

Future Planning for Muslim Americans with Intellectual and Developmental Disabilities and
their Families

Amal Alsamawi

Connecticut Leadership Education in Neurodevelopmental and Related Disabilities

August 15, 2021

Introduction

There are approximately 7.3 million individuals with intellectual and developmental disabilities (IDD) in the United States (Larson et al., 2018). Only 16% of individuals with IDD receive formal supports from their state's Developmental Disabilities Agency and even among these individuals a majority live at home and are supported by their families (Anderson et al., 2018). Informal caregiving is the primary mode of support for people with intellectual and developmental disabilities living in the United States. Between 75%-80% of all adults with intellectual and developmental disabilities live with their parents or other family members (Anderson et al., 2018; Braddock et al., 2013; Mahar et al., n.d). More than 25% of family caregivers are over the age of 60 (Heller, 2011). As family members continue to age, individuals with IDD are increasingly outliving their parents (Burke et al., 2018; Fujiura, 2014). As such, it is imperative to support families in developing plans for the future. Future planning is described as a set of activities to ensure supports are available for individuals with IDD in the future (Burke et al., 2018).

Future planning can involve a wide range of topics such as planning for future living arrangements, financial planning and the identification of a primary support person. Future planning is necessary to ensure the consistency and quality of supports for individuals with IDD, particularly as family members age or pass away. In addition to aging, another important area of consideration is supporting families using culturally and linguistically competent approaches. As the United States' population ages and becomes more diverse over the next several decades, service systems must meet the needs of the changing demographics. One community under reported about within the IDD literature are Muslim Americans. Muslim Americans are a diverse and growing population within the United States.

Study Objectives & Research Questions

Table 1
Research Aims and Questions

Research Aim	Research Question
Investigate residential and financial planning patterns of Muslim's with IDD and their families.	Do Muslim families engage in long-term financial and residential planning to ensure supports are available to their adult family members with intellectual and developmental disabilities as parents age or pass away?
Explore any barriers Muslims with IDD and their family members experience when planning for the future.	Do Muslim families experience any barriers to financial and residential planning for the future?

Hypothesis

It is expected that similar to the general population, Muslim families rarely participate in future financial and residential planning. Additionally, Muslim families, particularly immigrant and non-English speaking families, may experience additional or compounded barriers to future planning as a result of language barriers and challenges navigating complicated and fragmented service systems.

Background

Research suggests that people with intellectual and developmental disabilities (IDD) who live, work and play in community settings, alongside their peers without disabilities have more control over their lives, are engaged in their communities, are safer and have greater life satisfaction (American Association on Intellectual and Developmental Disabilities [AAIDD], 2015). Additionally, adults with disabilities who live in their own home enjoy greater choice and control over making life decisions when compared to individuals living in congregate or group home settings (Reed et al, 2014). Across all outcome areas people who live in their own home, family home, or in small residences ranked higher and consistently achieved positive outcomes when compared to their peers living in moderate and large agency residences (Nord et al.,

2013). Lakin and colleagues (2011) systematic review on the effects of deinstitutionalization and quality of life for adults with ID, analyzed the findings from 36 studies. Eighty six percent of the studies consistently reported positive outcomes in four areas of skill development, (1) social skills, (2) language and communication, (3) self-care and domestic skill development and (4) community living skills. Additionally, individuals with developmental disabilities who transitioned from an institutional setting to a community-based setting developed these skills at a higher level than their peers who live in institutionalized settings.

Unfortunately, when families do not develop plans and the relative providing care can no longer support their family member, individual's with IDD are more likely to move into institutional settings (Burke et al., 2018). Anderson and colleagues' analysis of national survey of over 3,000 caregivers revealed that over 80% of respondents reported that their family member with an IDD lives with them (2018). The respondents shared their concerns about their son or daughter's future when the family is not able to provide support. Family members were worried that their relative with a disability will experience a decrease in quality of support (91%), that they would lose their friends and become socially isolated (82%), that no one else will provide support (80%), that their family member with a disability will be forced to live somewhere they do not want to live (81%), that their health will deteriorate (78%), that they will be abused, neglected (77%) and financially exploited (68%) (Anderson et al., 2018). These concerns may cause families undue stress and anxiety that may be alleviated with appropriate future planning.

