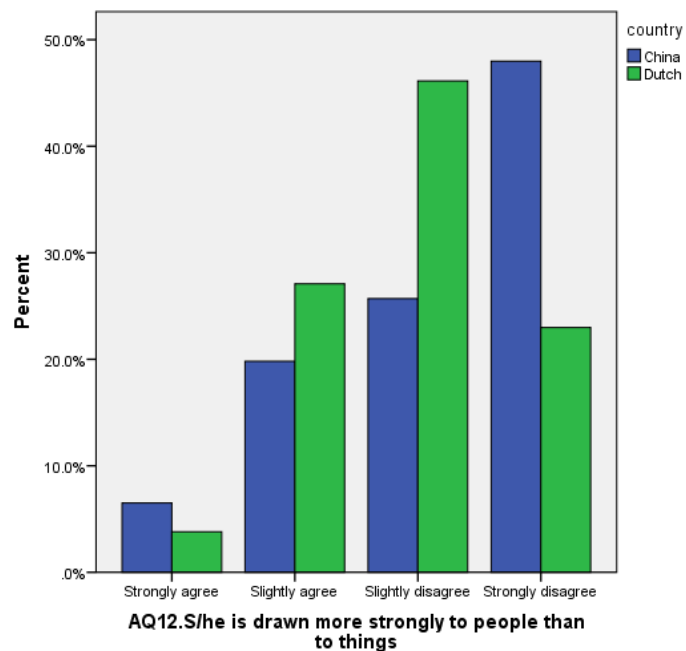
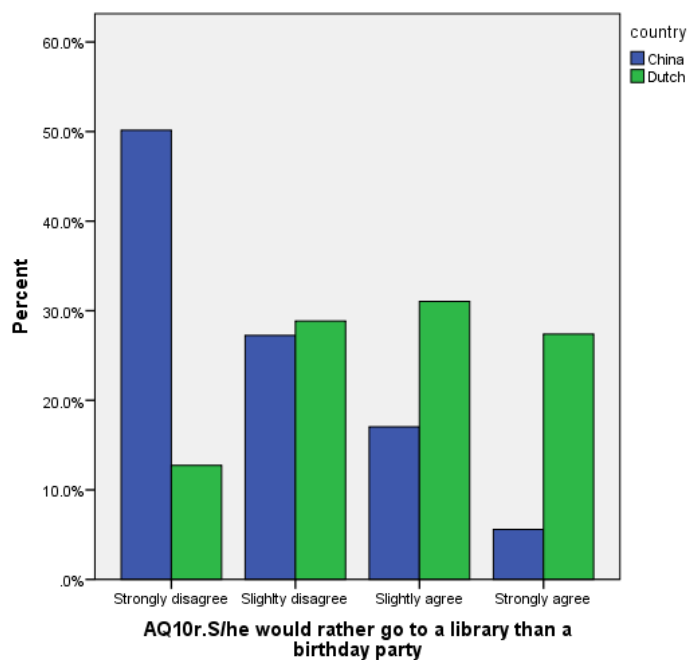
Original Numbers and Patterns

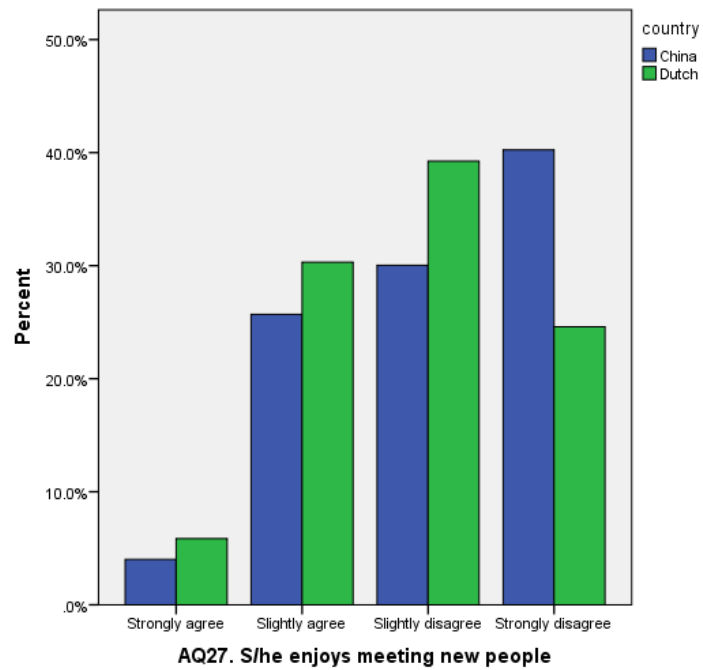




Original Social Skills

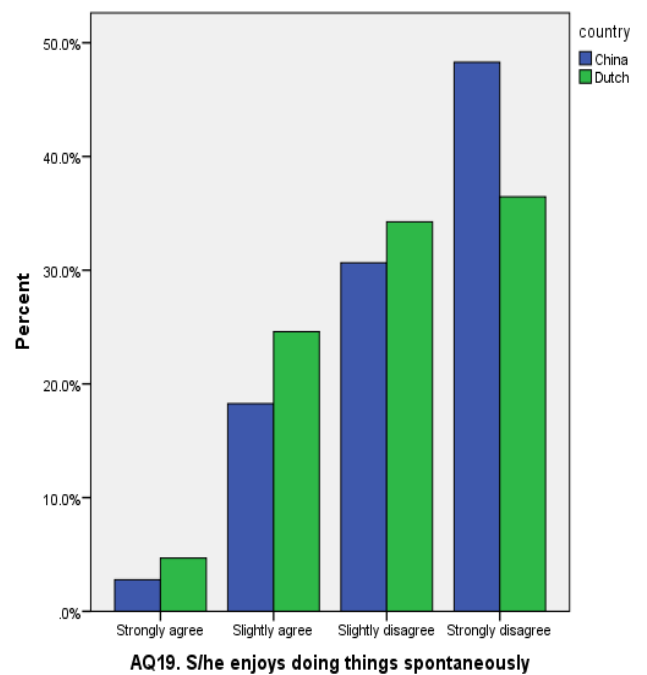
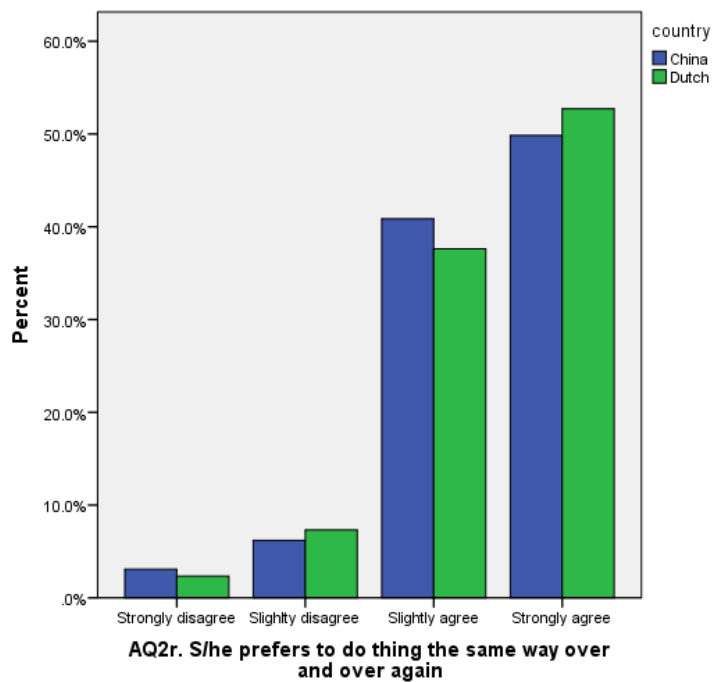




