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## Evaluation of the Dementia Programme

World Jewish Relief

Final Report

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impact

This evaluation was performed by Key Impact in cooperation with Info Sapiens Ukraine. The team comprised five Evaluators (Dr. Yuval Ofek, Krisztina Varga, Alina Volkova, Oleh Koval and Dmytro Sydorenko). This report is the sole product of its authors, and responsibility for the accuracy of data rests with the authors alone. The findings, interpretations, and conclusions presented in this report do not necessarily reflect the views of the funder or the implementing organisations.

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## List of Abbreviations

FGD	Focus group discussion
FSU	Former Soviet Union
JDC	American Jewish Joint Distribution Committee
ToC	Theory of Change
ToR	Terms of Reference
ToT	Training of Trainers
WJR	World Jewish Relief

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## Preface

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Key Impact, in collaboration with Info Sapiens Ukraine, has performed an evaluation for the Dementia Programme, established by World Jewish Relief and implemented in partnership with Jewish Care and the American Jewish Joint Distribution Committee (“the Joint” or “JDC”) at various Heseds<sup>1</sup>. Running since 2015 in Ukraine, Belarus, Moldova and Georgia the programme set out *“to improve the wellbeing of older people in the Jewish community living with dementia and/or disability through enhanced quality of care and increased understanding.”* The evaluation was carried out over the course of three months, in January-March 2024. The primary audiences for this evaluation report are the funders, implementers and supporters of the Dementia Programme, WJR staff members and the management and implementation teams at the various Heseds. The report consists of four chapters:

- Chapter 1 describes the context and the programme evaluated.
- Chapter 2 presents the scope of the evaluation, with its approach, methodology and limitations.
- Chapters 3 presents the evaluation findings on the following issues:
  - Relevance
  - Intervention models
  - Results among Hesed workers and volunteers
  - Results among family caregivers
  - Results among people living with dementia
  - Results among other organisations and partners
- Chapter 4 concludes, identifies lessons learnt and lays out forward-looking recommendations.

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<sup>1</sup> Heseds are Jewish social welfare organisations operating in the former Soviet Union.

## Chapter 1. Context and Programme Description

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### 1.1 Context

World Jewish Relief (WJR) has been supporting Jewish communities in the former Soviet Union (FSU) since the 1990s, with a primary focus on providing for the well-being of older people. The number of older people (aged 65+) in the FSU region is fast growing, while the proportion of the population made up of children and those of working age is shrinking, leading to an aging demographic profile and a disproportionate increase in the dependency ratio (Koziel et al., 2021; Mehrabian et al., 2019). Given that the primary risk factor for dementia is old age, the condition is becoming a severe societal challenge in the region. Members of the Jewish communities in FSU countries tend to live longer than the general population, making them even more vulnerable and at risk of developing dementia.

According to a 2019 report that estimated the prevalence of dementia, there were about 140,000 people in Belarus, 47,000 in Moldova and 650,000 in Ukraine living with dementia (Nichols et al., 2022). These form the main target countries of WJR's Dementia Programme. Underdiagnosis remains a common challenge in the region. The Nezabutni Foundation reports that undiagnosed dementia may account for up to 94% of the cases in Ukraine, while other researchers estimate the actual number of people living with dementia in Belarus to be at least four times higher than the relevant figure in state records (Zborovska, 2022; Egsevneev, 2021).

Continued increase in life expectancy, coupled with population ageing, further compound the likelihood of people developing dementia. Mehrabian et al. (2019) estimate that the number of people affected by dementia is expected to rise by 50% between 2015 and 2030 in Eastern Europe. Other reports put the increase at 80% in Belarus, 155% in Moldova and 55% in Ukraine by 2050, increasing the total number of dementia cases at least by two thirds in these countries (Nichols et al., 2022).

WJR and the literature review have identified a range of challenges that people with dementia and their carers face in FSU countries, including the following:

- Despite the growing societal challenge represented by dementia, a void is evident as far as state-wide strategies or actions on the condition in the health and social care policies of the target countries.
- Moreover, there is a lack of understanding or misunderstanding when it comes to the basics of dementia, leading to misconceptions and widespread stigmatisation in the wider societies.
- Timely medical diagnosis of dementia is largely absent and usually no differentiation is applied when it comes to the different types of the condition. When the different types of dementias are detected, vascular dementia is often mis- or over-diagnosed, while other forms, such as Alzheimer's disease, often remain underdiagnosed.
- There is a lack of specialised institutional care for people living with dementia: residential, respite and day care services are largely insufficient and the majority of people with dementia are looked after in their own homes (by family members), rather than in institutions.
- In dementia care, there is an overemphasis on '*prevention*', as opposed to how to live with the condition. Moreover, there is a lack of person-centred approaches and suitable activities available for people with dementia at their home and/or in institutional settings.