Although families have concerns about the future, many do not develop advance care plans. In a national survey of almost 400 parents of individuals with intellectual and developmental disabilities, researchers found that the majority of respondents did not make advance care plans for their children's long-term needs such as identifying a successor to the family caregiver or planning for future living arrangements (Burke et al., 2018). The lack of

future planning can have negative outcomes for people with disabilities and their families. Individuals with disabilities who do not have residential and financial arrangements are at greater risk for inappropriate placements and crises situations (Burke et al, 2018; Hewitt, et al., 2013; Thompson & Wright, 2001).

Burke and colleagues' research identified correlates and barriers to future planning by surveying nearly 400 parents of individuals with intellectual and developmental disabilities. The authors found that parents who were older, more educated and attended more parent training were more likely to engage in future planning (Burke et al. 2018). The barriers identified by the authors included a lack of available services, financial challenges, lack of time and reluctance and/or lack of family members ability to take on the support role, often assumed by parents.

Similar to Burke et al. (2018), Anderson and colleagues (2018) also confirmed that parent or caregiver characteristics impacted whether or not the family planned for the future. Anderson et al. reported that caregivers with lower household incomes were less likely to report having a plan compared to caregivers with higher household incomes. Heller and Factor (1991 as cited in Burke et al., 2018) found that when caregivers were white, had higher incomes, and were older they were more likely to conduct financial and residential planning.

Anderson et al. (2018), Burke et al. (2018) and their colleagues present valuable information about the experiences of families when it comes to future planning. However, one limitation of their studies is that the national samples were predominately white (89% and 85%, respectively). As the United States population ages and becomes more diverse over the next several decades, service systems must meet the needs of the changing demographics. It is predicted that between 2016 and 2060, the population of adults aged 65 and older in the U.S. will nearly double, from 49.2 million to 94.7 million (PHI, 2020). The number of adults aged 85 and older is expected to nearly triple, from 6.4 million to 19 million (PHI,2020). At the same

time, the proportion of older adults of color will increase from 23 percent to 45 percent, and the proportion of older adults who are immigrants will increase from 14 percent to 23 percent (PHI, 2020). Therefore, it is important to learn about these populations and their needs to improve service systems ability to serve a culturally and linguistically diverse population.

One such community under reported about within the IDD literature are Muslim Americans. Muslim Americans are a diverse and growing population (Pew Research Center [PRC], 2017). In 2017 there were an estimated 3.5 million Muslims in the United States (PRC, 2017). Fifty-eight percent of U.S. Muslim adults are first generation Americans who originate from countries all around the world (PRC, 2017). Both immigrant and U.S.-born Muslim populations are racially and ethnically diverse. A large number of foreign-born Muslims are Asian, while many U.S.-born Muslims are Black or Hispanic (PRC, 2017). Additionally, many foreign-born and U.S.-born Muslims identify as white, and this category includes Arab, Middle Eastern and Persian.

Despite racial and ethnic diversity in this population, Muslims may share religious traditions or beliefs that may influence how families plan for the future. Attum et al. (2021) and Jagatheesan et al. (2010) describe the importance of the family unit for Muslims. Jagatheesan and colleagues (2010) explain that for some Muslim families, particularly immigrant families tend to value collectivism.

Few studies exist on Muslim Americans with intellectual and developmental disabilities within the scientific literature. However, the studies that do exist confirm the need for increased training and supports for families. In a recent study on existing community support structures available to South Asian Muslim families of children with IDD living in the United States, authors Shikarpurya and Singh (2021) identified a need to support parents to develop a working understating of how to navigate systems of informal and formal support structures. In a

separate study, Jegatheesan and colleagues (2010) found that South Asian Muslim families, experienced both cultural and language barriers that impeded the families' abilities to access resources to support their child with a disability. This study aims to investigate residential and financial planning patterns of Muslim families with a member who has an intellectual and/or developmental disability and explore the perceived barriers to planning for the future.