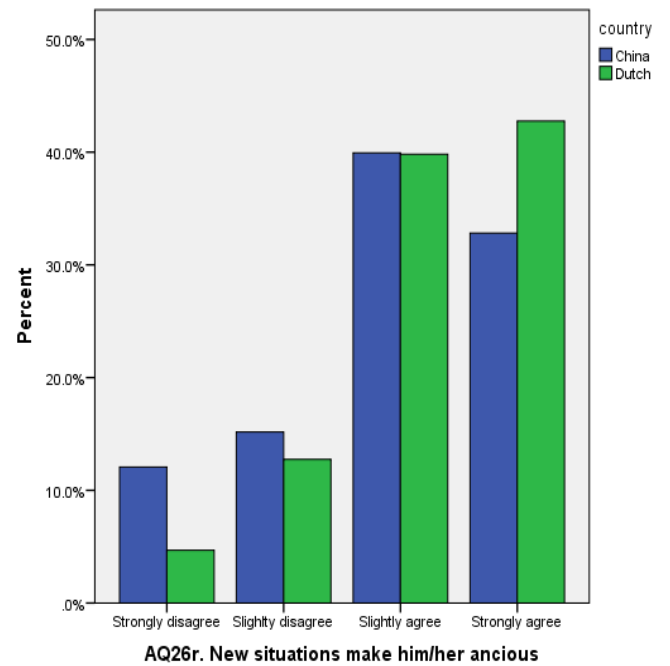
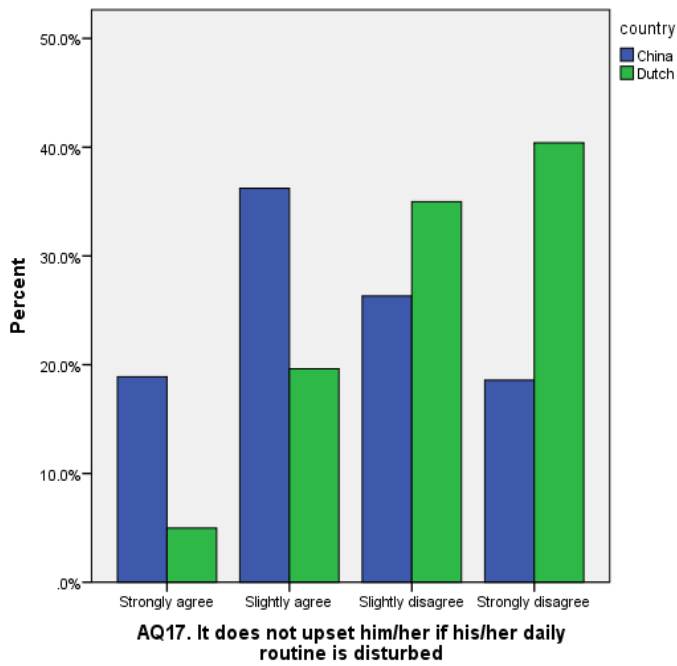


Original Routine

Item 19 was dropped in Dutch sample

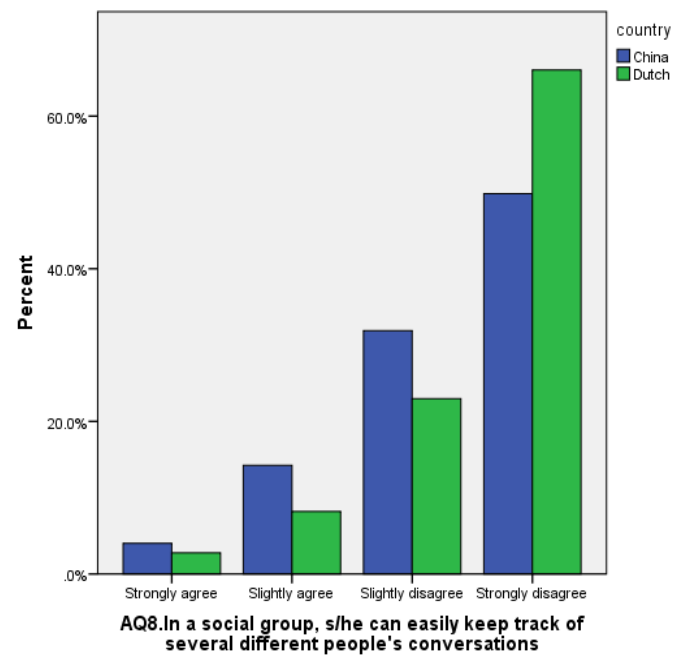
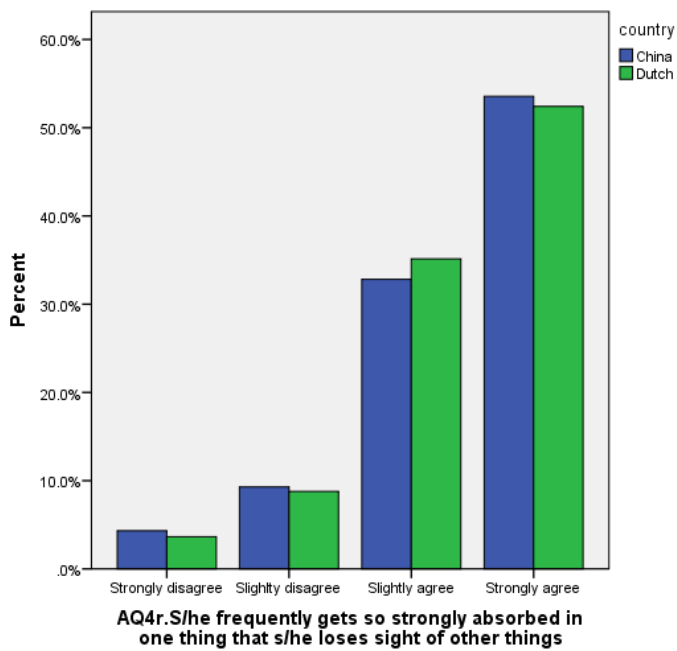


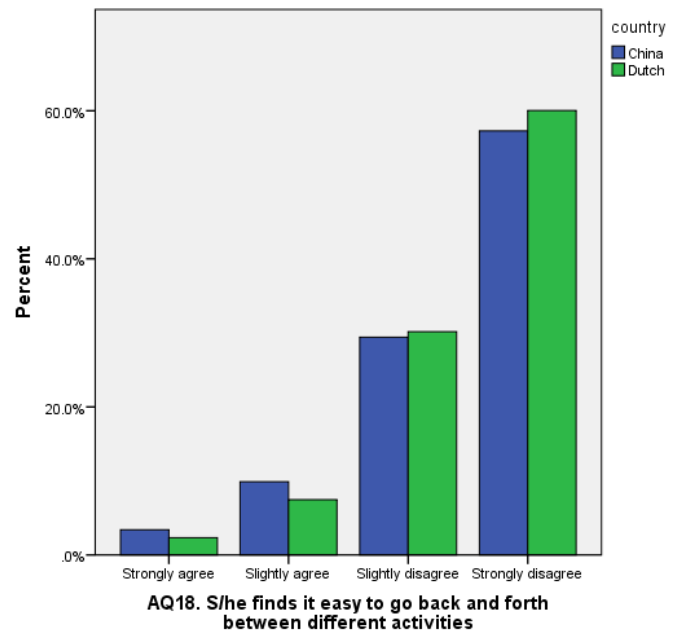
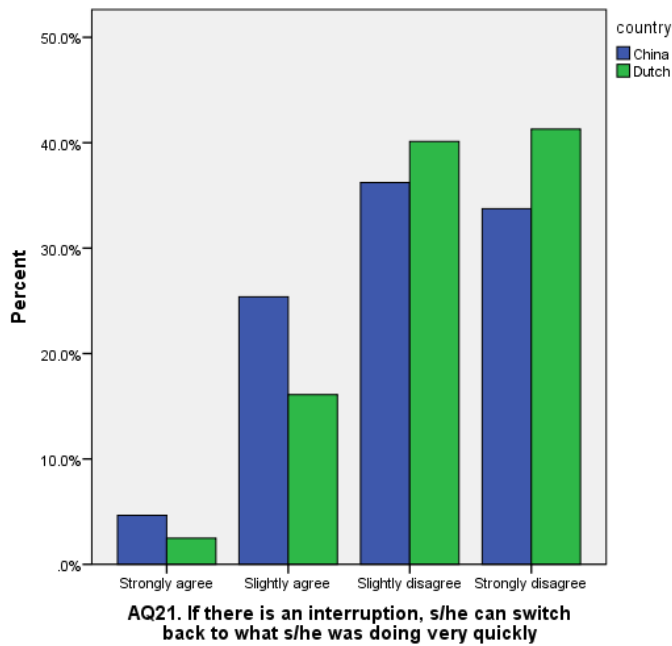
Item 17 was dropped in Chinese sample



Original Switching

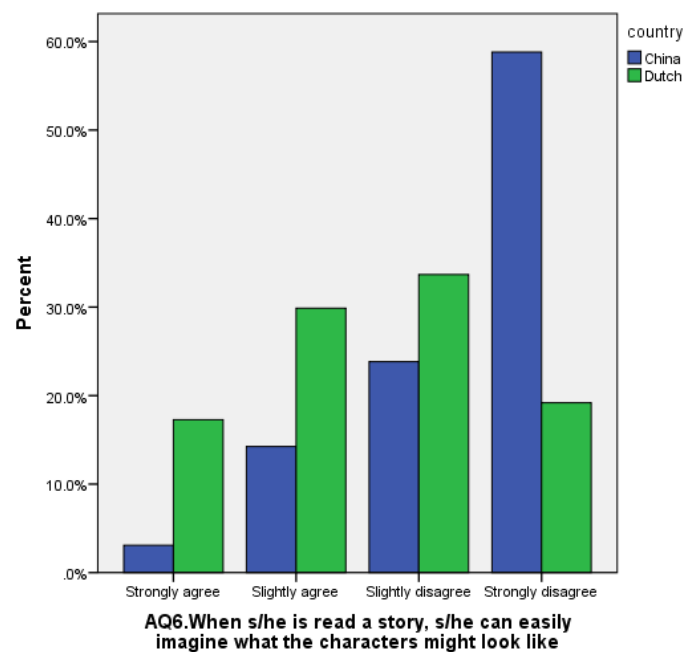
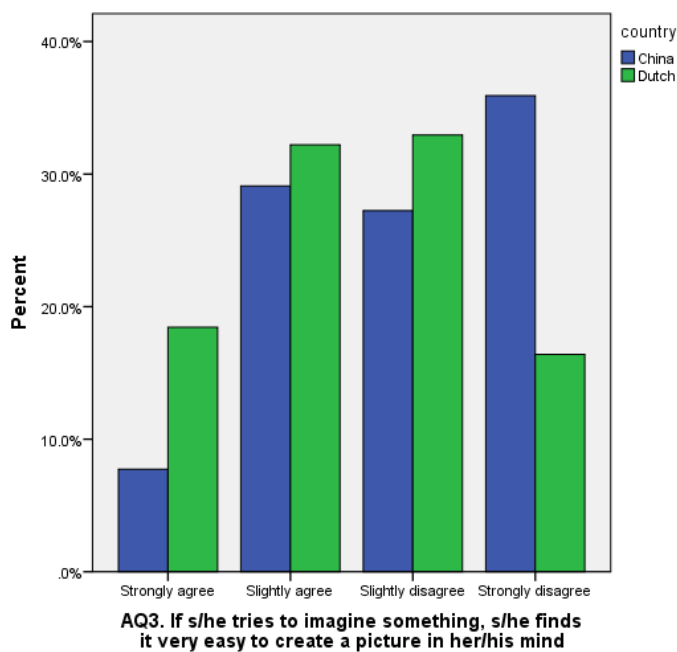
Item 8 was dropped in Dutch sample



