

Choice within the Israeli Welfare State:

Lessons Learned From Legal Capacity and Housing Services

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Abstract

This chapter examines the way that the choices of Israeli adults with intellectual disabilities are shaped by different disability laws and other state policies in two domains: legal capacity and housing services. In Israel, legal capacity issues are regulated by the 1962 Legal Capacity and Guardianship Law, which has recently been amended to provide preference for supported decision-making alternatives over guardianship. We show how prior to the amendment, the law and its practice infringed on individuals' right to freedom and autonomy, especially given the extensive use of plenary guardianship and lack of meaningful supervision and regulations. An additional concern is related to the limited consideration given to the individuals' voice in guardianship appointment processes. The new amendment moved the Israeli legal capacity system a major step away from this guardianship regime. This positive change is currently very much on paper with several concerns and challenges still in need of being addressed.

With regard to housing services, we first focus on the process through which services are provided to adults with intellectual disabilities and the role assigned to service users in the process. We then describe the current housing solutions available in Israel, from the most common, large congregate facilities to community apartments and family homes. Finally, we show how each of these living schemes affects the individuals' right to choice in their daily lives. We conclude by providing several recommendations that represent initial steps in overcoming some of the aforementioned challenges within the two fields.

Introduction

The freedom to choose is inherent to modern, democratic society. However, as with many fundamental rights, choice has rarely been allocated on equal terms, with people with disabilities being a prime example. Usually perceived as lacking the required reason and capabilities, people with disabilities, especially those with intellectual disabilities (ID), have been frequently denied the right to choose. An increasing body of knowledge has shown that compared to able-bodied individuals, individuals with disabilities, including those with ID, have fewer choices and exercise less self-determination in both minor and major life decisions (Wehmeyer & Abery, 2013).

Assuming that social policy is a key determinant of peoples' choices and informed by a relational, positive, and multifaceted understanding of choice, this chapter demonstrates how the Israeli welfare state has (or has not) promoted the realization of choice among people with ID. In what follows, we provide a definition and conceptualization of choice. Next, we review the Israeli welfare system with regard to people with ID. We then examine how the choices of Israeli people with ID are shaped by different disability and other state policies in two specific domains: legal capacity and housing services. Our analyses are based on secondary literature, unpublished research, laws and regulations as well as interviews with key stakeholders. Note that both empirical and administrative data in the two fields is extremely scant. Where available, these are also employed in the analyses.

What is Choice?

Choice is not a straightforward, consensual concept. Seen from multiple and often contradictory ideological perspectives including neoliberalism, consumerism, empowerment, the new public management tradition and social perspective of

disability — choice is a matter of ongoing debate. In understanding choice, scholars, policymakers, professionals and laypeople have relied on different disciplines, including psychology, social policy, sociology, education and philosophy. With this complexity in mind, this section defines choice and discusses some of its key features and controversies.

Choice is "making unforced selection of a preferred alternative from two or more options" (Stancliffe, 2001, p. 92). This conceptualization stresses three essential elements: the availability of (at least two) options, the freedom involved, and the act of choosing (compared to passive acceptance). Emphasizing the latter, and taking a psychological perspective, Beresford and Sloper (2008) view choice as "the outcome of a process which involves assessment and judgement; that is, the evaluation of different options and making a decision about which option to choose" (p. 2). Moreover, the available alternatives "should have some positive value; hence, a 'choice' between something which is definitely desired and something which is definitely not desired is not a true choice" (p. 2).

Choice as a Relational Construct

Liberal theories understand choice as individuals' ability to evaluate their situation independently. However, drawing on feminist ideas, the disability movement and disability studies scholars criticize this (neo-)liberal notion of choice, arguing that viewing independence as the primary value of personhood neglects other core values such as trust, caring, and interdependence. Moreover, while the common liberal view perceives self-reliance to be a prerequisite for autonomy and choice, both the feminist and the disability movement view relatedness and interconnectedness not as their antitheses, but as their prerequisites (Ells, 2001; Nedelsky, 1989). It is through our

relationships with others in a supportive environment, it is argued, that we acquire the necessary skills and confidence for choice (Lotan & Ells, 2010).

Furthermore, by viewing rationality, individualism and independence, as preconditions for choice, and by stressing that choice can and should be realized in the absence of interference by others, the liberal tradition has historically excluded from the right to autonomy people who need substantial support in the decision-making process, especially those with ID. Lastly, understanding choice and autonomy as an individual enterprise leads to blaming and depreciating those who fail to achieve the liberal ideal of autonomy (Davy, 2015).

Following these critiques, in this chapter we employ a relational understanding of choice that challenges the dependence/independence dichotomy and recognizes that all humans are interdependent (Leece & Peace 2010). This account of choice speaks substantially to the experience of people with ID who “are often able to make decisions for themselves, but not necessarily on their own” (Davy, 2015, p. 140).

Choice in Practice

For choice to be meaningful, it should be realized in practice. Hence, an important conceptual distinction is that between negative and positive freedom of choice. Negative freedom of choice refers to the absence of any restraint that prevents a person from choosing, while positive freedom of choice refers to available resources in order to realize choices, without which choice would remain an empty concept. For example, if the state does not interfere with decisions of individuals with ID to live in the community, but does not make sure they have sufficient material, educational and emotional resources to exercise their choice, we can say that while their negative freedom to choice has not been violated, their positive freedom has (Boyle, 2008; Stainton, 2002). Since a narrow, negative notion of choice runs the risk of obscuring

fundamental inequalities (Fyson & Cromby, 2013), this chapter relies on a positive notion of choice, and views it not only as a civil or political but also as a socioeconomic right (Carney, 2017).