Methodology

This study is a mixed methods research design that combines elements of qualitative and quantitative methods. An online survey was administered between May-August 2021. The survey included 38 questions with three main sections. The first section asks respondents to answer demographic questions. The second section asks about the supports and services the individual with IDD currently receives (both formal and informal supports). Finally, the third section of the survey asks about future planning and the barriers the individual and the family have experienced. Thirty-six out of the 38 question survey collected quantitative data. Qualitative data will be collected from the two open-ended questions within the survey that ask respondents about the supports they have used or need to help with related to caregiving for their family member. Family members will also be asked about the barriers (if any) they've experienced when accessing supports.

Study Design

This study consists of two main parts: (1) literature review and (2) survey. The literature review was conducted to provide a background and summary of the of the current ideas and discussion around future planning for individuals with intellectual and developmental disabilities and their family members. In addition, a cross-sectional survey was released to collect data on the residential and financial planning patterns of Muslim families and the barriers (if any) they experience when supporting their family member with intellectual and

developmental disabilities to plan for the future. This cross-sectional study will ideally allow for a closer examination of the relationship between planning patterns using the Future Planning Scale and other variables of interest (i.e., education, socioeconomic status, etc.). As an initial study exploring the topic of American Muslims with IDD and future planning, a cross-sectional study will be useful to generate hypotheses to better understand planning patterns especially for this community that is under-represented in the published scientific literature.

Nonetheless, the weaknesses associated with cross-sectional studies may include the difficulty interpreting the associations identified. Since cross-sectional studies are collecting information at a moment in time, individuals responding to the survey may have challenges remembering or answering questions that ask about past experiences or activities. Unfortunately, this may introduce non-response and recall biases to the study. However previous studies have confirmed the reliability and validity of the survey tool and this may alleviate some of these concerns (Burke et al., 2018).

Study Population

Family members of individuals with intellectual and developmental disabilities were recruited to participate in this study. An effort was made to recruit individuals who identify as Muslim, but the survey was open to all parents, siblings and other family members who play a role in supporting their relative with IDD. Survey respondents must be adults ages 18 years and older to participate.

Participants

Participation in this study was voluntary. Individuals that take part in this study were asked to answer questions about themselves, their family member with a disability and their family's experiences with future planning. Individuals who chose to participate could skip

questions and stop the survey at any time and for any reason. The survey took about 15-20 minutes to complete.

Consent

Qualtrics was used to capture consent of survey respondents prior to starting the survey. Informed consent was received anonymously by participants. The person responding to the survey was asked to answer a question that contains a brief description and what to expect from their participation in the study. The question included branch logic and if the participant selected 'yes, I consent' they were able to continue with the remainder of the survey. If the participant chose 'no, I do not consent', they were directed to the end of the survey.

Sampling Approach

A web-based recruitment strategy was undertaken to reach a diverse group of parents, siblings and other family members of individuals with intellectual and developmental disabilities through contacts at local, state and national disability agencies. A flyer describing the study and target population and that included a link to an online Qualtrics survey was distributed through contacts at 13 community-based organizations that serve large populations of Muslims with intellectual and developmental disabilities and their family members. A power analysis revealed that a sample size of 383 survey respondents will ensure a 95% (z score =1.96) confidence interval and 5% margin of error. The recruitment method relied on a convenience sample. Convenience sampling allows participants to self-select into the study.

Survey Tool

The survey that was used in this study is a modified version of the survey used in the Burke and colleagues' (2018) study on barriers and correlates to future planning. Written permission from the author to use and modify the survey was obtained. Burke and colleagues developed this survey using research about families of individuals with IDD and future planning.

The authors also piloted the survey with parents of individuals with different types of disabilities.