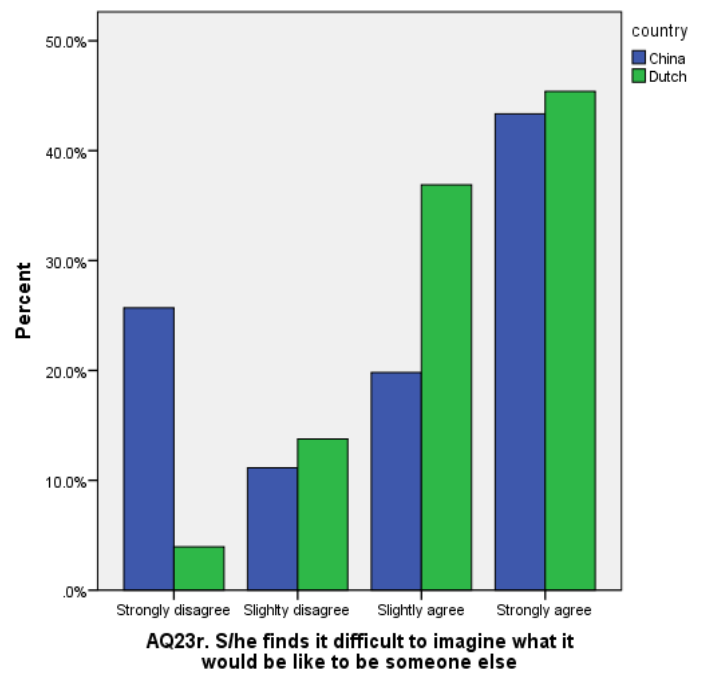
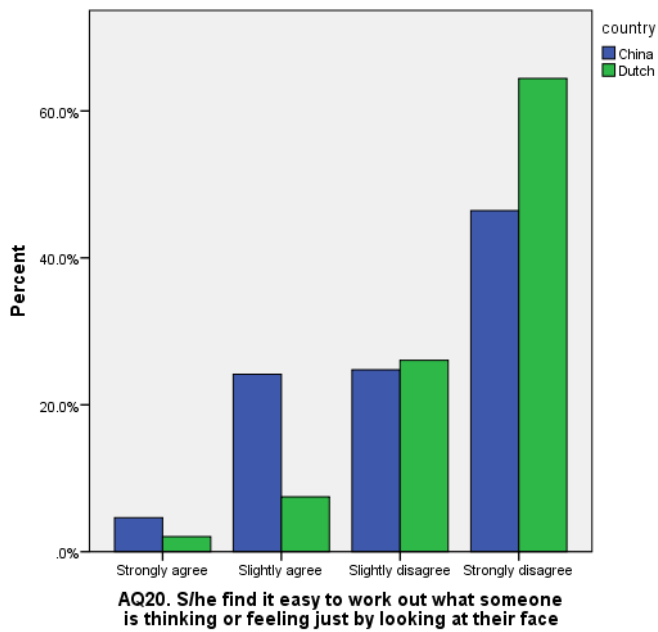
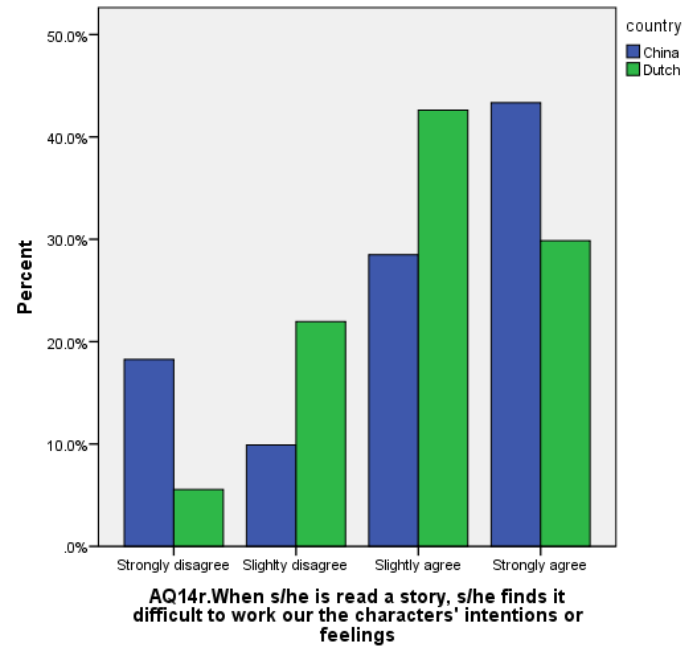
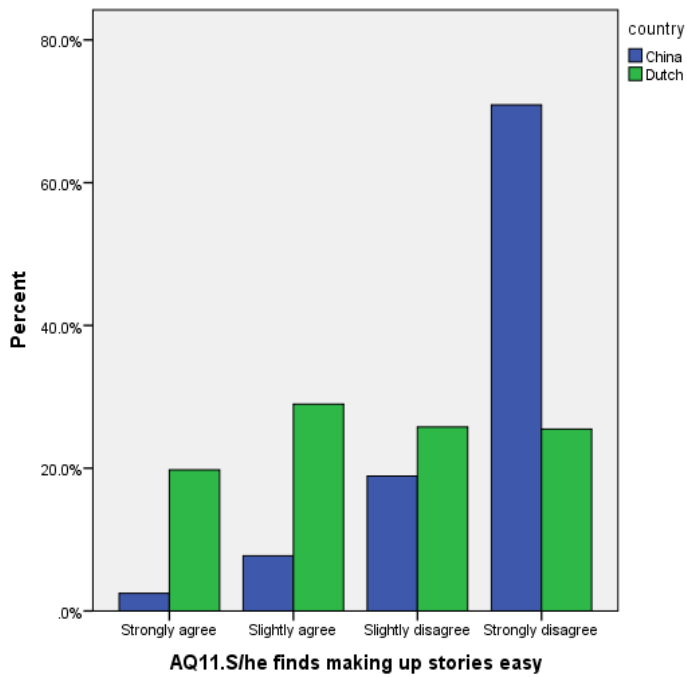


Original Imagination

Item 6 was dropped in Chinese sample



Item 11 was dropped in Chinese sample



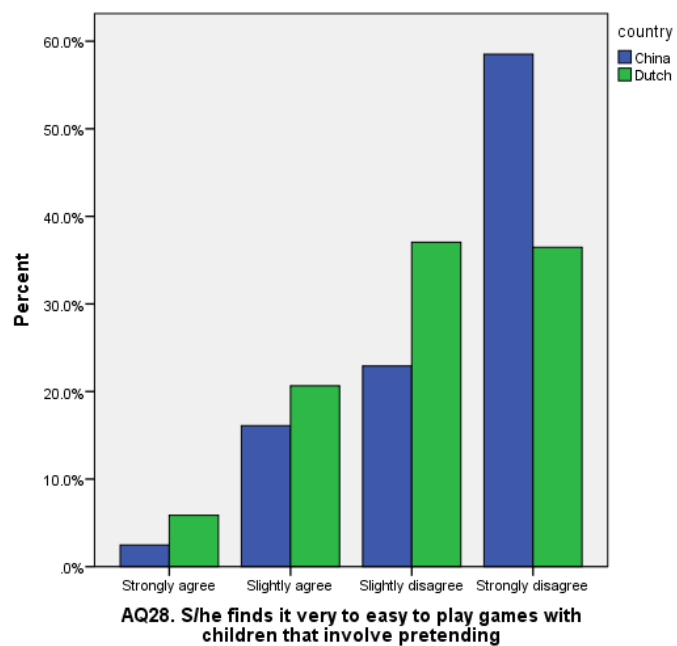
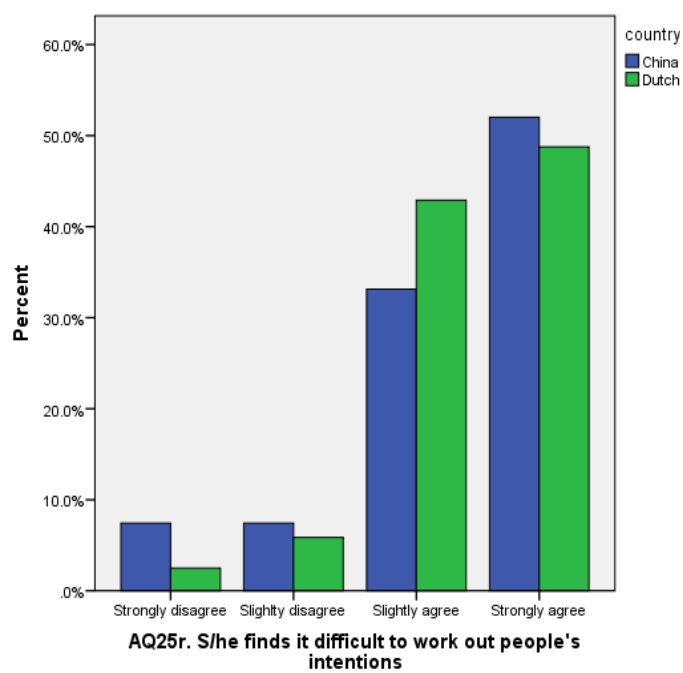