- Caregiver support is limited and it is usually concentrated in urban areas. Due to the lack of adequate social support, there are frequent conflicts at home between individuals with dementia and their caregivers, leading to burnout among family members. The fact that people with dementia in the target countries are often looked after by a single person further exacerbates the pressure on family members.
- There are challenges in the physical environment for older people in FSU countries in general, and for people living with dementia in particular.
- There is a lack of dementia-specific post-graduate education available for medical and social care professionals involved in the frontline work with people with dementia, such as GPs, nurses, social workers and occupational specialists.

## 1.2 Programme description

### 1.2.1 Programme goals and activities

To address the context and challenges outlined above, WJR, in partnership with Jewish Care and the JDC, embarked on a programme focused on improving the lives of older people living with dementia and on building the capacities of social care professionals and family caregivers, as well as the general public, to support Jewish communities. The Dementia Programme has been implemented mainly by local Heseds in three countries (Belarus, Moldova and Ukraine) and at four key locations, including Minks, Chisinau, Kyiv and Kharkiv, with additional activities and partners involved across Ukraine, as well as in Georgia.

The specific objectives of the programme according to the ToR were:<sup>2</sup>

- *"To build the capacity of the Jewish community caring for older people those living with dementia and/or disability through enhanced quality of care and increased understanding."*
- *"To make Jewish communities more 'dementia friendly' and accessible for those with disabilities in the long term."*
- *"To support the development of better social care for future Jewish generations."*

In order to advance towards its goals, the programme implemented a range of activities:

- A series of training courses (eight in total) were held in the four key locations, focusing on dementia and the person-centred approach in dementia care.
- Two exchange trips to the UK (London) were organised for Hesed staff members, allowing them to visit Jewish Care and other social care providers and participate in further training.
- A training for trainers was held in Odessa.
- Partner organisations (Heseds) at the four locations received additional funding to hire Dementia Coordinators.
- Partner organisations (Heseds) received additional funding to continue the professional development of their staff, roll out specific services for people living with dementia, offer support for family members/caregivers and raise awareness of dementia within the Jewish community and beyond.

In the first phase of the programme, WJR and its partners directly trained more than 300 Hesed workers, as well as social and health care professionals from other organisations. The Heseds at the

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<sup>2</sup> The original ToR can be found in Annex 1.

four locations recruited Dementia Coordinators, who then developed their own follow-on learning activities, engaging more than 1,000 homecare and daycare professionals, as well as volunteers and staff members at various Heseds.<sup>3</sup> Homecare and/or day centre group assistance was provided to at least 200 older people.<sup>4</sup> Moreover, Dementia Coordinators held various awareness raising training courses for hundreds of state employees, medical and social work students and/or professionals; they further organised and attended various conferences on the matter.

Besides distributing general information on dementia, WJR decided to focus on the person-centred care approach in their training courses. While various definitions exist for the person-centred approach in health and social care, the recurring elements of the concept include communication, shared decision making, and support for self-management (Robinson et al., 2008). Simply defined, the person-centred approach promotes patient involvement and individualisation of care as much as possible. Today, person-centred care is considered a fundamental part of dementia care, with various person-centred interventions demonstrating an immediate positive effect on the cognitive functions and on the reduction of behavioural and psychological symptoms of people living with dementia (Lee et al., 2022). By promoting this approach, the goal of WJR's Dementia Programme was twofold:

1. To raise awareness of the person-centred care approach among Hesed workers.
2. To encourage its integration into various Hesed activities, especially into the JDC-supported *Saving Memory* project, thereby making dementia activities more client-led.

### 1.2.2 Challenges facing the Dementia Programme

During its implementation period, the Dementia Programme faced several challenges. For instance, following an intensive kick-off and training period (2017-2019), the WJR Programme Director went on maternity leave and her absence admittedly interfered with the momentum during the implementation process.

Moreover, the Covid-19 pandemic in 2020-2022 severely limited the operation of Heseds. Homecare support for clients ceased at times or became less frequent, shifting its focus to minimal house chores. For clients with dementia, this meant less meetings with their Hesed homecare workers and other professionals, compounded by limited time for socialisation, recreational activities and cognitive stimulation, which had previously formed a part of the home visits. The Hesed warm houses were closed, limiting the opportunities for dementia awareness lectures/talks to clients who would visit these places. Moreover, the Hesed day centres also ceased their in-person activities and shifted some of their programming online, where possible. For the programme, it meant no face-to-face group activities for clients with dementia. The Heseds in Minsk, Chisinau and Kyiv were able to launch online group activities for clients but in Kharkiv, older people certainly lacked the necessary skills and technological equipment to participate. Educational and professional development and support activities to Hesed workers too became less frequent and shifted online, including the dementia training courses and other forms of support. Dementia Coordinators in Minsk and Chisinau noted that most, but not all, programme activities resumed by 2023. In Ukraine, however, the 2022 full-scale

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<sup>3</sup> Note that most of the Hesed workers who participated in the WJR seminars also attended the follow-on courses of the Dementia Coordinators. In the absence of accurate monitoring data from the field, however, the overlap between the two groups is unclear.