For this study, valid and reliable demographic questions used in national surveys were added to the survey so that information about the individuals' racial and ethnic backgrounds, country of birth, length of time residing in the US, the languages spoken at home and religious preference, could be collected and analyzed.

Description of Variables

The Future Planning Scale (FPS) is the dependent variable in this study. The Future Planning Scale was created using the sum of ten questions about future planning for individuals with intellectual and developmental disabilities. This is similar to previous studies on long-term planning (Burke et al., 2018; Heller & Caldwell, 2006). In studies by Heller and Caldwell (2006) and Burke and colleagues (2018), the Kuder-Richardson co-efficient was .91 and .82 respectively. This implies that that the FPS is a reliable measure. A similar analysis could not be conducted for this study due to the small number of survey responses.

The independent variables in this study are predominantly categorical and include parent/family member participation in training, parent/family member educational background, socioeconomic status, barriers to future planning, residence within the United States, and language(s) spoken at home. These variables were considered in relation to the dependent variable.

Data Analysis

Survey Findings

A total of 16 survey responses were received and 11 responses were included in the analysis. Five of the survey responses were removed from the analysis as the participants did

not answer any of the future planning questions. The low survey response limited the analysis to descriptive statistics and a thematic analysis of the qualitative responses.

In this study, 45% of the respondents identified as a sibling of an adult/child with a disability and 55% of respondents described themselves as a parent of an adult/child with a disability. The ages of the respondents ranged from 30-66 years of age and reside in 5 different states (Alabama, Delaware, Illinois, Michigan, Texas). All of the survey participants identified as both Muslim and female. Seventy-three percent identified as Asian and 27% as Middle Eastern/ North African. Among the respondents, 72% were married. When asked about their health, 92% perceived their health to be good or very good. Ninety-one percent shared that their child or sibling lived at home with them or another family member. Only 9% responded that their family member lives independently with supports.

Most of the survey participants (64%) responded that they are currently the primary support person for their family member. When asked about their current ability to take care of their family member with a disability 64% perceive that they have good or excellent ability to currently care for their family member while 36% said that they feel that their ability to currently support their family member is moderate to fair.

When asked directly about who will provide caregiving to the family member when the primary caregiver is no longer able to fill this role, more than half of the respondents (64%) said another family member would. Approximately, 27% responded that a paid staff member would assume this role.

Table 2
Future Planning Scale Questions
N=11

	Questions	% Yes (n)
1	Created a letter of intent	18.2% (2)

2	Located an attorney knowledgeable about disability issues	27.2% (3)
3	Established legal guardianship for your sibling with a disability	36.4% (4)
4	Established powers of attorney for health care and/or property	27.2% (3)
5	Established a special needs trust	18.2% (2)
6	Identified a successor to follow the current family caregiver	27.2% (3)
7	Looked into a residential program for your child with a disability	9.1% (1)
8	Made residential plans for/with your child with a disability	9.1% (1)
9	Discussed future plans with your child with a disability	18.2% (2)
10	Discussed future plans for your child with a disability with the entire family	36.4% (4)

Although less than half of the respondents participated in the following activities, families that participated in the survey were most likely to discuss future plans with their family (36.4%) and establish legal guardianship (36.4%). Participants were less likely to make residential plans with their family member with a disability (9.1%) or seek residential programs (9.1%).

The Future Planning Scale consists of ten items that were summed to create a Planning Score variable. Families that have completed 4-10 of the planning activities listed above were categorized as *Medium or High Planning*. Families that completed 0-3 of the planning activities listed above were considered *Low or No Planning*.

Education and Future Planning

Table 3

Respondent Education Level and Future Planning Activities

Future Planning Activities	HS Diploma		College Grad		Graduate		Overall Total	
	n	%	n	%	n	%	n	%
Medium or High Planning	0	0%	1	33%	1	17%	2	18%
Low or No Planning (0-3)	2	100%	2	67%	5	83%	9	82%
Total Respondents	2	18%	3	27%	6	55%	11	100%

Among the survey respondents, 55% have a graduate level degree and 27% identified as college graduates. Eighteen percent had a high school diploma. The proportion of college graduates that had medium or high planning was greater than individuals who had a high school diploma.