Table S6 Item comparison across country and sex

AQ-Short Item	Country		<i>p</i> -value ^a		Sex		<i>p</i> -value	
	Chinese	Dutch			Boys	Girls		
1. S/he prefers to do things with others rather than on her/his own	2.89 (1.05)	2.58 (0.95)	<.001*	C>D ^b	2.68 (1.01)	2.68 (0.95)	.997	
2r. S/he prefers to do thing the same way over and over again	3.36 (0.75)	3.39 (0.73)	0.517		3.38 (0.75)	3.38 (0.69)	.837	
3. If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind	2.91 (0.98)	2.46 (0.97)	<.001*	C>D	2.62 (0.99)	2.54 (1.02)	.473	
4. S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things	3.34 (0.84)	3.35 (0.80)	0.894		3.38 (0.79)	3.23 (0.89)	.094	
5. S/he usually notices car numbers or similar strings of information	2.17 (1.12)	1.87 (0.99)	<.001*	C>D	2.04 (1.06)	1.70 (0.91)	<.001*	B>G ^c
6. When s/he is read a story, s/he can easily imagine what the characters might look like	3.37 (0.85)	2.53 (0.99)	<.001*	C>D	2.85 (1.02)	2.62 (1.05)	.02*	B>G
7. S/he is fascinated by dates	1.68 (0.98)	1.83 (1.00)	.017*	C<D	1.83 (1.02)	1.59 (0.87)	.014*	B>G
8. In a social group, s/he can easily keep track of several different people's conversations	3.26 (0.87)	3.50 (0.78)	<.001*	C<D	3.39 (0.84)	3.56 (0.73)	.031*	B<G
9. S/he finds social situations easy	3.35 (0.84)	3.48 (0.70)	0.133		3.43 (0.75)	3.47 (0.77)	.473	
10. S/he would rather go to a library than a birthday party	1.78 (0.93)	2.72 (1.00)	<.001*	C<D	2.37 (1.07)	2.60 (1.05)	.024*	B<G
11. S/he finds making up stories easy	3.57 (0.76)	2.56 (1.07)	<.001*	C>D	2.94 (1.07)	2.66 (1.13)	.011*	B>G
12. S/he is drawn more strongly to people than to things	3.13 (0.97)	2.87 (0.81)	<.001*	C>D	2.98 (0.88)	2.84 (0.82)	.045*	B>G
13. S/he is fascinated by numbers	2.01 (1.09)	1.89 (1.03)	.161		2.01 (1.08)	1.62 (0.85)	<.001*	B>G
14. When s/he is read a story, s/he finds it difficult to work out the characters' intentions or feelings	2.96 (1.13)	2.96 (0.87)	.150		2.96 (0.96)	2.96 (0.96)	.997	
15. S/he finds it hard to make new friends	3.29 (0.91)	3.24 (0.88)	.281		3.29 (0.87)	3.15 (0.95)	.144	
16. S/he notices patterns in things all the time	2.34 (1.04)	2.67 (0.92)	<.001*	C<D	2.58 (0.98)	2.50 (0.94)	.384	
17. It does not upset him/her if his/her daily routine is disturbed	2.44 (1.00)	3.09 (0.90)	<.001*	C<D	2.85 (0.98)	3.01 (0.99)	.058*	B<G
18. S/he finds it easy to go back and forth between different activities	3.39 (0.82)	3.46 (0.75)	.354		3.43 (0.78)	3.46 (0.75)	.845	

19. S/he enjoys doing things spontaneously	3.23 (0.86)	3.00 (0.91)	<.001*	C>D	3.09 (0.90)	3.00 (0.92)	.3745	
20. S/he find it easy to work out what someone is thinking or feeling just by looking at their face	3.11 (0.95)	3.51 (0.74)	<.001*	C<D	3.38 (0.78)	3.42 (0.77)	.869	
21. If there is an interruption, s/he can switch back to what s/he was doing very quickly	2.98 (0.89)	3.18 (0.81)	.001*	C<D	3.09 (0.85)	3.23 (0.79)	.072*	B<G
22. S/he likes to collect information about categories of things (e.g. types of cars, types of bird, types of train)	1.94 (0.97)	2.80 (1.10)	<.001*	C<D	2.58 (1.12)	2.30 (1.16)	.011*	B>G
23. S/he finds it difficult to imagine what it would be like to be someone else	2.81 (1.24)	3.22 (0.84)	<.001*	C<D	3.09 (1.01)	3.11 (0.97)	.997	
24. S/he enjoys social occasions	3.17 (0.93)	2.74 (0.88)	<.001*	C>D	2.87 (0.92)	2.91 (0.90)	.837	
25. S/he finds it difficult to work out people's intentions	3.30 (0.90)	3.36 (0.72)	0.97		3.34 (0.77)	3.35 (0.82)	.845	
26. New situations make him/her anxious	2.94 (0.98)	3.19 (0.85)	<.001*	C<D	3.06 (0.92)	3.33 (0.80)	<.001*	B<G
27. S/he enjoys meeting new people	3.05 (0.91)	2.81 (0.88)	<.001*	C>D	2.88 (0.90)	2.90 (0.87)	.954	
28. S/he finds it very easy to play games with children that involve pretending	3.36 (0.85)	3.03 (0.90)	<.001*	C>D	3.15 (0.90)	3.05 (0.91)	.250	

Note: The values are expressed as mean (SD);

^a Mann-Whitney U test

^b C>D means Chinese children showed greater endorsement of autistic traits than Dutch children and vice versa.

^c B>G means Boys showed greater endorsement of autistic traits than girls and vice versa.

Appendix 2 Supplement to Chapter 3

Table S7 Demographics comparison between Selected and non-selected samples in China and the Netherlands

	Selected		Not selected		t / χ^2
	n (%)	M (SD)	n (%)	M (SD)	
Dutch sample					
Child's gender					1.12
Boys	67 (41.9)		93 (58.1)		
Girls	12 (32.4)		25 (67.6)		
Child's age	118 (59.9)	12.56 (2.73)	79 (40.1)	11.87 (3.16)	1.64
Caregiver's age ¹	118 (59.9)	45.13 (5.28)	45 (22.8)	44.42 (5.50)	.75
COVID-19 worries (5-30)	118 (59.9)	16.64 (5.30)	79 (40.1)	16.99 (5.27)	-.45
Primary caregiver educational level ¹					4.92
Low educational level	5 (45.5)		6 (54.5)		
Middle educational level	42 (56.0)		33 (44)		
High educational level	71 (69.6)		31 (30.4)		
Family income level ¹					1.17
Low income level	25 (86.2)		4 (13.8)		
Middle income level	58 (78.4)		16 (21.6)		
High income level	35 (76.1)		11 (23.9)		
Parenting Stress (11-66)	118 (59.9)	32.92 (11.69)	79 (40.1)	33.23 (11.13)	-.19
Chinese sample					
Child's gender					.06
Boys	76 (96.2)		3 (3.8)		
Girls	19 (95.0)		1 (5.0)		
Child's age	95 (96.0)	6.01 (2.70)	4 (4.0)	5.50 (1.53)	.38
Caregiver's age	95 (96.0)	35.99 (4.62)	4 (4.0) ²		
COVID-19 worries (5-30)	95 (96.0)	13.59 (6.07)	4 (4.0)	19.50 (4.34)	-1.92
Primary caregiver educational level ¹					1.45
Low educational level	10 (90.9)		1 (9.1)		
Middle educational level	17 (100)		0 (0)		
High educational level	68 (95.8)		3 (4.2)		

Family income level ¹					3.16
Low income level	13 (100)		0 (0)		
Middle income level	51 (98.1)		1 (1.9)		
High income level	31 (91.2)		3 (8.8)		
Parenting Stress (11-66)	95	43.36 (8.45)	4 (4.0)	39 (3.74)	1.02

1 In Dutch sample, there are missing values on caregivers' age, family income and educational level

2 In Chinese sample, there are 4 missing values on caregivers' age

Table S8 Pearson's correlations for whole selected samples

	country	child gender	child age	family income level	Caregivers' age	Caregivers' highest education level	COVID- 19 worries	Parenting stress
country		-.015	-.770**	.076	-.674**	.041	-.260**	.449**
child gender			.002	-.064	-.083	.063	.009	.056
child age				-.132	.753**	-.173*	.205**	-.340**
family income level					-.076	.306**	-.149*	-.042
Caregivers' age						-.015	.143*	-.301**
Caregivers' highest education level							-.222**	.027
COVID-19 worries								.181**
Parenting stress								

** $p < .01$ * $p < .05$

The Confirmatory factor analyses (CFA) on NPSI-PD

We used approximation fit indices including the Comparative Fit Index (CFI) (Hu & Bentler, 1998) and Tucker-Lewis Index (TLI) (Tucker & Lewis, 1973) and the root mean square error of approximation (RMSEA) (Steiger, 1980) to compare the relative fit of the models. CFI and TLI values above 0.90 above 0.95 indicate a good fit (Hu & Bentler, 1999; Marsh et al., 2004). RMSEA values below 0.06 indicate a good fit (Browne & Cudeck, 1993).

