

## Research Article

# Central Human Functional Capabilities of Children with Autism Spectrum Disorders: A Qualitative Research

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### ABSTRACT

Autism spectrum disorder (ASD) is one of the most commonly reported disabilities that have been increased significantly over the past decade. Individuals with ASD are more likely to experience lack of Central Human Functional Capabilities (CHFCs). This study explores the perspective of several parents of children with ASD in regard to the CHFCs and its relevance to their children's lives. Semi-structured

interviews were conducted with six parents of children with ASD in Fars, Iran. Interviews were recorded, transcribed, translated, and analyzed thematically. Results indicate the importance of enhancing the CHFCs of people with ASD.

**2. MeSh Headings/ Keywords:** Central human functional capabilities; Children with autism spectrum disorders; Qualitative research

### Introduction

Disability is considered as a human rights issue [1]. The human rights approach of disability is reflected in the United Nations Convention on the Rights of Persons with Disabilities. The Capabilities Approach may provide a meaningful basis for conceptualizing the rights of people with disabilities [2]. Capability is defined as "the opportunity to achieve valuable combinations of human functionings - what a person is able to do or be" [3]. The idea of capability is central to understanding human rights [3-4]. Human rights can be seen as claims to certain basic capabilities [4-7]. The extension of capabilities to people with disabilities may provide a rational means of improving the basic human rights and a better framework "for identifying the responsibilities of governments and external agencies in genuinely equalizing opportunities" [8].

Nussbaum suggested that the Central Human Functional Capabilities (CHFCs) should be considered a foundation for constitutional principles of respect for human dignity that must be valued equally by all nations, and one of the most important items that should be secured to all citizens. The CHFCs, as described by Nussbaum include: Life; Bodily Health; Bodily Integrity; Senses, Imagination, and Thought; Emotions; Practical Reason; Affiliation; Other Species; Play; and, Control over One's Environment [4] (Appendix). According to Nussbaum, people with disabilities, "like other human beings, have needs in the areas covered by all the capabilities" [5].

Autism spectrum disorder is a neurodevelopmental disorder that has been increased significantly over the past decade. Centers for Disease Control and Prevention (CDC, 2014) reported that the prevalence of autism is 1.5% [9]. The most recent estimate indicated 2.2% [10]. Studies in Asia, Europe and North America people with autism with moderate prevalence between 1 and 2 percent [9].

Little research has been done on the prevalence of autism in Iran. Samadi, et al. identified more than 1.3 million children under the age of six years with autism in Iran. They concluded that the prevalence of ASD in Iran is about 0.06% [11].

The purpose of this study is to explore parents of children with ASD views of Nussbaum's ten Central Human Functional Capabilities in order to raise awareness of policy makers and service providers to provide facilities that include all capabilities.

This paper described the findings from a thematic analysis of semi-structured interviews discussed below with respect to the following research question:

- 1) How do parents of ASD children understand the CHFCs in relation to their children's lives?
- 2) In what ways have their perceptions of CHFCs are related to their children's quality of life?

### Study Design

A qualitative research approach using narrative analysis was employed to explore the views of parents of children with ASD about their children's capabilities. This approach was selected to capture comprehensive insights about participants' perceptions of CHFCs. Narrative studies seek to understand the experiences of individuals, with respect to the phenomenon of the study's interest [12,13]. Narrative methods therefore enable us to explain how these capabilities are relevant to the lives of children with ASD. A qualitative research approach using narrative analysis was employed to analyze thematic concepts that emerged through conversation. This approach was selected to understand the lived experiences of parents and their perceptions of their children's capabilities.

### Sample

This research was approved by Research Ethics Committee

of the Fars ASD' Non-governmental Organization in Shiraz, Iran. The snowball sampling technique was used to recruit six participants for this study. Parents of children with ASD were recruited to participate in this study through this organization. The researcher contacted some members and explained the purpose of the study.

Snowball sampling is often used to find and recruit groups that are not easily accessible to researchers through other sampling strategies.

As guiding principles for the sample size, Creswell recommended that narrative sample sizes range from three to ten participants. This researcher originally proposed a sample size that would range from five to eight participants. A total of six interviews were scheduled and were completed. Despite a few participants, this author reached a point of "saturation" as new themes were no longer emerging [14].

Inclusion criteria included parents that were between 25-40 years old, and their children between 5 to 13 with ASD in Fars Province. Exclusion criteria were parents who had not registered in Fars ASD's NGO, and having had children younger than 5 years or older than 13 years.

The participants' children ages were ranging from 5 to 11 years old. Four of the children were firstborn children, and two were second born children.