Income and Future Planning

Table 4

Respondent Education and Future Planning Activities

Future Planning Activities	< \$20,000		\$20,000 -		> \$80,000		Overall Total	
	n	%	n	%	n	%	n	%
Medium or High Planning	0	0%	0	0%	2	33%	2	18%
Low or No Planning (0-3)	2	100%	3	100%	4	67%	9	82%
Total Respondents	2	18%	3	27%	6	55%	11	100%

Household income varied, as 45% of respondents made \$80,000 or less and 55% of the respondents' household income was \$80,000 or more. Forty-five percent of the participants (45%) responded that they are not employed. Respondents were not asked about household size and this limits our understanding of poverty levels among respondents. The pattern that arises from the responses is that the higher the income the greater the proportion of respondents who made future plans with their relative with a disability.

Age and Future Planning

Table 5

Respondent Age and Future Planning Activities

Future Planning Activities	25-45		46-65		66+		Overall Total	
	n	%	n	%	n	%	n	%
Medium or High Planning	0	0%	2	40%	0	0%	2	18%
Low or No Planning (0-3)	5	100%	3	60%	1	100%	9	82%
Total Respondents	5	45.5%	5	45.5%	1	9%	11	100%

Among the participants, family members that were between the ages of 46-65 completed more medium and high planning activities (40%) as opposed to zero among younger and older respondents.

Role and Future Planning

Table 6

Respondent Role and Future Planning Activities

Future Planning Activities	Parent		Sibling		Overall Total	
	n	%	n	%	n	%
Medium or High Planning	2	33%	0	0%	2	18%
Low or No Planning (0-3)	4	67%	5	100%	9	82%
Total Respondents	6	54.5%	5	45.5%	11	100%

Slightly more parents responded to the survey than siblings (54.5 vs 45.5). A higher proportion of parents engaged in medium/high levels of future planning activities when compared to siblings. All of the siblings engaged in a lower number of activities or no planning activities.

English Language and Future Planning

Table 7

Respondent English Language Proficiency and Future Planning Activities

Future Planning Activities	Not Proficient		Proficient		Overall Total	
	n	%	n	%	n	%
Medium or High Planning (4-10)	0	0%	2	22%	2	20%

Medium or High Planning	0	0%	1	33%	1	25%	2	20%
Low or No Planning (0-3)	2	100%	2	67%	3	75%	8	80%
Total Respondents	2	22.2%	3	33.3%	4	44.4%	9*	100%

*Two respondents did not answer question

Approximately, 78% of respondents lived in the U.S. for 10 years or more and 22% lived in the US less than 5 years. A greater proportion of respondents who have lived in the U.S. for 10 or more years (33%- 10+ years and 25%- entire life) completed more activities associated with future planning when compared to respondents who lived in the U.S. for five years or less (0).

A thematic analysis of the two open-ended questions that asked about barriers and needs for future planning revealed that the largest barrier to families is a lack of information. More than half of the respondents replied that the lack of information and specifically, the lack of culturally/ linguistically accessible information made it difficult to engage in future planning activities (55%). Additionally, 18% of respondents also described that financial barriers made it difficult to plan for the future. Others, (18%) explained that planning for the future requires family member engagement however this is an emotionally charged and difficult topic to discuss. Additionally, 9% described the challenges associated with making it through day-to-day obligations that take precedence over planning for the future. Eighteen percent of respondents reported that they have experienced prejudice while accessing services and that this is a barrier for their families. Finally, one respondent described that a checklist may be a useful guide for families about steps to prepare for the future.