The fit indices for the Chinese one-factor CFA model were: $\chi^2 = 2278.87$, $df = 55$, $p < .001$; RMSEA = .291; CFI = .834; TLI = .793. The fit indices for the Dutch CFA model were: $\chi^2 = 2986.75$, $df = 55$, $p < .001$; RMSEA = .120; CFI = .957; TLI = .946. The CFI and TLI values indicate a moderate to good fit to a one-factor model for both the Chinese and Dutch samples, but the RMSEA values suggest a poor model fit. The disparity in model fit between the CFI and TLI indices on the one hand and the RMSEA index on the other hand, might be because 1) the RMSEA index is sensitive to sample size and the number of variables, whereas the other measures are not (Kenny et al., 2014; Kenny & McCoach, 2009), and 2) the RMSEA index is an absolute fit index, indicating how far a hypothesized model is from a perfect fit, whereas the CFI and TLI indices are relative model fit indices, indicating how well the one-factor model is better than the baseline model (Xia & Yang, 2019).

Our Chinese sample size ($n < 100$) may be insufficient to test a one-factor structure of 11 items. This may have affected the reliability of our factor analyses, especially of the RMSEA estimate. Therefore, the findings of the CFA should be interpreted with care.

Figure S2 The scree plot for Chinese and Dutch samples

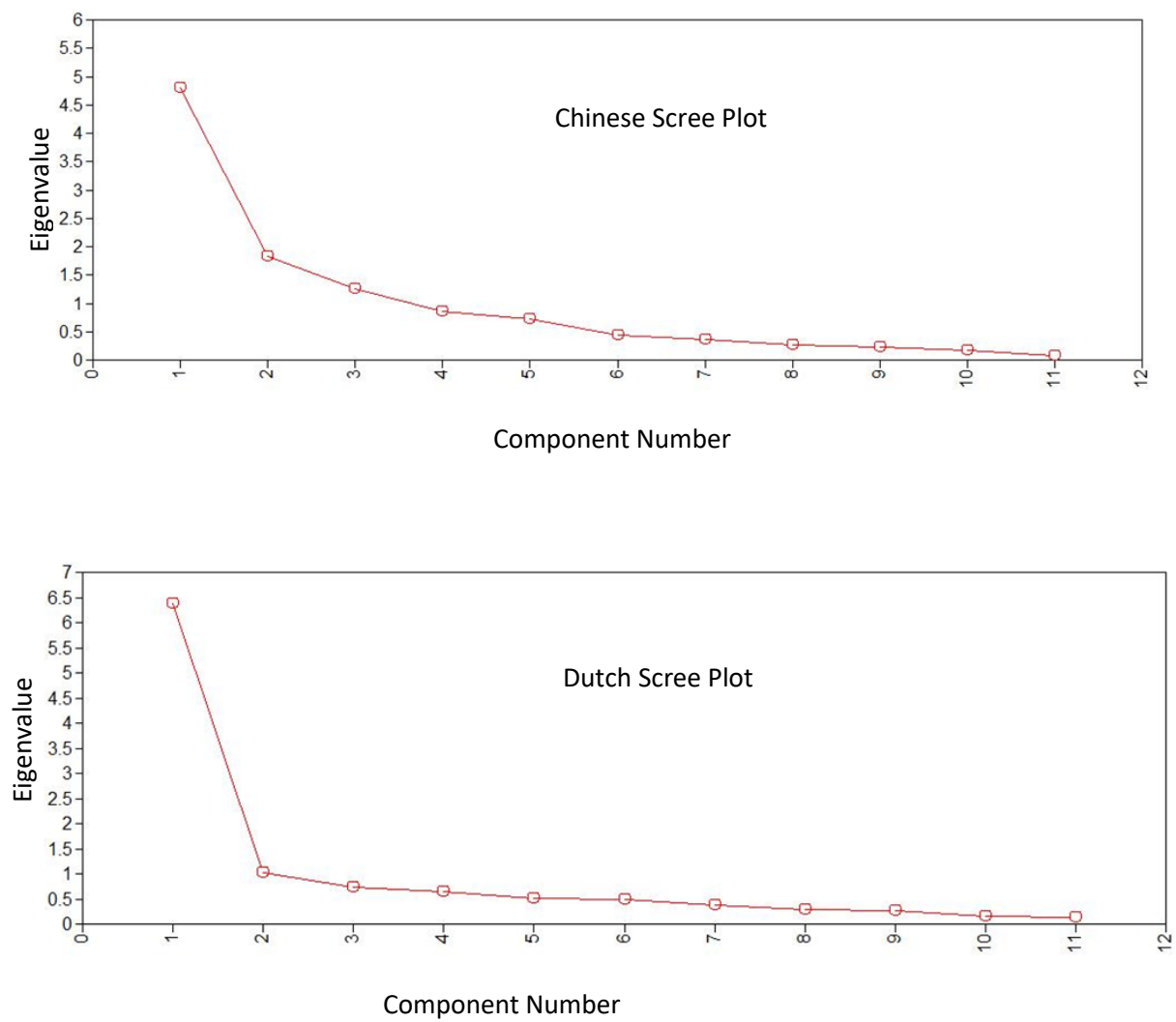


Table S9 Factor loadings for Chinese and Dutch models

Items	Factor loadings	
	Chinese model	Dutch model
1	0.912*	0.679*
2	0.909*	0.802*
3	0.517*	0.775*
4	0.664*	0.871*
5	0.790*	0.746*
6	0.792*	0.838*
7	0.628*	0.551*
8	0.767*	0.851*
9	0.620*	0.666*
10	0.569*	0.644*
11	0.240*	0.695*

NPSI 中文翻译版

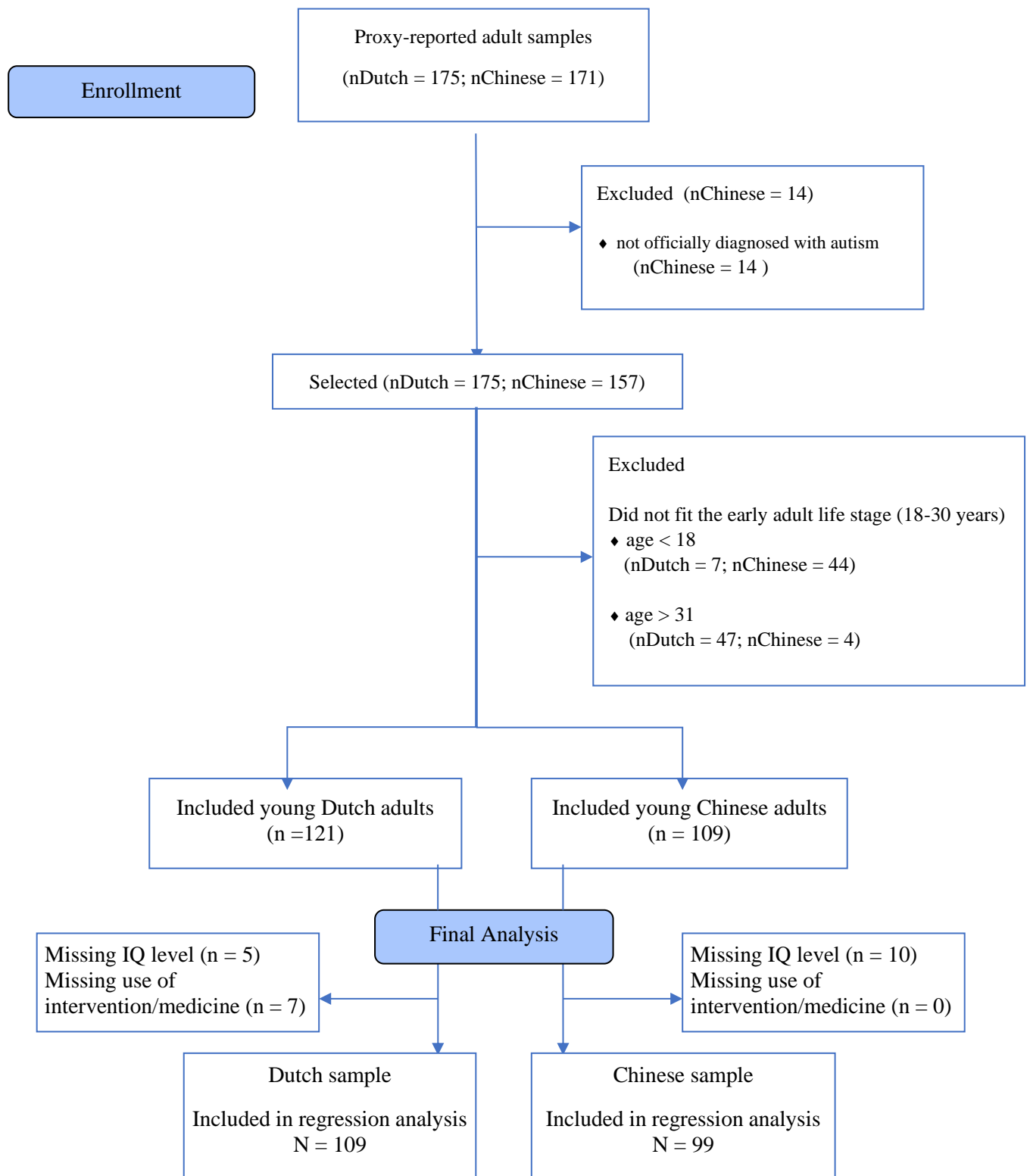
非常不同意=1 比较不同意=2 不同意=3 同意=4 比较同意=5 非常同意=6