### Data Collection

Data was collected through one-on-one, face-to-face, open-ended, semi-structured interviews. The interviews were audio recorded, transcribed, and translated from Persian to English. Interviews were conducted in September 2016. Each interview lasted approximately 60 minutes. The interviewer wrote memos while conducting the interviews, listened to the audio recordings of the interviews, and read the transcripts.

Prior to the interviews the participants' consents were obtained and informed about the purpose of the study and a definition of each capabilities. They also informed that they were free to refuse to answer any question. Participants were asked about their understandings of the CHFCs in relation to their children's lives. Interview recordings were transcribed by a professional transcription and translation service with an agreement of confidentiality. The transcripts were free of information that would identify participants.

### Data Analysis

A qualitative research approach using narrative analysis was employed to analyse thematic constructs and patterns that emerged through discourse. Thematic analysis "can be used within different theoretical frameworks, can be used to do different things within them" [15]. It can be a "realist method, which reports experiences, meanings and the reality of participants..." [15].

A six-step process was used to inductively develop themes based on the guidelines of Braun and Clarke (2006). Data analysis consisted of: (1) familiarization, (2) generating initial

codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report [15].

In this study, first, the researcher read and repeated reading to become familiar with the data. Second, in order to generate initial codes, she reduced the data based on 10 CHFCs and read each sentence in search of the answer to the question what is this about, or what does it mean? Third, the researcher used memo writing to reflect on ideas that emerged when reading the data set. She synthesized initial codes and memo writing to explore thematic concepts that emerged through each interview. She coded the data manually in order to feel close to the data [14]. Fourth, she reviewed initial themes in order to categorize and refine them. Fifth, she used a thematic map to define and name themes. A total of ten thematic maps were generated through this analysis. She compared and contrasted the emerging themes across ten thematic maps. Six, the researcher read each transcript again to ensure the themes clearly present or absent.

Various strategies have been mentioned to ensure the credibility of the data set. credibility is one important aspect of trustworthiness [14,16]. Creswell recommends that at least two of following eight procedures be included: 1. Prolonged engagement and persistent observation in the field; 2. Triangulation; 3. Peer review; 4. Negative case analysis; 5. Clarifying researcher bias, 6. Member checks, 7. Rich, thick description; and 8. External audits [12].

To achieve methodological rigor, the researcher used three of these strategies were thought to be most relevant to the data set, namely; clarifying researcher bias, member checks, and thick description. Clarifying Researcher Bias is indicated because the researcher is the key instrument of the data collection, and her biases may threaten the credibility of data. Writing about her background, identifying her assumptions in carrying out this research, articulating what shaped her reflections about the work, and interpretation of the results helped with clarifying researcher bias. The researcher identified and documented her assumptions to minimize the risk of researcher bias in the data analysis. Her reflections revealed that she had some assumptions; for example: CHFCs can be closely linked to quality of life, or parents struggled to explain how these capabilities could be relevant to their children's lives. Some assumptions were opposed during the interviews. Thick Description is a method for enhancing the quality of research by quoting the participants' exact words. This method was employed to allow the reader to determine the accuracy of interpretation. Member checks, the researcher has participants verify findings and interpretations.

### Findings

This study explored the views of parents of children with ASD regarding Nussbaum's CHFCs, with respect to their own experiences. The themes emerged from the analysis of the data are as following:

The participants were asked about their understanding of Life capability in relation to their children's lives. The results described the two themes: Loneliness, and Longevity. The following describes the quotes that support these themes.

### Loneliness

Participants addressed the meaning of life is different for children with ASD.

They do not like to come out of their own world... (Participant D)

They are like someone who lives in a cave, but happily living in isolation. (Participant B)

Children with ASD can struggle to socialize, making it hard for them to establish friendships and interact with others.

They prefer to avoid social situations, and are in fact happier when they are simply left alone. (Participant F)

### Longevity

Participants asserted that the lifespan of people with ASD may be shortened and they may die some earlier ages. Participant E noted:

Sometimes seizures may cause falls, injures, or unexpected death.

The participants were asked about their perceptions of Bodily Health capability in relation to their children's lives. Four themes emerged:

### Sensory processing disorder

Almost all participants mentioned that many people with ASD have difficulty processing sensory information. It can result in the person being hypersensitive or hyposensitive to stimuli inappropriate immune response.

They [children with ASD] do not have the ability to recognize and avoid dangerous situations, for example, they would not know what to do to protect themselves from burns. (Participant B)

Because people with ASD have sensory processing disorder, they might have food challenges.