<sup>4</sup> In the absence of reliable identification process, this figure includes older people with light, moderate and severe forms of dementia, as well as people who are at high risk of developing dementia (e.g., Hesed clients who suffered a stroke).

invasion by Russia prevented life from getting back to normal. During the first few months of war alone, more than 6 million Ukrainians, including many thousands of Jews, left their homes, emigrated or were evacuated from the most dangerous territories. While the Heseds continued some of their operation, many of them refocused their assistance on humanitarian and material aid and the evacuation of their most vulnerable clients. Two years into the war, and the Hesed warm houses and day centre with no bomb shelter remain closed in Kyiv, while the other day centre operates under some limitations. As a result, most of the Dementia Programme activities at Hesed Bnei Azriel continue in the online space. Being on the frontline and actively bombed, circumstances in Kharkiv have changed dramatically. A significant number of Hesed clients were evacuated from the city, while roughly 60% of the workforce have also left. Other than some online training courses for newly recruited homecare workers, the local dementia programme in Kharkiv has largely come to a halt.

## Chapter 2. Evaluation Design and Methodology

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### 2.1 The scope of the evaluation

According to the ToR, the main goals of this evaluation were as follows:

1. To assess the extent to which initial challenges vis-à-vis dementia awareness, perception and care persist at the different Heseds in the four key locations.
2. To assess the extent to which the Dementia Programme has reached its objectives.
3. To identify the least and most effective programme components.
4. To identify any unintended positive and/or negative outcomes and impacts of the programme.
5. To produce strategic recommendations for future programme directions.

Alongside these goals, the evaluation has also assessed issues of programme relevance, effectiveness and impact. The evaluation has had its focus on the results achieved (accountability objective), as well as on the implementation process (learning objective). The accountability objective provides an accurate account of the intended and unintended results in relation to the various units of analysis (see below), locations, and programme components. The improvement objective illustrates why expected and non-expected results were achieved or otherwise, while generating lessons.

### 2.2 Evaluation design

The evaluation was primarily based on the Dementia Programme's logic model (see in Annex 1, as part of the ToR), with the key objectives listed therein. The evaluators complemented these objectives with a range of success indicators, designed by using actor-oriented theory of change. Actor-oriented theories of change do not revolve entirely around what programmes should do or should have done. Instead of using specific (SMART) indicators, evaluators using actor-oriented theories of change frame the expectations of each actor separately within the theory of change, and analyse these expectations against the backdrop of actions by other actors and by programme management, emphasising behavioural change and changes in perceptions (see Deprez, 2013; Ofek, 2017). In line with this approach, the research team identified the main actors of the programme and kept the evaluation focused on these units of analysis. The main groups of actors (units of analysis for the evaluation) include:

1. Trained Hesed workers/volunteers (especially curators, homecare and daycare workers)
2. Family members caring for relatives living with dementia (family caregivers)
3. People living with dementia (Hesed clients)
4. WJR partners

Finally, some parts of the evaluation followed a case study design. A case study may be understood as the intensive study of a single or several cases where the purpose is, at least in part, to shed light on a larger class of cases. As requested by WJR, the Dementia Programme was analysed in all four locations (Minsk [Belarus], Chisinau [Moldova], Kyiv [Ukraine], Kharkiv [Ukraine]), whereby each location contributed new information about various actors and success indicators, resulting in a set of general lessons learnt on the programme.

## 2.3 Evaluation methodology

For the data collection, a mixed method approach was used – a combination of qualitative and quantitative methods. Data collection was carried out in four phases: 1. preparatory phase, 2. qualitative phase 3. quantitative phase and 4. analysis and completion.

### 2.3.1 Preparatory phase

The evaluation team started the preparation with a desk phase, during which relevant programme documents were reviewed (including the narrative reports of each Hesed) and a brief literature review was completed. The preparation then continued with in-depth interviews, targeting members of the WJR and Jewish Care programme team, as well as the Dementia Coordinators at the four locations, with the aim of understanding the background. Finally, the evaluation team developed additional success indicators.

### 2.3.2 Qualitative phase

Based on the results of the preparatory phase and the initial interviews, the evaluation team first prepared detailed interview and observation guides for various target groups that held relevance to the evaluation, including Hesed management, Hesed workers and volunteers, family members caring for relatives with dementia, people living with dementia and programme partners. Interview protocols were drafted in English and translated into Russian and Ukrainian.