1. 作为自闭症孩子的家长比我想的更困难
2. 在抚养孩子方面，我遇到的问题比我想的要多
3. 我经常想放弃
4. 我觉得我不能像我想的那样照顾好我的孩子
5. 我很难做出关于我的孩子的决定
6. 我常常觉得无法把事情处理的很好
7. 自从有了孩子，我比以前累得更快了
8. 无论我怎样努力抚养孩子，有时我觉得我不能很好地控制事情
9. 通常我看到其他父母带着孩子，我会想“我也想成为那样的父亲、母亲”
10. 我通常不理解我的孩子
11. 我有信心将来抚养好我的孩子

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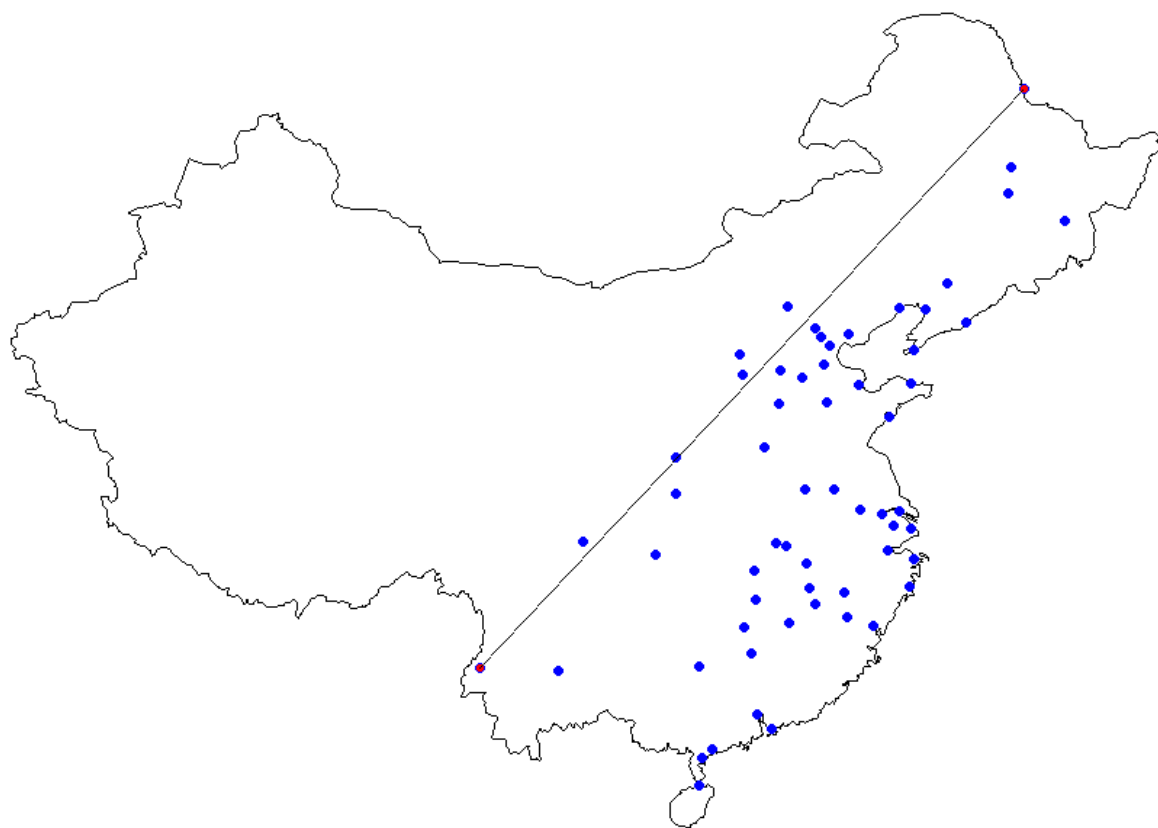
Appendix 3 Supplement to Chapter 4

Figure S3 Sample selection process



Note: Missing values on the predictors were excluded, resulting in 109 Dutch participants and 99 Chinese participants being included in the final multiple regression analysis.

Figure S4 The city distribution of Chinese participants on the map of China



Note: The blue dots only represent the cities where the Chinese participants of this study come from.

The line represents the Heihe-Tengchong Line.

Table S10 Coding of Employment, Independent Living, Friendships and Overall Community integration

Scale item	Coding points of each
Employment scale (0-3)	
Regular paid employment/self-employed for at least 16 hrs. per week; Or studying for at least 24 hours per week	3
Regular paid employment/self-employed for less than 16 hrs. per week; Or non-regular/non-paid employment	2
Not any kind of (paid or unpaid) employment	1
No structural day time activities for 40 hours or more per week	0
Independent living scale (0-3)	
Independently	3
Independently with some housing assistance ¹	2
With parents/family	1
Form of housing with support and/or care; Or a care facility ²	0
Friendship scale (0-2)	
Close friendships	2
Other friendships (other than parents, siblings, family members or own children), but no close friendships	1
Hardly any friends (except for contact with parents, siblings, family members or own children)	0

Overall community integration (0-8)

Very good outcome: regular paid job/self-employed for at least 16 hrs. per week, living independently, close friendships	8
Good outcome: one life domain with suboptimal outcome (e.g., social contacts, but no close friendships)	7
Fair outcome: one or more life domains with suboptimal outcome	4-6
Poor outcome: two or all life domains with a relatively poor outcome (e.g., not any kind of (paid or unpaid) employment)	1-3
Very poor outcome: no structural daytime activities, no form of housing with guidance or a care facility, hardly any social contacts	0

*This table is cited from Scheeren et al. (2021)