Limitations

Unfortunately, the low number of survey responses has limited the analysis and findings of this study. The survey that was developed for this study combines questions from previous studies on future planning that were tested for validity and reliability. However, it is unclear

whether the adapted survey is a valid and reliable tool for the target population (i.e., a population that is not predominately white). The adapted survey for this study was piloted with two individuals. Both individuals identified as Muslim American and one racially identified as South Asian and the other identified as Arab. Both individuals are siblings to a person with a disability and one also identifies as a person with a disability. Although both individuals offered feedback and minor edits were made to the survey based on recommendations, it is necessary that the survey is tested with a larger number of people to ensure the cultural and linguistic appropriateness of the survey tool, particularly since the survey responses in this study were limited in number during data collection. Additionally, the limited response to the survey may indicate the need to find alternative approaches to engage individuals with disabilities and their family members.

Compared to other sampling methods, convenience sampling is relatively easy and can be both low cost and time efficient. A major disadvantage to convenience sampling is that it can lead to over-representation of particular groups and the under-representation of others. For example, this approach may not be accessible to individuals who may not have access to the internet. This strategy also limits the research team's ability to reach families who do not interact or receive services from the provider organizations that distributed the survey flyer. Additionally, families who interact with disability agencies may be more likely to seek out support to plan for the future. All of these concerns can introduce selection bias into the cross-sectional study. This is a concern, particularly if the respondents to the survey are not representative of the general population. Identifying additional strategies to reach families that are not connected to delivery service systems and organizations is necessary to reduce bias and to recruit a sample that is reflective of the entire population. Alternative approaches may include conducting a focus group at community centers that are accessible to a wide range of

community members. Additionally, focus groups can be used to field test the survey and/or generate survey questions that are valid, reliable and culturally and linguistically appropriate for the target population.

As previously mentioned, this study is an exploratory cross-sectional study, and this design has certain shortcomings that makes it difficult to determine the direction of causality. Conducting a longitudinal study that follows individuals with IDD and their families over time may increase the opportunity to identify predictors of future planning and understand the factors that facilitate or hinder families' engagement in future planning.

Finally, a major limitation of this study is that it does not survey individuals with IDD. It is important that any study about IDD involve the individuals who are most impacted by the study findings. Studies about future planning should center the voices of individuals with intellectual and developmental disabilities.

Conclusion

Although this study has limitations, it explores and documents the planning patterns and the barriers experienced by some American Muslim families that are supporting their relatives with disabilities. Future planning is essential to the well-being and quality of life outcomes of people with intellectual and developmental disabilities who may require day-to-day supports and services. This is especially true for people who receive all or many of their supports from aging caregivers.

Additionally, supporting families prepare and plan for the future can reduce the stress and concern about the well-being and quality of life of the individual they support in the event that the caregiver can no longer provide this support. Supporting caregivers of people with disabilities is a national priority established by the US Department of Health and Human Services in their recently published Healthy People 2030. DH-D01 (reduce anxiety and

depression in family caregivers of people with disabilities) is a high-priority public health issue that does not yet have reliable baseline data. Once baseline data are available, the Department states that this objective may be considered to become a core Healthy People 2030 objective.

Although, it is difficult to draw conclusions from this study, however, the findings parallel the current literature on future planning. Few families engage in activities related to future residential and financial planning. Additionally, social factors, such as socioeconomic status and length of time living in the United States may impact family participation and access to planning activities and/or resources. Further research is necessary to improve our understanding of the factors that impact future planning among all families and particularly immigrant families who may not have access to culturally and linguistically appropriate resources. This research can be used to inform the development of culturally and linguistically appropriate resources for future planning that will provide families with additional tools to prepare for the future.