The qualitative data collection continued with two field visits in Kyiv (Ukraine) and Chisinau (Moldova). The field visit in Kyiv was conducted by an Info Sapiens researcher, while the field visit in Chisinau was conducted by a Key Impact evaluator. During the two field visits, evaluators conducted face-to-face interviews, held seven focus group discussions (FGDs) and observed five programme activities. Observations included in-person and online group activities for people living with dementia and their family caregivers. Most of these activities took place at the Heseds, while one activity was organised in a residential home for older Jewish people, with another one held in a café. In Minsk (Belarus) and Kharkiv (Ukraine), the evaluation team gathered data over the phone and online. Interviews and FGDs lasted about 45-75 minutes, and were mostly conducted in Russian or Ukrainian with English translation. The evaluation team gathered qualitative information from 140 people in total. Table 1 shows the number of interviewees/FGD participants per actor group.

Target groups	No. of interviewees	No. of FGD participants	TOTAL
Hesed Directors	4	-	4
Dementia Programme Coordinators	4	-	4
Hesed staff members (Programme Managers, psychologists, curators, homecare workers, daycare workers)	25	23	48
Hesed volunteers	6	15	21
Family members caring for relatives with dementia	7	11	18
People living with dementia	6	32	38
Programme partners (including other Heseds, local NGOs, state organisations)	7	-	7
<b>TOTAL</b>	<b>59</b>	<b>81</b>	<b>140</b>

**Table 1. Number of interviewees/FGD participants participating in the evaluation (per actor group)**

## 2.3.2 Quantitative phase

### Survey design

The quantitative inquiry included two questionnaires, and targeted trained Hesed workers/volunteers, as well as family members caring for their relatives with dementia. Each survey had been developed based on the programme objectives and success indicators, as well as on qualitative information gathered beforehand. Prepared in English, each draft questionnaire had been shared with the WJR programme management for their comments. Each survey had then been translated into Russian and Ukrainian. Prior to its mass distribution, the survey targeting Hesed staff members/volunteers had been piloted with interviewees in Minsk and Kharkiv. Table 2 below lists the main issues tackled by the two surveys. The surveys themselves can be seen in Annex 2.

Survey targeting Hesed workers/volunteers	Survey targeting family caregivers of people with dementia
<ul style="list-style-type: none"> <li>• Participation in WJR and other training courses</li> <li>• Programme contribution to knowledge/perception/behaviour change vis-à-vis dementia and dementia care</li> <li>• Challenges of implementing a person-centred approach in dementia care</li> <li>• Additional Hesed assistance provided to workers/volunteers</li> <li>• The influence of Hesed assistance on people living with dementia, as seen by the workers/volunteers</li> <li>• Ways for improvement</li> </ul>	<ul style="list-style-type: none"> <li>• Programme contribution to knowledge/perception/behaviour change vis-à-vis dementia and dementia care</li> <li>• Hesed assistance provided to people living with dementia and their family caregivers</li> <li>• Satisfaction with Hesed assistance</li> <li>• The influence of Hesed assistance on family members</li> <li>• The influence of Hesed assistance on people living with dementia, as seen by the family members</li> <li>• Ways for improvement</li> </ul>

**Table 2. Scope of Hesed employee/volunteer and family carer surveys**

### Sampling and survey administration

The target groups of the two surveys were sampled differently. The survey targeting Hesed workers/volunteers was administered online by the Programme Coordinators, among people who had attended WJR and/or other dementia training courses. The survey was ultimately completed by 130 people.<sup>5</sup>

The sample of family caregivers included 36 people in total. Each Dementia Coordinator was asked to choose 12-15 family members from among their beneficiaries for the sample.<sup>6</sup> The survey was then administered by the Info Sapiens call centre. Each person in the sample was contacted at least three times. If a person was unavailable or uncooperative, another person was randomly selected from the respective list, until all names on files were exhausted. Out of the 36 family members targeted, 25 filled the survey, in a 69% response rate.

<sup>5</sup> 92% of the survey respondents were current or former Hesed workers, while 8% were Hesed volunteers. Of the Hesed workers/volunteers, 68% of the respondents were homecare workers, 16% were curators, 9% were Hesed volunteers, 9% other Hesed professionals, while 3% were day centre staff, with 2% psychologists. 61% of the survey respondents were from Moldova, with 21% from Ukraine and 16% from Belarus, while 2% were from other countries.

<sup>6</sup> The evaluation team received nine contact details from Minsk, 12 from Chisinau, 13 from Kyiv and two from Kharkiv.

### 2.3.4 Completion

All data and materials were analysed aggregately. Qualitative information from interviews was manually coded by success indicators, then summarised and translated into English. Quantitative data from the surveys were statistically analysed by using SPSS. Descriptive and comparative statistical tests were performed (when possible), and finally, qualitative and quantitative information was triangulated, with data clustered by actor groups, the main success indicators and locations.

### 2.4 Challenges and limitations

The evaluation team enjoyed high cooperation on the part of the WJR programme management, Dementia Coordinators and other actors. Most staff members at the Heseds and partner organisations too were highly responsive to queries. There were, however, some challenges that influenced the evaluation.