1 Housing assistance entail different kinds of support for independent living, such as help with finances.

2 Care facility entails specialized 24/7 services and care by trained professionals.

Figure S5 Overall community integration score in China and the Netherlands

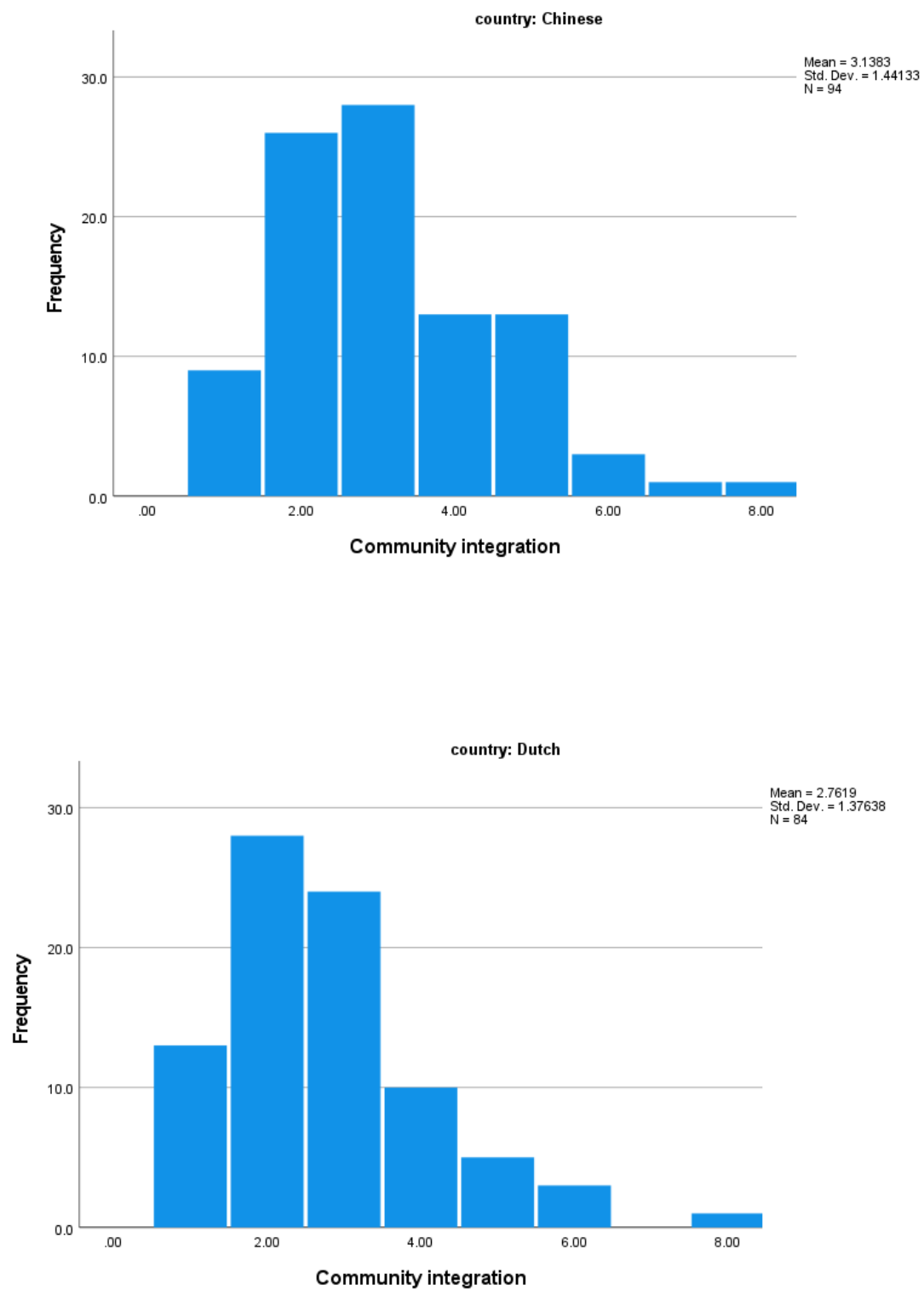


Table S11 Country specific models of demographic factors on community integration

Country	Predictors	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>
Dutch	Constant	3.727	1.074		3.471	<.001
	Sex	-.209	.283	-.070	-.738	.463
	Age	-.081	.040	-.192	-2.023	<.050
	IQ Level	.466	.090	.492	5.173	<.001
	Co-occurring Psychiatric Diagnosis	.138	.272	.050	.506	.614
	Use of Intervention and Medicine	-.423	.199	-.213	-2.128	.036
Chinese	Constant	2.233	1.232		1.813	.073
	Sex	-.246	.340	-.066	-.723	.472
	Age	-.012	.044	-.025	-.271	.787
	IQ Level	.462	.079	.535	5.829	<.001
	Co-occurring Psychiatric Diagnosis	.128	.317	.039	.402	.689
	Use of Intervention and Medicine	-.043	.225	-.018	-.190	.849

Table S12 Country specific models of demographic factors on life satisfaction

Country	Predictors	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>
Dutch	Constant	9.424	1.201		7.845	<.001
	Sex	-.246	.322	-.068	-.764	.447
	Age	-.074	.043	-.153	-1.700	.092
	IQ Level	-.304	.097	-.282	-3.147	.002
	Co-occurring Psychiatric Diagnosis	.777	.328	.228	2.369	<.050
	Use of Intervention and Medicine	-.425	.240	-.172	-1.774	.079
Chinese	Constant	4.339	2.170		2.000	.048
	Sex	-.161	.611	-.027	-.263	.793
	Age	.029	.077	.041	.380	.705
	IQ Level	.061	.139	.046	.441	.660
	Co-occurring Psychiatric Diagnosis	.604	.558	.120	1.083	.282
	Use of Intervention and Medicine	.232	.393	.063	.590	.557

Table S13 Ordinal regression analyses of demographic variables of autistic adults and country as predictors of independent living scale

	Predictor	<i>B</i>	<i>SE</i>	Wald χ^2	<i>p</i>	<i>OR</i>	95% CI for <i>OR</i>
Threshold Dependent Variable	living = 0	-2.775	1.505	3.398	.065	.062	[.003, 1.192]
	living = 1	2.287	1.5120	2.288	.130	9.84	[.508, 190.626]
	living = 2	3.250	1.5563	4.362	.037	25.797	[1.221, 544.824]
Explanatory Variables	Country = Netherlands (ref = China)	-2.069	.4452	21.587	<.001	.126	[.053, .302]
	Sex = female (ref = male)	-.495	.4106	1.451	.228	.610	[.273, 1.364]
	Co-occurring psychiatric conditions = YES (ref = No)	.765	.3895	3.855	.050	2.149	[1.001, 4.610]
	Use of intervention and medicine (ref = 2)						
	Use of intervention and medicine = 0	.882	.6535	1.821	.177	2.415	[.671, 8.694]
	Use of intervention and medicine = 1	.765	.6360	1.446	.229	2.149	[.618, 7.474]
	Age	-.009	.0553	3.210	.073	.906	[.813, 1.009]
	IQ level	.448	.1233	13.228	<.001	1.566	[1.230, 1.994]

Note: Independent living scale (0-3): 3: living independently; 2: living independently with housing assistance; 1: living with parents / family; 0: living in a form of housing with support and / or care; Or living in a care facility

Country: 0 = Netherlands. 1 = China

Sex: 0 = female, 1 = male,

Co-occurring psychiatric conditions: 0 = Yes, 1 = No

Use of intervention and medicine: 0 = no use of service, 1 = receive intervention or medicine, 2 = receive intervention and medicine

Table S14 Ordinal regression analyses of demographic variables of autistic adults and country as predictors of friendship scale

	Predictor	B	SE	Wald χ^2	p	OR	95% CI for OR
Threshold Dependent Variable	Friendship = 0	1.069	1.1623	.846	.358	2.913	[.299, 28.421]
	Friendship = 1	3.619	1.1947	9.176	.002	37.298	[3.587, 387.818]
Explanatory Variables	Country = Netherlands (ref = China)	.309	.2984	1.073	.300	1.362	[.759, 2.445]
	Sex = female (ref = male)	.135	.3298	.167	.682	1.145	[.600, 2.184]
	Co-occurring psychiatric conditions = YES (ref = No)	-.483	.3131	2.376	.123	.617	[.334, 1.140]
	Use of intervention and medicine (ref = 2)						
	Use of intervention and medicine = 0	.142	.5117	.077	.781	1.153	[.423, 3.144]
	Use of intervention and medicine = 1	.166	.5002	.110	.740	1.181	[.443, 3.147]
	Age	-.001	.0431	.001	.979	.999	[.918, 1.087]
	IQ Level	.357	.0903	15.602	<.001	1.428	[1.197, 1.705]

Note:

Friendship scale (0-2): 2: close friendships 1: other social contacts (other than close friendships, contact with parents, siblings or own children) 0: hardly any social contacts (except for contact with parents, siblings or own children)

Country: 0 = Netherlands. 1 = China

Sex: 0 = female, 1 = male,

Co-occurring psychiatric conditions: 0 = Yes, 1 = No

Use of intervention and medicine: 0 = no use of service, 1 = receive intervention or medicine, 2 = receive intervention and medicine

Table S15 Ordinal regression analyses of demographic variables of autistic adults and country as predictors of employment scale

	Predictor	<i>B</i>	<i>SE</i>	Wald χ^2	<i>p</i>	<i>OR</i>	95% CI for <i>OR</i>
Threshold Dependent Variable	Work = 0	-3.120	1.1818	6.971	.008	.044	[.004, .448]
	Work = 1	.318	1.1450	.077	.781	1.374	[.146, 12.961]
	Work = 2	1.391	1.1514	1.459	.227	4.019	[.421, 38.385]
Explanatory Variables	Country = Netherlands (ref = China)	-.224	.2962	0.571	.450	.799	[.447, 1.429]
	Sex = female (ref = male)	-.327	.3257	1.009	.315	.721	[.381, 1.365]
	Co-occurring psychiatric conditions = YES (ref = No)	-.364	.3102	1.377	.241	.695	[.378, 1.276]
	Use of intervention and medicine (ref = 2)						
	Use of intervention and medicine = 0	.480	.5182	0.857	.355	1.615	[.585, 4.460]
	Use of intervention and medicine = 1	.546	.5071	1.158	.282	1.726	[.639, 4.662]
	Age	-.082	.0426	3.662	.056	.922	[.848, 1.002]
	IQ Level	.464	.0913	25.863	<.001	1.591	[1.330, 1.902]

Note:

Work scale (0-3): 3: regular paid employment / self-employed for at least 16 hrs per week; Or studying for at least 24 hours per week; 2: regular paid employment / self-employed for less than 16 hrs per week; Or non-regular / non-paid employment; 1 not any kind of (paid or unpaid) employment; 0 no structural day time activities for 40 hours or more per week