Relatedly, for choice to be practical the individual must also have some familiarity with the available options. This leads us to two other related features of choice: the ability to imagine available options and access to information about them. People with ID may not be able to imagine a wide range of possibilities mainly due to limited past experience (e.g. growing up in institution could result in difficulty imagining an alternative way of life). Second, they may have restricted access to information resulting in limited familiarity with the available options (Björnsdóttir, Stefánsdóttir & Stefánsdóttir., 2015; Shogren, Wehmeyer, Lassmann & Forber-Pratt, 2017). Importantly, and as elaborated below, these two difficulties are not mainly a result of personal deficiency, but rather of social barriers.

Another issue relates to the spheres of life in which choice is to be realized. Here too, we take a broad view of choice and argue that it does not have to be based on consumerist discourse and logic. This citizenship understanding of choice implies that choice does not have to be realized in a market-style mechanism (Glendinning, 2008); and that it can be embedded in all fabrics of citizens' life and not only those related to their role as consumers. Prime examples are the right to choose where to work or whether to vote in an election (Rabiee & Glendinning, 2010).

Social Services for People with Intellectual Disabilities in Israel

Services for people with ID in Israel are mainly under the responsibility of the Ministry of Social Affairs and Social Services. In 2016, close to thirty-five thousand individuals with ID were documented by the ministry (Shalom, Ben Simchon & Goren, 2017). The ministry's responsibility can be traced back to the 1960s, when the Service

for the Retarded was established (1962) and the Care for People with Mental Retardation Law (1969) was passed (Hovav & Ramot, 1998).¹ According to this law, every person suspected of having ID is mandatorily requested to undergo examination by a multi-professional diagnostic committee that determines their condition, treatment, and service needs, including the need for appointing a guardian,² and recommended housing and community services (e.g. employment, health, education and leisure) (Care for People with Mental Retardation Law, 1969). Very few changes have been made in the law since its enactment. One of the more noteworthy was the 2000 amendment, which states that any person recognized by the committee as having ID is entitled to services from the ministry, and calls for priority to community services (Amendment to the Care for People with Mental Retardation Law, 2000).

Another important milestone is the 1998 Equal Rights for People with Disabilities Law. Inspired by the landmark Americans with Disabilities Act of 1990, it entitles people with disabilities to equal rights in all aspects of life without discrimination, as well as the accommodations required for that purpose. Although the first drafts of the law granted people with disabilities the right to community services, in its final form, and due to financial and ideological considerations, the law was narrowed to focus mainly on employment and accessibility rights (Kanter, 2012).

Legal Capacity

In a modern democracy, a key manifestation of choice is *legal capacity*, that is, the right to be recognized as a full person before the law on an equal basis. Legal capacity includes legal agency – the right to make legal decisions for oneself (Flynn &

¹ Welfare services for people with ID were provided by the Ministry before the 1960s. However, the establishment of the service and enactment of the law expanded services dramatically.

² The committee's decisions over guardianship are not anchored in law; only recently, following a public critique, has the ministry instructed the committee to avoid taking such decisions. As of yet, it is too early to ascertain if and to what extent this recommendation is followed.

Arstein-Kerslake, 2014). Traditionally, based on atomistic, individualistic and rationalist conceptions of the self, legal capacity has been contingent upon *mental capacity*. This coupling of legal and mental capacity has led to the appointment of guardians to decide for people assessed or even only assumed as lacking the skills to do so (Glen, 2012). Amongst persons with disabilities, those with ID have been highly prone to this kind of substitute decision-making practice. As elaborated below, this practice raises many concerns with regard to choice, leading the UN Convention on the Rights of Persons with Disabilities (CRPD, 2006) to view legal capacity as an unconditional right and to urge member states to replace guardianship with other, less restrictive alternatives, including supported decision-making (SDM).

In Israel, legal and mental capacity issues are approached via the 1962 Legal Capacity and Guardianship Law (hereinafter: Capacity Law) that has undergone major reform in 2016. As evident from the review below, the reform has taken Israel a step forward in supporting people with ID to realize their personhood and choice. Yet, there are still unresolved questions and challenges.

The Israeli Capacity Law before the 2016 Reform

The Capacity Law declares that "every person is capable of performing legal acts", however it also restricts this right by stating, "unless such capability has been revoked or restricted by law or judgment of a court" (article 2). Accordingly, a guardian may be appointed for persons "unable to look after their own affairs" (article 33). In order to take care of such a person, the court gives the guardian the duty and power to make different legal decisions on behalf of the individual (Ben David, 2015).

Reviewing the law through the prism of freedom of choice raises substantial concerns, some of which are unique to the Israeli experience. These concerns touch on the nature of guardianship, the appointment procedure and supervision of guardians. As

for its nature, guardianship has far-reaching effects on the individual's right to freedom and autonomy. Under this practice, a guardian makes the most important decisions of the individual's life and the individual is no longer considered as having legal status, but rather is "owned" by her guardian and must comply with her decision (Ben David, 2015; Doron, 2010).