1. Due to the in-person field visits, most qualitative information was gathered at two locations: Chisinau and Kyiv. Qualitative information in Minsk and Kharkiv was gathered through phone and/or online interviews only, from significantly fewer beneficiaries. The qualitative data from these two locations are therefore more limited.
2. While the survey aimed at Hesed workers/volunteers intended for a census, Dementia Coordinators chose different strategies to distribute the survey and targeted different professional groups. For instance, 87% of homecare worker respondents were from Moldova, with 13% from Ukraine, while no homecare workers filled the survey in Belarus. Regarding Hesed volunteers, 73% were from Belarus, while 27% were from Ukraine, but no volunteers filled the survey in Moldova. Due to the disproportionate (over- or under-) representation of certain professional groups at certain locations, we will present survey results only at the programme level.
3. The evaluation team faced some challenges and delays in obtaining the contact details of interviewees and family caregivers to be surveyed, particularly in Kharkiv, where the programme operated with limited means. As a result, some of the findings from Kharkiv are limited. Detailed information on this location will only be presented when available. Moreover, quantitative results among family caregivers are merely indicative due to the small sample size. However, coupled with the qualitative information, they present valid findings.
4. The final challenge concerns the strongly intertwined WJR and JDC-supported dementia programme activities on the ground. For instance, Hesed workers who participated in the training courses of both organisations were often unable to tell them apart. To decrease bias, the researchers asked Hesed Directors, the Dementia Coordinators and other Hesed management team members about the particular contribution of WJR to their activities and to the professional development of their staff members. Their views guided some of the analysis and interpretation of results.

## Chapter 3. Evaluation Findings

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This chapter presents the findings of the Dementia Programme evaluation. The first section assesses the programme relevance. The second section presents the various intervention models that the evaluation team identified in the four locations. The third section presents results among Hesed workers and explains the changes triggered by the programme as far as workers' knowledge, perceptions and behaviour/practices. The fourth section presents results among family members caring for relatives with dementia, while the fifth section explains how the Dementia Programme has contributed to older people themselves. The final section summarizes findings among other organisations and partners.

### 3.1 Relevance

Looking at the wider context, Hesed managers and staff members interviewed for this evaluation have revealed that in none of the four locations where WJR's Dementia Programme has been running were there other organisations that provide social care for older people with dementia (not least for elderly Jews).

As an interviewee in Minsk shares: *"there are no psychological or social support services in the city for people living with dementia. There are medical facilities and some hospices, but these are mostly for situations when family members can no longer take care of their relatives. The employees of state social care facilities also come and learn from us,"* she adds.

Another interviewee at Kharkiv shares similar thoughts when talking about the situation in the city prior to the Russian invasion: *"There were naturally the medical establishments that provided health care to people with dementia. And there was the synagogue that offered some sort of psychosocial support. But there was no one else, no state facilities or other NGOs."*

Finally, an interviewee in Chisinau notes that *"our Hesed was the first social care organisation in Moldova to take systematic action on dementia."*

Prior to the WJR programme, knowledge on dementia had been scarce across the Heseds, with specialised dementia care largely absent from their work. To cite an interviewee from Kharkiv:

*"Prior to the programme, we wouldn't pay any attention to dementia. We'd focus on the psychology of older people and their care in general, but had had no specific activities or support for clients with dementia. Even when we'd hold a series of staff training courses in the past with a local expert gerontologist, he had not addressed dementia separately."*

Hesed interviewees in Kyiv and Chisinau have given similar accounts and explained that knowledge on dementia was *"nearly non-existent"* in their organisations or involved misconceptions and degrading attitudes. One interviewee in Ukraine has noted that Hesed staff members in the past *"considered people with dementia as mentally ill"*. In Moldova, an interviewee has said that *"a post-Soviet mentality prevailed at the Hesed and social workers did not know how to handle the behaviour of*

some clients, whom they considered as strange and aggressive.” These interviewees also confirm that dementia activities were “mostly absent” from their Heseds or rather “vague”. WJR’s Dementia Programme was therefore highly relevant in these locations, as it offered previously unknown information and encouraged new, specialised forms of support.