Country: 0 = Netherlands. 1 = China;

Sex: 0 = female, 1 = male,

Co-occurring psychiatric conditions: 0 = Yes, 1 = No

Use of intervention and medicine: 0 = no use of service, 1 = receive intervention or medicine, 2 = receive intervention and medicine

Appendix 4 Supplement to Chapter 5

Table S16 Coding of Employment, Independent Living, Friendships and Overall Community integration

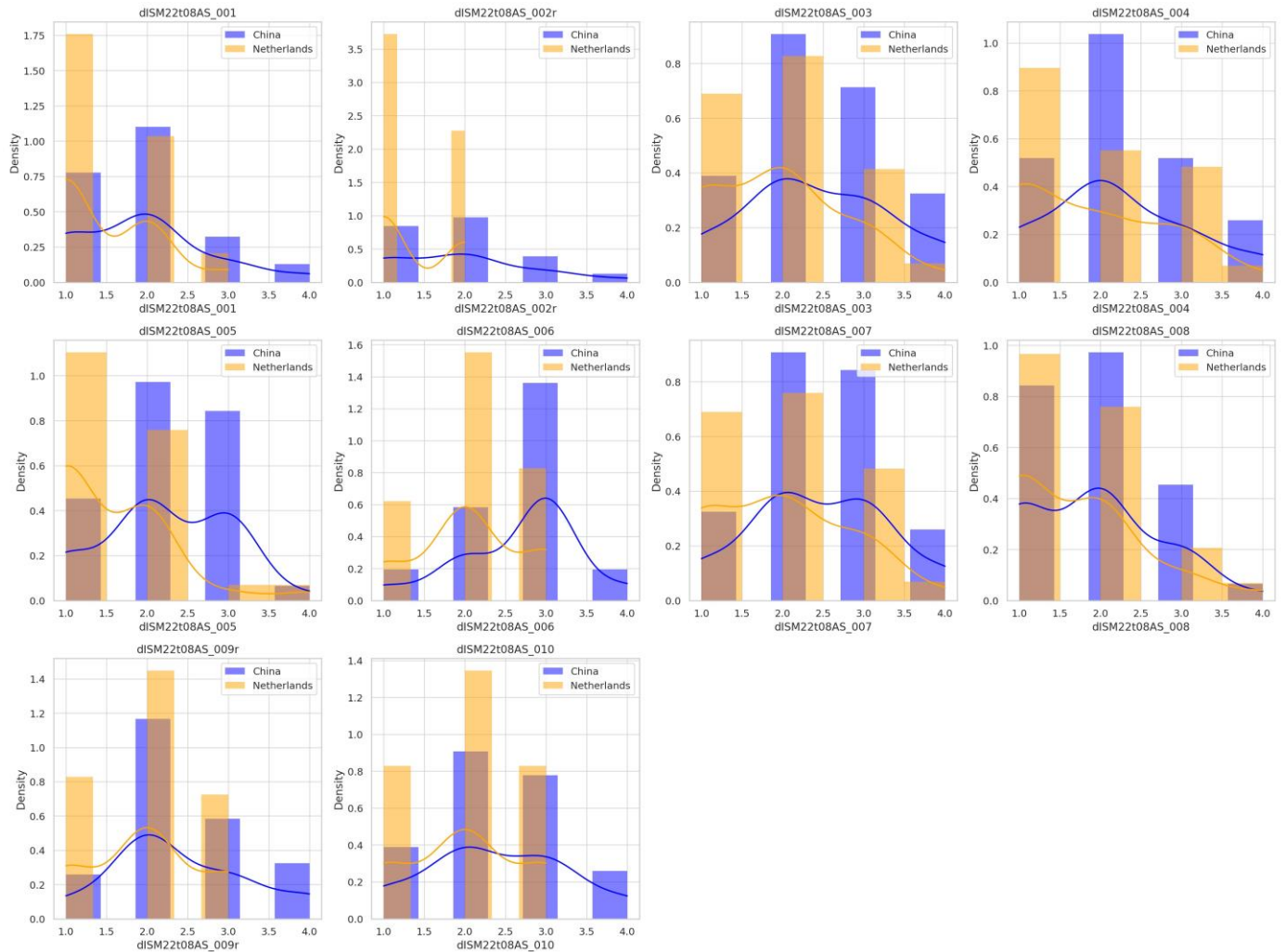
Scale item	Coding points of each
Employment scale (0-3)	
Regular paid employment/self-employed for at least 16 hrs. per week; Or studying for at least 24 hours per week	3
Regular paid employment/self-employed for less than 16 hrs. per week; Or non-regular/non-paid employment	2
Not any kind of (paid or unpaid) employment	1
No structural day time activities for 40 hours or more per week	0
Independent living scale (0-3)	
Independently	3
Independently with some housing assistance	2
With parents/family	1
Form of housing with guidance and/or care; Or a residential care facility	0
Friendship scale (0-2)	
Close friendships	2
Other friendships (other than parents, siblings, family members or own children), but no close friendships	1
Hardly any friends (except for contact with parents, siblings, family members or own children)	0

*This table is cited from Scheeren et al. (2022)

Table S17 Mann-Whitney U Test Results for Item Scores Between China and the Netherlands

Item	MChinese	MDutch	U Statistic	p
dISM22t08AS_005	2.22	1.55	764.5	< .001
dISM22t08AS_006	2.67	2.07	742.5	0.002
dISM22t08AS_002r	1.92	1.38	701.5	0.009
dISM22t08AS_001	1.92	1.48	674.0	0.029
dISM22t08AS_007	2.44	1.97	674.5	0.035
dISM22t08AS_003	2.42	1.93	671.5	0.038
dISM22t08AS_009r	2.41	1.97	660.5	0.049
dISM22t08AS_010	2.39	2.00	643.0	0.092
dISM22t08AS_004	2.22	1.86	634.0	0.122
dISM22t08AS_008	1.89	1.69	597.5	0.286

Figure S6 Score ranges for Each item of ISMI-10 in China and the Netherlands



Internalized Stigma of Mental Illness Inventory (ISMI-10)

仅适用于成人孤独症自我报告。我们在下面的问卷中将使用“孤独症”一词。请您根据自身的感受，选出您对这些描述的同意程度。

1 = 非常不同意 2 = 不同意, 3 = 同意, 4 = 非常同意

1. 患有孤独症的人有暴力倾向。
2. 有孤独症的人也可以对社会做出重要贡献。
3. 我的社交活动比以前少了，因为孤独症可能会让我的样子或行为很“古怪”。
4. 孤独症破坏了我的生活。
5. 我为了不让家人或朋友尴尬而远离社交场合。
6. 没有孤独症的人根本不可能理解我。
7. 只是因为我有孤独症，人们就忽视我或不把我当回事。
8. 因为有孤独症，所以我无法对社会做任何贡献。
9. 尽管有孤独症，我仍然能过得很好、很满意的生活。
10. 因为我孤独症，别人认为我一生中不可能取得许多成就。

ISMI-10

Only for self-reporting adults. In the questionnaire below, we will use the terms “autism” or “autistic” to refer to people with an autism diagnosis. Always choose the answer that best corresponds to your opinion.

For each question, please mark whether you strongly disagree (1), disagree (2), agree (3), or strongly agree (4).

1. Autistic people tend to be violent.
2. People with autism make important contributions to society.
3. I don't socialize as much as I used to because my autism might make me look or behave “weird.”
4. Having autism has spoiled my life.
5. I stay away from social situations in order to protect my family or friends from embarrassment.
6. People without autism could not possibly understand me.
7. People ignore me or take me less seriously just because I have autism.
8. I can't contribute anything to society because I have autism.
9. I can have a good, fulfilling life, despite my autism.
10. Others think that I can't achieve much in life because I have autism.

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Autism and Developmental Disorders

Personal development

PhD success and personal efficacy

Creating a societal impact strategy

Research Methods

Data Science: Statistical Programming with R

How to evaluate Psychological Interventions Through Systematic Review and Meta-Analysis

Introduction to structural equation modelling using Mplus

Survey Research: Statistical Analysis and Estimation

Scientific Writing and Presenting

Conferences

Oral presentations

Liu F, Scheeren AM, Grove R, Hoekstra RA, Wang K, Guo D, Wang C, Begeer S. (May, 2021) *Structural Validation of the Autism-Spectrum Quotient Short Form (AQ-Short) in Children with an Autism Spectrum Disorder: A Comparison between China and the Netherlands*. 20th The International Society for Autism Research (INSAR) Annual Meeting

Liu F, Scheeren AM, Grove R, Hoekstra RA, Wang K, Guo D, Wang C, Begeer S. (May, 2021) *The Autism-Spectrum Quotient Short Form (AQ-Short) in China and the Netherlands: A Cross-Cultural Comparison*. the Dutch Society for Developmental Psychology (VNOP)

Poster presentations

Liu, F., Begeer, S., Hoekstra, R.A., Bai, Q., Wang, C. & Scheeren, A.M. (May, 2022) *Brief Report: Parental Stress in Parents of Autistic Children in China and the Netherlands*. 21st The International Society for Autism Research (INSAR) Annual Meeting

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Publications

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