Compared to other Western countries, this direct infringement on the individual's autonomy is further extended in Israel. First, although the law states that the authority of guardians should be limited to issues specified by the court, in the great majority of cases a plenary guardian is provided with power over a wide range of decisions including the individual's assets, health, body and personhood (Barel, Doron & Strier, 2015). Second, legal capacity is not static and depends on sociocultural factors (Flynn & Arstein-Kerslake, 2014). For example, while most people do not need to prove legal capacity to enter a romantic relationship, living in an institutional setting where such relationships are limited, or even prohibited, leads to situations where their realization depends on legal agency. As elaborated below, social forces in Israel, primarily housing arrangements, limit the lives of individuals with ID in many different ways. In this kind of geographic exclusionary regime (Soffer, Koreh & Rimmerman, 2017), the lack of legal capacity has even harsher implications. Third, the law provides little in the way of clear guidelines regarding the boundaries of this practice. For example, third parties often ask the guardian's permission for the individual with ID to use services or to allow them perform various acts (e.g. participate in leisure activities or research), although the law itself does not require such permissions. This is often due to legal ignorance and fear of incompliance. Whatever the reason, this de-facto extension of the power entrusted with the guardian leads to "civil death", whereby the

individual is no longer entitled to participate in the community without the guardian's involvement (Dinnerstein, 2012).

Another key concern relates to the guardianship appointment procedure, which in the case of people with ID is frequently the default practice without any prior substantial discussion regarding the appointment and with little weight placed on the individual's preference. This taken-for-granted procedure usually starts prior to age of 18, when the diagnostic committee makes its recommendations. Further, many social services, including housing services require guardianship before serving individuals with ID (Kanter & Tolub, 2017; Ministry of Labor, Social Affairs and Social Services [MOLSA], *Guardianship*, n.d.). At all these initial stages of the appointment procedure, guardianship is framed by the various stakeholders as inevitable and universal.

Based on the recommendation of the diagnostic committee, parents (usually) initiate the appointment of a guardian with the help of a municipal social worker. The social worker writes a report that should be based on opinions of professionals familiar with the individual (e.g. teacher, physician), her family and her own. A letter of recommendation is also provided by a psychiatrist or the family physician who meet with the individual and advise on the individuals' status, ability to take care of their own needs, need for guardianship and ability to understand the meaning of guardianship appointment. The social worker's and physician's report are submitted to the family court that decides on the appointment of a guardian (MOLSA, *Guardianship*, n.d.).

Although the law required the court to hear the person's stand before ruling, in practice this is often not the case, and only individuals deemed capable of understanding the issue and stating their opinion are given this right. Based on random sampling of court files, an Israeli study found that a medical certificate attesting that the individual was unable express her view was included in 95.2% of cases (Doron, 2004). Similarly,

in only about 10% of cases was such a hearing conducted (Tolub & Shlomai, in press). This situation is exacerbated by the lack of state-provided legal representation, leaving most individuals with ID without legal support in protecting their rights and representing their preferences (Doron, 2004, p. 71). Moreover, the wishes of individuals with ID and their family, even when heard by the social worker before writing her report, are also mediated by her. This communication runs the risk of biasing or misrepresenting information. Further, the law does not clarify how much weight should be placed on the individual's wishes within this report or within the judge's decision, such as when the individual refuses guardianship or a specific guardian. Finally, even when the individuals' voice is heard, they are usually not given any real alternatives. On the one side, there was the threat of being subjected to guardianship and losing one's legal capacity. On the other hand, given that before the reform SDM alternatives were not recognized by the Israeli legal system, there was a threat of being left with no formal and recognized support to enable people to exercise their legal capacity.

Although not specific to ID, in approximately 85% of cases the appointed guardian is a family member, while in the remaining 15% the guardian is employed by a legal guardianship corporation (<https://brookdale.jdc.org.il/regulating-guardianship/>). Once a guardian has been appointed, another concern has to do with how the Israeli legal and welfare systems ensure that guardians, whether family members or corporation's employees, act not only for the (presumed) benefit of the individual, but also according to their will and preferences. This involves three key issues. First, as stated by the State Comptroller repeatedly throughout the years, the state's supervision of guardians (e.g. State Comptroller, 2012). An illustrative example for this "regulatory deficit" (Levi-Faur, Gidron, & Moshell, 2015) is the fact that in 2017, less than half the guardians have submitted the required annual report (Derech, Rotler & Tolub, in press).

Second, supervision is limited to financial and property issues, leaving important issues such as personal matters unsupervised (State Comptroller, 2012). Third, these financial requirements focus on protecting the person's "best interests" rather than her choice. In fact, prior to the reform, the only reference in the law to the individual's will required the guardians to hear the individuals' opinion "as long as they are capable of understanding the issues at stake and their opinions can be understood" (Article 36 of the Legal Capacity and Guardianship Law, 1962). Lastly, very few resources have been invested in supporting guardians, especially family members, in fulfilling their task, and particularly their ability to understand and represent the choices of the individual with a disability.

The Amended Law and its Implications for Choice

Given the above criticisms and thanks to the combined efforts of civil society organizations, led by Bizchut: Israel Center for Human Rights of People with Disabilities, an amendment was enacted to the Legal Capacity Law in March 2016 (Kanter & Tolub, 2017; Tolub & Shlomei, in press). The amendment included several significant progressive changes, which refer to the nature of guardianship, the guardians' appointment procedure and the extent of their use. These changes moved the Israeli legal capacity system a major step away from the previous guardianship regime to a new "support paradigm" (Series, 2015), in which support is provided in order to enable people with disabilities to exercise their legal capacity on an equal basis with other citizens. However, these positive changes still exist only on paper, and as detailed below, they too raise important concerns and challenges (Kanter & Tolub, 2017; Soffer, Koreh, & Rimmerman, 2017).