The only exception was Hesed-Rahamim in Minsk, where some initial knowledge could be found even before the WJR programme started (at least among some staff members), with an isolated dementia project, thanks to the support of various German organisations. The goal of this early intervention was to provide socialisation to clients with dementia and stem loneliness among them. Some key staff members had also attended dementia training courses in Germany. However, as interviewees in Minsk have noted, systematic and large-scale dementia activities were only made possible thanks to the WJR support. One staff member explains the WJR programme’s relevance as such:

*“With the WJR training seminars and financial support, we were able to launch a more systematic dementia intervention. We’ve broadened the circles of beneficiaries, included new groups of older people in it and started focusing on family members. It was also this support that encouraged us to raise awareness on dementia in the wider public and to communicate with state agencies on the matter. It’d never occurred to us to do that before.”*

WJR’s Dementia Programme was initially launched in partnership with the JDC, in order to complement its *Saving Memory* project and make it more client-led. Interviewees at the various Heseds have revealed that in most cases, the WJR assistance was indeed used in order to support beneficiary groups and activities that fell outside the scope of the JDC intervention. For instance, the Heseds used some of their WJR funding to support non-Nazi victims living with dementia, a beneficiary group usually not eligible for JDC support. Its flexible and complementary nature further increased the relevance of the WJR programme and made it much appreciated by the implementing teams at the Heseds. At the same time, it is also important to note that due to the flexible nature of the funding, some specific cases saw the Heseds support activities/beneficiaries that were not fully in line with the programme goals (see below).

### 3.2 Intervention models

As noted above, at each Hesed, various initiatives of different funders added up to one locally led dementia programme. The local programmes usually involved WJR-supported activities, as well as the JDC’s *Saving Memory* project. In addition, at Hesed-Rahamim in Minsk, some additional activities were also financed by the German Mutual Understanding Fund. The local dementia programmes were quite similar to one another and usually involved similar components and sets of activities. These components and sets of activities included the following (see below in Table 3):

1. Awareness-raising training courses and other support for Hesed workers/volunteers	2. Assistance to people with/at high risk of dementia	3. Assistance to family members caring for relatives with dementia	4. Public awareness-raising and advocacy activities
1. Training courses targeting curators, homecare workers	1. Some form of homecare support for clients with severe dementia	1. Awareness-raising lectures for family members caring for	1. Public lectures to raise awareness on dementia among Hesed clients/the general public

and other Hesed staff members	2. Group activities for clients with mild, moderate or severe forms of dementia (in-person at the Hesed day centres and/or online)	relatives with dementia	2. Awareness raising activities on dementia targeting social care professionals at other Heseds/state institutions, decision makers, and policy shapers
2. Training courses targeting Hesed volunteers		2. Psychological support for family carers (one-on-one or in a group)	
3. Other forms of support to Hesed staff/volunteers	3. Other forms of support	3. Other forms of support	

**Table 3. The main components of the local dementia programmes implemented at the Heseds**

While the main components in the local dementia programmes were quite similar, there were, however, some differences in their implementation processes. Moreover, the exact activities and beneficiary groups supported by the WJR funding also show some differences. The sections below describe each component in detail. Moreover, Table 4 on page 21 provides an overview of the WJR-supported activities at each location.

### 3.2.1 Awareness-raising training courses for Hesed workers/volunteers, and other forms of support

Together with Jewish Care and the JDC, WJR organised eight training courses for Hesed staff, co-workers and partners. Moreover, a core group of Hesed employees attended exchange visits to the UK and a training of trainers (ToT) in Odessa. Later on, the Heseds used their WJR funding to further build the capacities of their staff and volunteers. Dementia Coordinators developed and delivered their own locally developed training courses, while other organisations, such as the JDC, offered additional learning activities. These follow-on training courses varied slightly by format and frequency. In Kyiv, for instance, local training courses were usually multi-day seminars (two/four-day learning events) and held every two months. In Chisinau, on the other hand, local training courses in the early years of the programme were shorter but intensive, and held frequently: every month or more often.

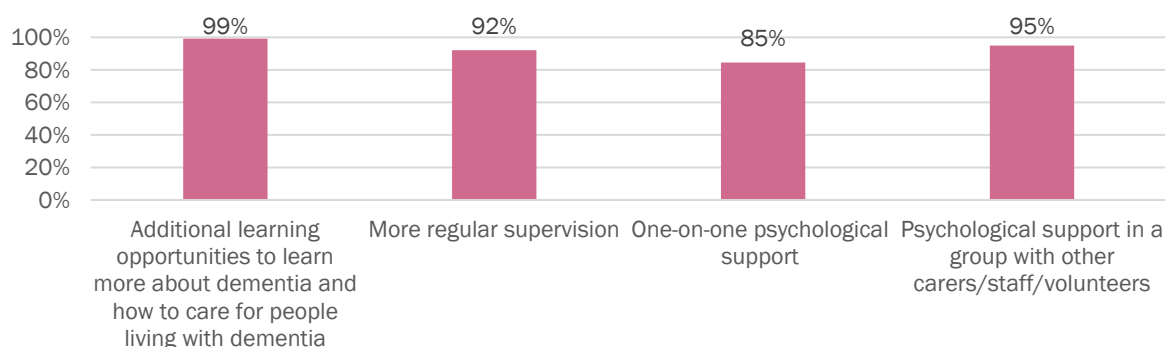
Local training courses at the various Heseds tackled similar issues. At each location, the courses offered basic knowledge on dementia, with its signs, symptoms and consequences. Moreover, the courses also focused on dementia care in general: how to support the cognitive functions of people with dementia, for instance, or communicate with them more attentively (a frequently discussed topic), what behaviours to expect, how to handle challenging behaviours or how to resolve conflicts vis-à-vis such individuals. Interviews with Hesed homecare workers at the various locations have confirmed that they also received plenty of new information and concrete ideas on how to personalise their care and what activities worked best for people with dementia. This is an important achievement, in line with WJR's goal of promoting a person-centred approach in dementia care. Finally, the issues of burnout and self-care for caregivers were also discussed at each location. As noted by interviewees, local training courses usually included case studies and practical exercises that helped to practice and internalise the topics discussed.