My child has significant food dislikes and has trouble chewing and swallowing. (Participant F)

They are more prone to being overweight or to lose weight than others. (Participant D)

### Pain insensitivity

Some participants mentioned that children with ASD show reduced sensitivity to pain or unusual reaction to pain.

His pain sensitivity is lower than normal... acute pain expressions appear to be delayed. (Participant E)

Her pain threshold is higher than others. (Participant A)

### Inactive lifestyle

Almost all participants noted that children with ASD are at risk for an inactive lifestyle and obesity. They mentioned sometimes lack of social skills and communication, or difficulty processing sensory information may cause physical inactivity in these children. And physical inactivity in turn, may cause major

diseases, such as heart disease and diabetes in individuals with ASD. (Participant F)

There are various disadvantages of urban life that may impact social interaction and communication problems in children with ASD, such as living in small apartments, pollution, etc. (Participant E)

The participants were asked about their understanding of Bodily Integrity capability in relation to their children's lives. Only one meaningful theme emerged:

### Sexual abuse

The majority of participant asserted that children with ASD may be targeted for abuse. As noted:

These children are more at risk for abuse than other kids... it is hard to teach them how to protect themselves from sexual abuse and violence. (Participant B)

The participants were asked about their understandings of Senses, Imagination, and Thought capability in relation to ASD. The results described the two themes: Emotionally sensitive, and Imaginative play. The following describes the quotes that support these themes.

### Emotionally sensitive

Although most participants asserted that children with ASD have difficulty to communicate, they also noted that they have a very good sense of understanding your feelings.

He is not able to talk about his feelings, but is able to understand your emotions. (Participant E)

She has difficulty controlling her emotions or expressing them, but still feels empathy. (Participant A)

### Imaginative play

They have different imagination rather than lack of "imaginative" play.

Promoting pretend play development is a critical for them. (Participant D)

Sometimes they have amazing imaginations...They love drawing or painting. (Participant C)

The participants were asked about their perceptions of Emotions capability in relation to ASD. Only one meaningful theme emerged:

### Recognize children's emotions

Some participants mentioned that children with ASD express their feeling in different ways. As noted:

... this is our job as parents to discover their emotions. (Participant D)

We have to understand their basic emotions such as happiness, sadness, anger, fear feelings in their tone of voice. (Participant B)

The participants were asked about their understanding

of Practical Reason capability in relation to ASD. A theme emerged:

### Lack of practical reason

The majority of participants stated that individual with ASD have problems with conceptual thinking.

...my child cannot apply logic. (Participant C)

They are unable to make decisions for themselves. (Participant E)

They do not recognize boundaries... they do not understand what to say in various contexts. (Participant B)

The participants were asked about the relevance of Affiliation capability to ASD. The results described the two themes: Specific belongings and Lack of social skills. The following describes the quotes that support these themes.

### Specific belongings

Some participants mentioned that their children have a different sense of belonging. They noted that human beings need to sense a connection to someone, to feel included and supported by others. But,

Her sense of belonging may appear differently. (Participant A)

He shows a special interest in objects that bring him relaxation. (Participant E)

### Lack of social skills

Some participants noted that most children are capable of interacting with each other, but children with ASD appear to have difficulty to communicate.

My child has significant difficulties with social interaction... sometimes I feel as if nothing in particular interests him. (Participant B)

She does not appear to have any interests in talking to people and getting to know them. (Participant D)

They have difficulty trying to build word combinations and fail to ask appropriate questions in order to continue guiding them through activities or conversations. (Participant A)

### Other Species

The participants were asked about the relevance of Another Species Capability to ASD. A theme emerged:

Good relationship with some animals and plants

Some participants mentioned that their children often have a very good relationship with some animals and plants.

He loves animals very much. He enjoys smelling flowers and playing with dogs. (Participant E)

My child enjoys being with pigeons. But she does not like insects. (Participant B)

The participants were asked about the relevance of Play Capability to ASD. The results described the two themes:

### Engage in different types of play

Some participants asserted that their children are less likely to engage in play like their peers.

She does not like to play with other kids. She doesn't enjoy participating in different kinds of games. (Participant A)

My child's play tends to be less complex, and has very few interests. (Participant C)

### Do not know how to play

Almost all participants asserted that their children miss social cues that are required to play a game.

My child does not know how to commence playing a game. (Participant E)

She cannot ask someone to play with her... Even if a child invites her to play, she could not ask questions or speak to him/her. (Participant D)

The participants were asked about the relevance of Control over One's Environment capability to ASD. The results described the two themes: ASD occupations and Dependent life. The following describes the quotes that support these themes.

### Dependent life

All participants agree that individuals with ASD do not have capability to control their environment, in other words, they do not have independent life.