A key change is that the law adopts the "necessity" and "last resort" principles by stating that guardianship must only be used if it is necessary in order to protect the

person's interests, rights and needs, and only after considering other, less restrictive, options. Moreover, the amendment obligates judges both to limit the term of guardianship appointments and to restrict the authority of guardians to specific areas of need (e.g., medical, personal, or property issues).

Alternatives to guardianship, first and foremost SDM, are now recognized as legitimate legal practices.³ The aim is for SDM to allow persons with ID to make their own choices about their life while getting support from others who can explain the issues, interpret the individuals' words and behaviors, and understand their preferences, desires, and choices (Blanck & Martinis, 2015; Devi, 2013; Dinnerstein, 2012; Shogren et al., 2017). This is designed to help people with diverse needs to exercise their right to legal capacity. In accordance with Article 12 of the Convention for the Rights of Persons with Disabilities (CRPD, 2006) and its relational understanding of decision-making and choice, the underlying rationale is that support and relationships are not a threat but often major facilitators of legal capacity and choice, particularly for people with ID (Series, 2015; Browning, Bigby & Douglas, 2014).

Another set of changes touches on the proper conduct of guardians. Most importantly, the amendment states that their decision-making should be guided by the wishes of the individual subjected to guardianship. When these are impossible to determine, or when individuals are not in a condition to understand the issue involved, the guardian is obliged to act in accordance with their will as expressed prior to their current condition or in accordance with their past actions. The only reservation is in cases where the guardian has reason to believe that deciding according to the individual's explicit or implicit wishes may cause real harm. Relatedly, the new

³ Another key alternative recognized by the new amendment is enduring powers of attorney, which are not within the scope of this chapter.

amendment provides people under guardianship with several key rights, from receiving information from the guardian, through providing free legal representation in medical decisions, to securing the rights to independence and privacy.

These changes seem to hold real promise for the freedom of choice of people with ID, particularly in challenging the previous automatic resorting to guardianship. The amendment, however, is not without flaws.

First, although appointing a guardian has been restricted, and although the new changes (potentially) challenge the automatic appointment procedure, it has not been repealed and consequently it is yet unclear to what extent, if at all, judges and social workers will embrace this change and limit their use of guardianship. This concern is exacerbated by the fact that despite the demand by organizations that represent persons with disabilities, the new amendment does not include the individual's will as a *crucial* factor in the appointment decision, leaving this decision based entirely on professional discretion. Added to this is the fact that the reform does not touch upon the practice of social workers and the way they should integrate an individual's will into their assessments of decision-making capacity. As Browning et al. (2014) rightly remind us, the SDM regime requires these assessments to include the support provided to the person; without this interdependent redefinition of mental capacity, "the full potential of the concept will not be realized" (p. 41). Further, the law still does not mandate that the individual involved appear in the legal proceeding, nor does it require or subsidize their legal representation. All these not only violate the freedom of choice of people with ID, but run the risk that the restriction on using guardianship will remain a dead letter.

An additional set of concerns has to do with the proper conduct of guardians. According to the new amendment, the wishes of the individual should be the primary

guiding principle in the guardians' decisions. However, studies in other countries have highlighted the difficulty in making decisions that are based solely on the wishes of the individual. Specifically, studies have shown that in making decisions some carers also employ their own views on wider social norms, their own values or what they perceive as the individual's wishes (Dunn, Clare, & Holland, 2009; Williams, Boyle, Jepson, Swift, Williamson, & Heslop, 2012). Given the above-mentioned "regulatory deficit" of the Israeli legal and welfare systems, the fact the supervision is limited to financial and property issues, and the low level of support for guardians in fulfilling their tasks, it is questionable to what extent this progressive change will not be only on paper.

Other concerns deal with the the proper implementation of SDM. First, although the amendment gives legal standing to supporters, due to budgetary constraints, the amendment and its current guiding principles⁴ do not say anything about their funding. Hence, people whose family has limited means or who do not want to rely on their family will hardly be able to benefit from SDM in practice. The result is that, if given the opportunity to do so at all, many individuals with ID will be forced to "choose" between making it on their own or to be subjected to guardianship.

A second concern is related to the quality of supporters. According to the new guidelines, supporters are required to take part in a formal training course that should cover such issues as social perspectives of disability. These trainings, however, are relatively short-term, target non-relatives, and do not provide field training. Further, these training of only just began and there is yet no available data on their utility or efficacy. Relatedly, the current regulations do not offer any kind of substantial, formal training for the person asking for support. A recent pilot study found that this kind of

⁴ At the time of writing, although the law mandates regulations, these have not yet been promulgated.

training is helpful in understanding the new SDM tool (Holler, Werner, Lester-Keidar, Wasser & Ronen, 2017). More broadly, most of the international research on SDM has adopted normative or policy analysis methodologies, while systematic, empirical evidence on what really works and how is scarce, posing a real challenge to the development of proper training and supervision for supporters (Arstein-Kerslake, Watson, Browning, Martinis & Blanck, 2017; Bigby et al., 2017; Shogren et al., 2017).

A final concern regarding the implementation of SDM is in how third parties (e.g. physicians, banks) will embrace this new tool. These third parties, as well as the public, may continue questioning the ability of individuals with ID to understand and exercise choice. This questioning may also be fueled by fear that in situations involving risk, they might be at blame for decisions made. Thus, “old” guardianship alternatives may be required, or at least the permission of the individual’s relative, before providing services to the individual.