The Heseds also offered locally developed awareness-raising lectures to a large number of volunteers. As one Dementia Coordinator observes:

*"It was thanks to the WJR-organised exchange visit in London that we decided to involve volunteers in our dementia work. It had never occurred to me before. Afterwards, however, their training became an integral part of our work."*

Volunteers have become involved in the local dementia programmes at each location: some visited clients at their homes and engaged with them in different social activities (as in Chisinau), others made regular phone calls to the clients, to chat with them and follow up on their wellbeing (e.g., in Chisinau); others still helped with the organisation of group activities at the day centres or online (see Minsk, Chisinau and Kyiv). The content of their training courses was usually the same as those offered to Hesed workers.

Finally, in addition to the training courses, the Heseds also offered other forms of support to their staff members, co-workers and volunteers. In Minsk, for instance, the volunteers hold regular (monthly) meetings with the Dementia Coordinator (the Hesed psychologist), in order to plan for upcoming activities, receive new information and discuss challenging cases/situations. In Kyiv and Chisinau, prior to the Covid-19 pandemic, Hesed homecare workers would attend regular group consultations with a psychologist. Survey results also confirm that the Heseds provided a wide range of additional assistance to their workers and volunteers, in order to support their professional growth and care for people with dementia (see Figure 1). As shown by the literature review and interviews with Hesed staff and partners, such dementia-specific education for social care workers is usually insufficient in the target countries. Therefore, these results are an important achievement for the Dementia Programme.



**Figure 1. Additional support for Hesed workers/volunteers involved in the local dementia programmes**

While the initial years of the Dementia Programme were marked by intensive capacity development among staff members and volunteers, the Covid-19 pandemic interrupted this positive trend. Awareness-raising seminars shifted online across locations and became less frequent. In Minsk and Chisinau, the Coordinators have been trying to resume in-person training courses. In Kyiv, the professional development of homecare staff shifted from the Dementia Coordinator to the Coordinator of the *Saving Memory* project (herself trained by WJR). She now holds monthly seminars for homecare workers (though with no specific focus on dementia), while a separate training course on dementia is available every three months to those interested in the topic. In Kharkiv, since the Russian invasion, nearly 60% of social workers have left the organisation and there is an urgent need to educate newly recruited homecare workers. While an online dementia course is on offer for them, the Dementia Coordinator notes that *"mass awareness raising on dementia is to start from scratch"*.

### 3.2.2 Assistance to people with or at high risk of dementia

#### Homecare support

In order to support clients with dementia, the Heseds would usually offer some form of home-based care, group activities (in-person or online) and other forms of assistance. In Minsk, for instance, people with severe forms of dementia who were unable to leave their apartments received weekly one-hour cognitive stimulation by a trained professional (psychologist, speech therapist, occupational therapist). A similar model was implemented in Kharkiv as well, where people with severe dementia received specialists' cognitive stimulation at home. During the Covid-19 pandemic, however, all face-to-face activities stopped, including homecare support. To date, these have not resumed, due to the subsequent Russian invasion. In Chisinau, weekly two-hour socialization and stimulation was provided by specially trained homecare workers, in addition to regular homecare hours. Findings suggest that this model was particularly effective. As explained below, most trained homecare workers went through a significant perception change vis-à-vis their role, while many started focusing their visits on energising and stimulating their clients, rather than just completing house chores. Therefore, having more homecare hours delivered by the same (trained) social worker allows him/her to allocate more time to such activities. This in turn results in a more active engagement of older people than the one/two-hour stimulation from specialists. Finally, people with severe forms of dementia in Kyiv did not, for the most part, benefit from homecare support under the WJR funding, but some could have received such support from other sources.<sup>7</sup>

#### Group activities

Interviews reveal that in Chisinau, Kyiv and Kharkiv, the WJR programme gave a big impetus to dementia-specific group activities at the Hesed day centres. Prior to the programme, no separate groups aimed at people living with dementia could be found at these locations. Following the WJR training courses and thanks to the additional funding, the Heseds established one or more such groups. In Chisinau, one weekly dementia group has been running for people with mild, moderate and more severe dementia. The group includes eight-ten women and two facilitators.