Our main concern for them is their ability to live an independent life, otherwise we would be more at ease about their future. (Participant B)

### ASD occupations

Some participants noted that although they do not have independent life but may be able to gain some skills and seek employment with some kinds of social supports.

They may be able to work in certain jobs, such as working at a zoo. (Participant D)

### Discussion

The findings of the study will be discussed in relation to the Capabilities Approach.

CHFCs as related to quality of life

Quality of life (QoL) has been defined widely across disciplines and academic areas, for example, health care, economics, and the social sciences [17]. Conceptualization and measurement of QoL across disciplines are varied [17-19].

According to the Capabilities Approach, QoL means the freedom or real opportunities that people manage to do or be in leading a life [4,5,20,21]. Sen discussed that QoL and well-being are best understood in terms of capabilities [22,23]. In other words, QoL can be understood in relation to "actual ability to achieve various valuable functionings as a part of living" [21].

The findings of this research indicate that children with ASD



struggle for an adequate quality of life. All are of them have major barriers towards achieving basic capabilities. “For all, then, the Capabilities Approach supplies insight” [24].

The findings reveal that parents of children with ASD understand the CHFCs as important factors of their kids’ QoL. There are many examples that show the relationship between the CHFCs and QoL. The majority of participants suggest that people with ASD are more likely to experience a shorter lifespan because they have difficulty processing sensory information and pain perception. The findings also indicate that most children with ASD have inactive lifestyle. Furthermore, they are exposed to non-communication diseases, such as heart disease and obesity.

Similar to other studies, this study indicates that children with ASD experience a much lower QoL, and their parents have major concerns about their children’s QoL during their childhood and adolescence years [25,26].

Increasing and improving children with ASD’s quality of life should be a priority. As the treatment of these children is complex, there is a need for a team of professionals to work together to develop their QoL. Experts must suggest strategies that better the quality of life of these children through promoting health, preventing injury and diseases, developing interventions, and improving social participation.

### CHFCs as a social justice approach

The present study indicates that the CHFCs are relevant to ASD through the lens of social justice. There are various examples showing the relationship between the CHFCs and social justice. The findings show that children with ASD have struggled to socialize and interact with others, and are unable to establish friendships. They may also be more prone to be a victim of abuse and violence. They do not have the capability to control their environment, and have an independent life.

The Capabilities Approach is “about basic social justice” [24]. As Nussbaum claimed:

The capabilities approach simply specifies some necessary conditions for a decently just society, in the form of a set of fundamental entitlements of all citizens. Failure to secure these to citizens is a particularly grave violation of basic justice, since these entitlements are held to be implicit in the very notions of human dignity and a life that is worthy of human dignity [5].

The Capabilities Approach supports “each person as an end” principle [24]. This approach aims “to produce capabilities for each and every person” [24]. There is a conceptual connection between the CHFCs and the idea of duties [24]. Thus, policy makers and experts have a duty in promoting children with ASD’s capabilities. They must provide opportunities and consider strategies to improve their CHFCs in order “to enhance physical and emotional health, support for family care and love, a system of education, and much more” [24].

There is a need to improve children with ASD’s central capabilities in order to enable them to socialize, to make friendship, to protect them from sexual abuse, to be able to

make decision, and to increase their logical thinking. Experts must provide opportunities for children with ASD to develop their communication and improve social interaction with human beings and other species, and create a supportive environment for them to adjust and cope with their problems. Service providers must help them in overcoming barriers, and enable them in order to achieve their goals.

### Limitations

There are some limitations associated with a qualitative research for this study. The first limitation of this study is due to using interviews as the main data-collection method, which only allows the researched to self-report her data. Second, researcher bias may influence the processes of data collection and analysis. Third, the generalizability of the findings may be limited because the sample size was small. Fourth, all participants were recruited from the same city. Steps were taken to assure rigor, and to identify and minimize the limitations. For example, the researcher took measures to ensure saturation was reached in establishing this number. Fifth, because of children with ASD communication problems, they did not have the opportunity to give their perspectives.

### Conclusions

The CHFCs are closely linked with the Convention on the Rights of Persons with Disabilities. The findings have helped identify how the CHFCs could be extended to promote the basic rights of ASD clients. This study reflects our duties and responsibilities in providing appropriate services that meet children with ASD’s basic needs. This perspective may help policy makers and service providers better understand their role in supporting the quality of life of children with ASD. With respect to further research, exploration of the views of more parents of ASD from other countries regarding to CHFCs would be highly informative.