Housing Support Services

An additional and central field of social policy with significant repercussions for choice is housing support services. In this section, we focus on the process through which housing services are approved and how they affect the freedom of choice of service users with ID.

Procedures for Obtaining Housing Services and their Implications for Choice

Housing services for people with ID in Israel are provided through the Care for People with Mental Retardation Law (1969). Once an individual is diagnosed with ID, the diagnostic committee recommends the type of housing service that meets their needs. This recommendation is made based upon information provided to the committee by the family and the social worker as well as upon a series of assessments

made by professionals from the committee regarding the individuals' level of ID, capacities and preferences.

While originally the law did not grant any statutory right to housing services, since 2000 they are provided as rights. Moreover, as part of public demand for deinstitutionalization, the 2000 amendment obligates the diagnostic committee to give priority to community-based services (Amendment to the Care for People with Mental Retardation Law, 1969, 2000; Kanter, 2012). Nevertheless, this deinstitutionalization reform is still in relatively early stages. As shown below, most people who receive housing services still live in institution-like settings.

After the diagnostic committee selects the type of housing support, a local placement committee provides the individual and his family with two to three concrete alternatives. These alternatives are based on a range of considerations, including the individual's cultural background, perceived needs, availability, and proximity. Next, the individual and his family (guardian) are invited to visit each setting, participate in an admission committee and select the setting that best fits their wishes and needs.

This procedure raises some major concerns regarding the realization of choice. First and most directly, while the diagnostic committee is obliged to hear the individual and his guardian and consider their wishes, neither the law nor ministerial regulations clearly specify how much weight should be placed on these wishes. This flaw is even more significant given that in practice, the decision over the type of housing support is guided not only by the individual's needs, but also, and perhaps mainly by the availability of services and resources. This leaves little room for the individual's preferences, especially when these differ from those of professionals. No less problematic are cases where the individual's preferences differ from those of the family. The fact that many family members are also appointed as guardians gives rise to

situations in which the guardian's wishes receive priority and these are often wrongly considered as representing those of the individual with ID.

The role of the local placement committee is even more problematic as this committee is not anchored in law, but ministerial regulations. Although these regulations empower the committee to meet with the individual and her family, this is not mandated. Thus, in reality, many committees never see or hear the future resident before determining placement alternatives, and even if they do, as with the diagnostic committee, regulations do not specify state how much weight should be placed on individual's wishes.

Another procedural flaw concerns the relational nature of choice. Even if the individual's voice is heard and their wishes taken into account, in order for choice to be exercised service users may still need support in imagining and understanding the available alternatives and in making sure their voice is properly articulated and encouraged. This support is even more important for individuals who are non-verbal or of lower functioning, for those who have lived in institutions for years without gaining firsthand knowledge about community-based services, and in situations in which this wish diverges from that of other stakeholders, including the family. In Israel, a key potential player in providing this support is the municipal social worker. Although little is known about the actual exercise of this responsibility, , the large caseloads of municipal social workers are a barrier to establishing high-quality relationships with clients (Krumer-Nevo & Barak, 2007) and prioritizing what are perceived by policymakers as non-urgent tasks.

Similar difficulties arise when individuals wish to move from one housing setting to another. While the diagnostic committee is legally required to convene every three years, it usually only meets on demand (Lef & Rivkin, 2015). Thus, much

responsibility is placed on the residential social worker who is (theoretically) responsible for helping individuals understand their right for re-diagnosis, available living arrangements, and potential impact on their lives, initiating the procedure and making sure their voices and wishes are articulated and encouraged. Here too, little is known about the actual exercise of this responsibility. However, the inherent tension between the social workers' obligation to residents and to service providers places many social workers in a conflict of interests (Lev & Ayalon, 2015). The growing privatization of housing services (Madhala-Brik & Gal, 2016) only exacerbates this dilemma.

An additional problem is that the placement committee typically provides few options. This problem is exacerbated given that residential settings in Israel are unequally distributed among regions, cities, and neighborhoods (Rimmerman, 2017; Yogev, Yogev & Man, 2012). According to a yet unpublished study by the authors, some families even relocate in order to use services provided elsewhere. In many other cases the individual and her family choose not to make use of any of the options offered by the placement committee (Ben Ari, 2016; Klarman, 2004). This may be related to preference for a different type of housing than that selected by the diagnostic committee or discontent with specific options offered. Importantly, this refusal also implies that the decision to stay and live within the family home, as most people with ID do (see next section), is not necessarily the result of real choice.

The options offered by the placement committee are further limited by the monopoly of a relatively few number of providers within the Israeli assisted living market, leaving little room for "shopping". For example, 93% of the ministry's payments to residential settings in 2015 were made to only 10% of the providers (Madala-Brik & Gal, 2016).

Housing Alternatives

A persistent finding in the choice literature is that the type of housing, including its level of segregation and size, is a key predictor of choice opportunities for people with ID. In particular, a substantial body of research indicates that smaller, community-based settings generally provide more opportunities for choice than larger, congregate facilities (Kozma, Mansell, & Beadle-Brown, 2009).