References

- Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018) Family and individual needs for disability supports (v.2) community report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. https://thearc.org/wp-content/uploads/forchapters/FINDS_report-2017-FINAL-VERSION.pdf
- American Association on Intellectual and Developmental Disabilities (AAIDD). (2020). Family support joint statement of AAIDD and the Arc. <https://www.aidd.org/news-policy/policy/position-statements/family-support>
- American Association on Intellectual and Developmental Disabilities (AAIDD). (2015). Community living and participation for people with intellectual and developmental disabilities: What the research tells us. https://www.aucd.org/docs/publications/2015_0723_aucd_aaidd_community_living3.pdf
- Attum B, Hafiz S, Malik A., Shamoan, Z. (2021). Cultural competence in the care of Muslim patients and their families. *StatPearls Publishing*. <https://www.ncbi.nlm.nih.gov/books/NBK499933/>
- Burke M, Arnold C, Owen A. (2018). Identifying the correlates and barriers of future planning among parents of individuals with intellectual and developmental disabilities. *Intellect Dev Disabil*. 56(2):90-100. DOI: 10.1352/1944-7558-117.1.33
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., Lulinski, A., & Wu, J. (2013). The state of the states in developmental disabilities 2013: The great recession and its aftermath (Preliminary ed.). Boulder, CO: University of Colorado, Department of Psychiatry and Coleman Institute, and University of Illinois at Chicago, Department of Disability and Human Development.
- Family Voices. (n.d.). Immigration issues: Ways to ask people about immigration status.

<http://familyvoices.org/wp-content/uploads/2018/06/FV-Immigration-Toolkit-How-to-Ask-about-Immigration-Status-English-8.2017r.pdf>

- Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and other developmental disabilities*, 25(2), 98–109. <https://doi.org/10.1177/1088357610361344>
- Jegatheesan, B., Fowler, S. A., & Miller, P. J. (2010). From symptom recognition to services: how South Asian Muslim immigrant families navigate autism, *Disability & Society*, 25:7, 797-811. DOI: [10.1080/09687599.2010.520894](https://doi.org/10.1080/09687599.2010.520894)
- Lakin, K.C., Larson, S. A., Kim, S. (2011). Behavioral outcomes of deinstitutionalization of people with developmental disabilities: Third decennial review of studies, 1977-2010. *Policy Research Brief*, 22 (1). <https://ici.umn.edu/products/prb/212/212.pdf>
- Mahar, E., Sladen, J., Nitsch, C. (n.d.). Older caregivers of people with intellectual and developmental disabilities. <https://www.giaging.org/issues/older-caregivers-of-people-with-intellectual-developmental-disabilities/>
- McCallion, P, Janicki, M, Grant-Griffin, L. (1997). Exploring the impact of culture and acculturation on older families caregiving for persons with developmental disabilities. *Family Relations*. 46:4, 347-357.
- Nord, D., Luecking, R., Mank, D., Kiernan, W., Wray, C. (2013). The state of the science of employment and economic self-sufficiency for people with intellectual and developmental disabilities. *Intellect Dev Disabil*, 51 (5): 376–384. doi: [10.1352/1934-9556-51.5.376](https://doi.org/10.1352/1934-9556-51.5.376)
- Shikarpurya, S. & Singh, S. (2021). Value them as members of the community: existing support structures in mosques for south Asian Muslim families of children with IDD living in the United States. *Journal of Disability & Religion*, 25:2, 159-180. <https://doi.org/10.1080/23312521.2020.1821863>

Pew Research Center. (2017). Demographic Portrait of Muslim Americans.

<https://www.pewforum.org/2017/07/26/demographic-portrait-of-muslim-americans/>

U.S Department of Health and Human Services. (2010). Rethinking MCH: The life course model as an organizing framework. Concept paper. [https://fhop.ucsf.edu/sites/fhop.ucsf.edu/files/custom_download/HRSAPaperRethinknigMCAH-](https://fhop.ucsf.edu/sites/fhop.ucsf.edu/files/custom_download/HRSAPaperRethinknigMCAH-TheLifeCourseModelasanOngoingFramework.pdf)

[TheLifeCourseModelasanOngoingFramework.pdf](https://fhop.ucsf.edu/sites/fhop.ucsf.edu/files/custom_download/HRSAPaperRethinknigMCAH-TheLifeCourseModelasanOngoingFramework.pdf)

Williamson, H. (2014). Application of family theory in future planning for individuals with intellectual and developmental disabilities: A critical review. *American Association on Intellectual and Developmental Disabilities*.