### References

1. United Nations. Handbook for parliamentarians on the convention on the rights of persons with disabilities and its optional protocol. United Nations: Geneva. 2007.
2. Nussbaum M. Human rights and human capabilities. *Harv Hum Rts J.* 2007; 20: 21-24.
3. Sen AK. Human rights and capabilities. *Journal of Human Development.* 2005; 6: 151-66.
4. Nussbaum M. Women and Human Development: The Capabilities Approach. Cambridge: Cambridge University Press. 2000.
5. Nussbaum M. Frontiers of justice: disability, nationality, species membership. Cambridge. MA: Harvard University Press. 2006.
6. Sen AK. Human rights and capabilities. *Journal of Human Development.* 2005; 6: 151-66.
7. Sen AK. Development as freedom. New York: Knopf. 1999.
8. Baylies C. Disability and the notion of human development:

- questions of rights and capabilities. *Disability and Society*. 2012; 17: 725-739.
9. Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders among children aged 8 years. *Surveill Summ*. 2014; 63: 1-21.
  10. Zablotsky B, Black LI, Maenner MJ, Schieve LA, Blumberg SJ. Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. 2015; 11: 87.
  11. Samadi SA, Mahmoodizadeh A, McConkey A. A national study of the prevalence of autism among five-year-old children in Iran. *Autism*. 2012; 16: 5-14.
  12. Creswell JW. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks. 1998.
  13. Patton MQ. *Qualitative research & evaluation methods (3<sup>rd</sup> Edtn)*. Thousand Oaks. 2002.
  14. Creswell JW. *Qualitative inquiry and research design: choosing among five approaches*. Thousand Oaks. 2013.
  15. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006; 3: 77-101.
  16. Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills. 1985.
  17. Cummins RA. Moving from the quality of life concept to a theory. *J Intellect Disabil Res*. 2005; 49: 699-706.
  18. Ruta D, Camfield L, Donaldson C. Sen and the art of quality of life maintenance: Towards a general theory of quality of life and its causation. *J Socio Econ*. 2007; 36: 393-423.
  19. Velde BP. Quality of Life Issues in Community Occupational Therapy Practice. *Occupational Therapy in Health Care*. 2001; 13: 145-151.
  20. Sen AK. *Commodities and Capabilities*. Amsterdam: North Holland. 1985.
  21. Sen AK. *Capability and Well-Being*. In M. Nussbaum & A. Sen (Eds.). *The Quality of Life*. Oxford: Clarendon Press. 1993.
  22. Clark DA. Sen's Capability approach and the many spaces of human well-being. *The Journal of Development Studies*. 2005; 4: 1339-1368.
  23. Gasper D. Is Sen's Capability Approach an Adequate Basis for Considering Human Development? *Review of Political Economy*. 2002; 14: 435-461.
  24. Nussbaum, M. *Creating capabilities: The human development approach*. Cambridge, MA: Belknap/Harvard University Press. 2011.
  25. Lee LC, Harrington RA, Louie BB, Newschaffer CJ. Children with autism: Quality of life and parental concerns. *J Autism Dev Disord*. 2008; 38: 1147-1160.
  26. Van Heijst BFC, Geurts HM. Quality of life in autism across the lifespan: A meta-analysis. *Autism*. 2015; 19: 158-167.

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## Appendix

1. Life Capability defined as “Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living”.
2. Bodily Health defined as “Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter”.
3. Bodily Integrity defined as “Being able to move freely from place to place; having one’s bodily boundaries treated as sovereign, i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction”.
4. Senses, Imagination, and Thought defined as “Being able to use the senses, to imagine, think, and reason – and to do these things in a “truly human” way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing self-expressive works and events of one’s own choice, religious, literary, musical, and so forth. Being able to use one’s mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to search for the ultimate meaning of life in one’s own way. Being able to have pleasurable experiences, and to avoid non-necessary pain”.
5. Emotions defined as “Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one’s emotional development blighted by overwhelming fear and anxiety, or by traumatic events of abuse or neglect. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)”
6. Practical Reason is defined as “Being able to form a conception of the good and to engage in critical reflection about the planning of one’s life. (This entails protection for the liberty of conscience.)”
7. Affiliation is defined as “A. Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another and to have compassion for that situation: to have the capability for both justice and friendship. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.) B. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails, at a minimum, protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.”
8. Other Species means “Being able to live with concern for and in relation to animals, plants, and the world of nature”.
9. Play Capability defined as “Being able to laugh, to play, to enjoy recreational activities”.
10. Control over One’s Environment Capability defined as “A. Political. Being able to participate effectively in political choices that govern one’s life; having the right of political participation, protections of free speech and association. B. Material. Being able to hold property (both land and movable goods), not just formally but in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure”.