In Israel, despite some recent deinstitutionalization efforts, residential services are still heavily institutional. Three kinds of institutional settings are available. The most common and problematic one is *meonot* (literally, “institutions”). Essentially, *meonot* are large-scale settings that meet Goffman’s (1961) description of “total institutions” as breaking down the barriers ordinarily separating the three main spheres of life: living, working and leisure. The 63 *meonot* in Israel vary widely in terms of population (e.g. age, religiosity, ethnicity, level of functioning); size (35 to 290 residents); and location (urban or rural, central or peripheral) (MOLSA, *Housing in a maon*, n.d.). They are uniform, however, in their Goffmanite bureaucratic logic.

While *meonot* date back to the early years of statehood, during the seventies, a new kind of institutional service – the hostel – has been established. Hostels are formally defined as housing between 12 and 34 residents (Shalom, Ben Simchon, & Goren, 2015). Unlike *meonot*, some of the services are provided in the community including leisure services and work settings.

The third and most recently developed type of institutional setting is called “branches”. These settings house up to 24 residents and are located within the community. However, “branches” are not only larger than bona fide community settings but are also organizationally part of the *meonot*, with residents receiving most (if not all) of the medical, employment and leisure services from the *meonot*

(Rimmerman, 2017; Shalom et al., 2015). Similarly, the “branches” share their staff and other resources with the *meonot* with which they are affiliated.

Movement towards community settings, formally defined as housing up to six residents (Shalom et al., 2015) began in the 1980s. Known as community apartments, these settings are owned or leased by an agency (NGO or for-profit), and are supported by the agency’s staff with varying degrees of intensity, according to the residents' needs. Residents are supposed to obtain many of their daily services from the community. Due to a recent change in the ministry’s policy, in recent years we have seen a slight rise in the number of people living in community apartments. Numerically speaking, however, this solution is still marginal, and this is especially true for people with greater needs.

Taken together, out of those living in supervised settings, 7,319 (68.4%) live in *meonot* and their branches and 1,924 (18%) in hostels, representing about 90% of the ministry’s spending on residential services. Only 1,456 (13.6%) live in community apartments (Shalom et al., 2017), representing only about 10% of the ministry’s spending on such services (Response of MOLSA to Freedom of Information Application, 2017). As elaborated below, most individuals with ID in Israel of all ages (68%) live at home. Although not enough data are available, it seems almost none of them live on their own or with roommates, but rather with parents or other family members. As we explained below, with regard to realizing choice, they too face many barriers.

Choice within *Meonot*, Hostels and “Branches”

Living in larger-scale institutions such as *meonot* poses many fundamental challenges for the realization of choice. Moreover, and as the experience of many European countries reveals (Mansell & Beadle-Brown, 2010; Mansell, Knapp, Beadle-Brown & Beecham, 2007), while being somewhat smaller in size and integrated in the

fabric of community life, in practice the organizational logic of small, modernized institutions such as hostels and “branches”, is in many ways similar to *meonot* and Goffman’s (1961) “total institution”. Among other things, the care provided in these settings is characterized by depersonalization, rigid routines, block treatment, and social distance between staff and residents (Mansell & Beadle-Brown, 2010).

In this section, we will highlight some of the implications of these kinds of care settings with regard to choice. Note that some of these are a result of the organizational logic that characterizes institutions in general and do not reflect weaknesses in managing these settings. Others are unique to the Israeli scene and are exacerbated due to the ministry’s policies and the management of the particular settings (e.g. Berenstein, 2011).

In order to manage everyday life, institutions serving many residents with diverse needs tend to enforce uniform norms and strict daily routines. Israeli residents at institutions, especially *meonot*, are provided specific times for activities, regular eating times and a fixed diet, regular sleeping hours, and participation in shared leisure activities. Residents are also expected to go to work each morning (usually within a sheltered workshop), even after retirement age (Lerner, 2008; Schwartz, 2003). Norms that are uniformly enforced require a high level of discipline. Residents are usually expected to conform to various rules, that are not applied to people without ID. In Israel, these include, for example, strict visiting hours, limited freedom of movement within and outside the institution, and limited opportunities for communication with the outside world, including access to digital media.

In addition, most institutional services, including health and leisure services, are provided in-house, or at least in a one-size-fits-all model. In this kind of block treatment, the individual lacks control over service design and is denied the right to

obtain supports within the community. This is even more so within institutions located far from the community. In some cases, the individual cannot even choose between the few alternatives available.

An additional key domain of choice relates to selecting the specific room an individual occupies and his or her roommates. Due to budget and space considerations, most rooms in institutions are shared between two to three roommates, and the choice of roommates is not theirs to make. Relatedly, living with a romantic partner is usually not a real option. More generally, privacy is a rare commodity. Living in a shared room, sharing a bathroom, having limited private space, being exposed to constant professional gaze, and forced to share information regarding your medical and psychological condition all lead to loss of privacy. This limits choice in various subtle and not-so-subtle ways, perhaps the most critical of which is the difficulty forming and maintaining intimate relationships and engaging in sexual activities (Hollomotz & The Speakup Committee, 2009).

Staff, especially direct care workers, are also highly influential in the realization of choice. As Goffman (1961) reminds us, total institutions tend to create social distance and a stratified social hierarchy between staff and residents. Within these unequal power relations, little room is left for residents to exercise choice and control over their lives. The restriction of choice by staff members is not, however, (only) a straightforward result of the institutional logic, but also stems from various policy and management variables, including staff working conditions, quality of training, and formal and informal guidelines and policies (Finlay, Walton & Antaki, 2008).

Specifically, several features of the Israeli residential care system have negative repercussions for choice. First, direct care workers in institutional settings come from low socioeconomic backgrounds and possess few academic qualifications. They are not

paid well, and work in very high-demand and stressful environments with low staff-to-resident ratios (Zakash & Gilad, 2010). Although employers rank trained direct support workers higher in their professional performance, including their ability to effectively support persons with ID to make choices (Barlev & Rivkin, 2016), most direct care workers are undertrained. While the ministry offers formal training, only approximately 30% of all residential care workers receive it (Barlev & Rivkin, 2016). This is because training is not mandatory, requires the employers' permission and recommendation, is offered only to veteran workers with more than 11 years of education and is usually paid for by workers themselves.

The performance of residential services reflects weaknesses in government regulation. Such services are primarily regulated by the outdated Supervision of Institutional Residences Law of 1965. Both the law and its regulation lack real enforcement mechanisms. More importantly, both focus almost entirely on setting health, safety, and hygiene standards at the expense of more subtle care issues, including choice. Geared towards protection rather than empowerment, the regulatory system is further weakened due to its other features including very limited attention to service users' input in the auditing process; inspectors' high work load; lack of clarity in defining the role and guidelines of inspectors; and lack of an independent ombudsman (Lahat & Talit, 2015; Rimon-Greenspan, 2014). In the absence of effective regulatory arrangements, and in a heavily privatized market, the performance of residential settings with respect to choice and related issues is at risk of being quite poor (Berenstein, 2011).

Choice in Community-Based Apartments

Studies in countries where the deinstitutionalization reform has already materialized repeatedly show that compared to larger, congregate settings, more

personalized, smaller, community-based services tend to provide their residents with more opportunities for choice and control (Kozma et al., 2009; Stancliffe et al., 2011). The relatively few studies conducted in Israel also indicate that residents of smaller settings report greater control of various decisions in their lives, such as the food they eat, their home styling, when to be visited by family and friends, the daily schedule and what to do with their money (Berenstein, 2011).

Nevertheless, as the experience of other countries shows, living in community-based settings does not guarantee that the institutional mindset has vanished and that high levels of choice-making is realized (James, Harvey, & Mitchell, 2018; Kozma et al., 2009). In Israel, this is due both to the nature of the community apartment services, and the way these services are designed, operated, and regulated.

One key concern is that although apartment and services are provided within the community, ownership and responsibility remain with the service provider. This leads to risk for the infringement of choice with respect to various issues, including how many residents will live in a room, who will be the room- and house-mates, when and where to go for vacation, and more. It should also be noted that most agencies are privately run and are funded according to the number of residents they support, while not required by the ministry to provide services according to the individuals' wishes.

The weak regulatory system described above also plays a key role. Based on an outdated piece of legislation focused on protection rather than empowerment, this regulation is doubly irrelevant to monitoring a rights-based community housing. Lastly, here too lack of training and low working conditions for the staff run the risk of providing low-quality care, with insufficient attention to residents' choice opportunities.

Choice within the Family Home

As suggested above, most individuals with ID in Israel remain at home, usually with their parents or other family members. Although the family home is considered by the ministry to be the most preferable and community-based setting, allowing for the greatest degree of autonomy, a closer look reveals that in practice this living arrangement is associated with major choice-related concerns, mainly due to poor policy design.

The state provides various community-based services to those living in their own homes or with family, including (usually sheltered) employment, day settings, leisure services and respite care. These, however, are not anchored in law but in ministry regulations, based on discretionary decisions, offer little (and in many cases no) alternatives from which to choose, and are standardized in nature. Moreover, these services include little in-home support. The ministry also offers some individuals personal assistance, but this is limited to 30 hours a month for up to six months. Further, unlike many Western countries, the Israeli welfare state does not operate any nationwide personal budget scheme allowing individuals with ID to control and select services according to their needs (Rimmerman, 2017). It also does not subsidize supported living – an arrangement in which individuals with ID live on their own or with roommates of their choice, in housing they own or rent, while receiving in-home support from providers who do not control the accommodation (Mansell & Beadle-Brown, 2010). All in all, the ministry devotes only about 16% of its housing budget to the majority of individuals with ID who live at home (Shalom et al., 2017).⁵

It is also important to acknowledge that the cost of living in Israel is very high, and this applies primarily to rental prices. Although individuals with ID are entitled to

5. The above information is processed from the data on page 389. The rest of the budget is designated to other functions such as diagnosing.

government subsidies, these fall far short of their expenses. Thus, without the family's support, such individuals cannot rent an apartment in the private market.

The described state of affairs affects choice in several ways., Due to the limited in-home support and lack of state's subsidies for supported living, individuals with ID do not have a real option to live on their own or with their partners, as most adults usually prefer. Research from other countries has also acknowledged that living in countries with particularly high costs of living potentially reduces choice opportunities for people with ID (Houseworth, Ticha & Stancliffe, 2018). Combined with the fact that the option of community apartments is also very limited, this means that the decision to live with family members is usually made due to lack of more attractive alternatives. Note also that the option of living with the family is not one that is equally available to all, as it depends on the family having adequate financial and other resources. Individuals whose families lack these resources are often forced into institutional settings (Nasser, Sachs, & Sa'ar, 2017).

The low level of state support provided to persons with disabilities requires the individual to be heavily dependent on parents and other family members for support. which can lead to these individuals exercising undue control over the individual's daily life. Finally, lacking any nationwide personal budget scheme means that service users have little control over the services they utilize.

Conclusions

In this chapter we sought to better understand how Israeli social policies impact upon the freedom to choice of individuals with ID. By taking a relational, positive, social, and multifaceted understanding of choice and focusing on two key policy domains – legal capacity and housing – our analysis highlights the decisive role of these policies in shaping opportunities for choice. Taken together, this analysis points to the

vast gap between Articles 12 and 19 of the CRPD (2006) and the freedom of choice provided to people with ID in Israel.

Within the legal capacity realm, we have shown how guardianship limits individuals' right to freedom and autonomy. This restriction is exacerbated due to massive use of plenary guardianship and the lack of clear boundaries with regard to guardians' authority. Another infringement of the individual's right to freedom lies in the process of appointing a guardian, in which the individual's voice is not only rarely heard, but guardianship itself is perceived and framed by professionals as the only possible solution for people with ID. The recent reform, and the establishment of SDM as a legal tool, surely carries vast potential for transforming this guardianship regime and for bringing about greater choice. However, as we have shown, several concerns must be addressed in order for this new policy not to become "another tick box exercise" (Arstein-Kerslake et al., 2017, "The Danger Zone" para. 2) with little meaningful change in the lives of people with disabilities.

In relation to housing services, our analyses highlight how choices of individuals with ID are limited at many points in the process via which housing is provided, from the diagnostic committee, through the local placement committee and in everyday decisions within specific settings. The main drawback relates to the way the individual is heard at various stages of this process – if at all. Most Israeli individuals with ID who live outside the home live in institutional settings. Within such settings, choices are highly restricted given that uniform norms are enforced and that most services are provided strictly within the institution. While smaller, community-based apartments provide residents with more opportunities for choice and control, they too suffer from flaws. Finally, although most individuals with ID still live within the

family home, our findings point to the coercive elements found in this kind of setting as well.

The two policy domains discussed above are closely related. For example, having the right to full legal capacity is a necessary (albeit not sufficient) condition for deciding where, with whom and how to live. Conversely, while the lack of in-home support and personal budgeting acts as a barrier for those wishing to live by themselves, this barrier is also greatly influential with regard to supporting people with ID in decision-making.

Before discussing our recommendations, several limitations of our analysis need to be considered. Despite being central to shaping the opportunities for choice in peoples' life, neither legal capacity policy nor housing policy are sufficient to enable people with ID to realize their freedom of choice on an equal basis with others. Additional policies not discussed here, such as self-determination interventions in school, disability benefits, contract and criminal law are important as well. In addition, , similar to some European countries (e.g. Germany and Austria), when it comes to legal capacity, policy, and housing services for people with ID, systematic and robust empirical and administrative data are extremely scant in Israel.

What works?

In this last section we would like to provide several recommendations in an attempt to overcome the abovementioned challenges. The Ministry of Social Affairs and Social Services and the Ministry of Justice need to provide knowledge and training to social workers, judges and other helping professionals on the legal amendment that in theory supports the rights of persons with ID to choice. This is necessary in order to challenge the long-lasting tendency of these professionals to embrace guardianship as the default solution for people with ID. Moving away from the guardianship regime

also requires the Israeli welfare state make sure that no one is left behind and support in exercising legal capacity is provided according to need.

Development of proper training and effective regulation over supporters is needed so that SDM does not in itself become a guise for exploitation and manipulation. This will be a challenge given that the SDM is a new policy tool that has hitherto rarely been implemented and more rarely studied. Thus, it will be useful for Israeli policymakers to learn from recent international developments and models (e.g. Bigby et al., 2017; Douglas, Bigby, Knox & Browning, 2015; Shogren, Wehmeyer, Uyanik, & Heidrich, 2017).

Full and effective implementation of all the above recommendations may enable Israel to reach the next point in the transition towards a support paradigm. Although the changes made so far in Israeli law allowed for massive steps forward towards the realization of CRPD's Article 12, the mental and legal capacity nexus has remained intact and, accordingly, left guardianship as a legitimate, if not default legal alternative. In order for Israel to realize the vision of Article 12, legal capacity must be treated as an unconditional right. Among other things, this will require Israel to decouple mental and legal capacity and reduce the prevalence of all forms of substituted decision-making, including that of guardianship.

Even more than in the legal capacity field, Israel still has a long way to go to realize the CRPD in relation to housing. A first major step towards that end is for the Ministry of Social Affairs and Social Services to determine a deadline by which all forms of institutions will close. Although an expert committee has already made that recommendation (Blanck et al., 2011), it was not followed.

We also call for the provision of living alternatives other than in out-of-home placements. This includes developing a generous personal budgeting scheme. In order

for these types of living arrangement to become a real alternative for people with ID, high rental costs in Israel will need to be taken into consideration. Several attempts have recently been made to translate the rights to community living and personal budgeting into the Equal Rights Law and efforts must be made to realize that vision (Blanck et al., 2011; Magor, Sandler-Lef, Stern, & Tolub, 2017; Proposed Amendment for the Equal Rights Law [Community Housing and Personal Budget], 2016).

Finally, it is important to acknowledge that laws reflect attitudes and perceptions. At the basis of the overuse of guardianship and institutional living lie social perceptions that do not recognize persons with disabilities (especially those with ID) as having equal rights, including the right to choice. Changing this perspective requires many steps, from education through affecting public and academic discourse. At the policy level, the first step would be to replace the outdated Care for People with Mental Retardation Law with new legislation more in line with the right-based perspectives of disability and the CRPD (2006). The right to choice, autonomy and control must be placed at the center of the new law and the services provided thereunder.

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