In Kyiv, prior to the Covid-19 pandemic, regular (bi-weekly) sessions would be held, offering cognitive stimulation, dance and art therapy for Hesed clients at risk, or with mild/moderate forms, of dementia. As many as 100 people would attend these sessions. During the pandemic, group activities shifted online, in large part thanks to the laptops purchased and distributed to clients from WJR support. Today, online group activities are held on a daily basis. Online activities are usually attended by 10-15 participants, and people with dementia, as well as their family members, are all welcome. In addition, in-person group activities have resumed in Kyiv and are now offered twice a month in one of the Hesed day centres. In-person activities are usually attended by 15-16 people, half of whom with mild, and half with moderate, cognitive impairment. Note that the Dementia Coordinator in Kyiv also facilitates a dementia group in the Eurodom retirement facility for Jewish older people. Activities at Eurodom take place once a week and they are attended by 15-20 people, some of whom are at risk of while other are with mild/moderate dementia.

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<sup>7</sup> Note that in Kyiv, people with severe forms of dementia may have received homecare support from the JDC's *Saving Memory* project if found eligible, including additional homecare hours for socialisation and cognitive stimulation. This funding, however, is mostly reserved for Nazi victims only.

In Kharkiv, the Hesed day centre initiated three groups for people with dementia and their carers. Each group was attended by 15 people. Participants were divided by the severity of their relevant condition, but other criteria also factored in, such as their personalities, abilities and logistical considerations. During the Covid-19 pandemic, however, all face-to-face activities stopped, including group activities. Older people in Kharkiv lacked the technical equipment and skills to engage in online activities, and groups therefore had to roll back their activities.

In-person and online group meetings observed in Chisinau and Kyiv involved socialisation around shared meals and various exercises, such as finger training, intuitive drawing, word games, puzzles, art and craft works, light physical exercises and breathing exercises. Qualitative information gathered from Hesed staff, volunteers and people with dementia, reveals that facilitators regularly introduced new exercises to diversify the meetings, and continuously tried to improve their content. The group work (including in the online group) was indeed dementia-friendly, as it exercised various skills, such as fine and gross motor skills, speaking, logical thinking, drawing, coordination and calculation. Most participants felt challenged, at least to some extent, yet very eager to take part. Participants usually performed the same exercises (with no choices or adaptations), but people with difficulties might have received additional help. The atmosphere of each meeting was very positive, friendly and pleasant. Socialisation – an essential part of dementia group activities – was most apparent in the in-person group in Kyiv, where participants were divided into smaller groups of three-four, allowing them to lead personal discussions. Moreover, this format also allowed for teamwork and cooperation, something seen in neither online activities nor at the day centre in Chisinau.

As noted above, Minsk had had some initial dementia work done even before the WJR programme. The WJR support, however, facilitated the expansion of this work. Three groups were formed in the day centre, one for people at risk and in need of prevention (this is now an online group), one for people with mild and moderate dementia, and another group for people with moderate and more severe dementia (who were nevertheless able to attend in-person activities). WJR offers partial funding for activities of this last group. The group meets each week and includes 10-15 people. As a volunteer explains, *"some group members have barely any hand function and usually can't remember each other's names, only faces."* Group activities in Minsk include similar exercises to those found in other locations. Some group members are accompanied by family members or homecare workers. Moreover, the sessions are facilitated by the Dementia Coordinator and a volunteer, who provide additional support when needed. According to interviewees, the atmosphere in the group is positive and *"participants treat each other like family"*.

### **Other forms of support**

Alongside some form of homecare support and participation in group activities, the Heseds also offered other forms of support to people with dementia. Occasional daily excursions and visits to cultural events, for instance, were offered in all four locations. Moreover, inspired by their WJR-supported visit to London, Hesed Yehuda staff members in Chisinau have rolled out a highly successful activity, Memory Cafe, which includes regular monthly meetups in a pizza restaurant for people with mild/moderate dementia, along with their family carers, a psychologist, several Hesed social workers and volunteers. The Memory Café session observed by the evaluation team was essentially an in-person dementia group that allowed participants to engage in various stimulating, fun activities (often of their choice), while exchanging information and receiving specialised support, when needed. As a break from everyday routine, the activity usually takes place in a restaurant,

providing people with dementia with additional stimuli and an opportunity for their carers to enjoy themselves and meet. According to the Dementia Coordinator, the Memory Café in Chisinau is the only initiative of its kind in the FSU region.

Lack of suitable activities for people with dementia in and outside their homes had been identified by WJR as significant challenge prior to launching their programme. The positive results cited above, however, show that in Heseds where the local programmes continue today, this is no longer an issue. Jewish older people with dementia are likely to benefit from some form of dementia-specific services in those locations, at home and/or in the Hesed day centres. As we show below, most of the dementia-friendly homecare services provided today by the Heseds are person-centred, at least to some extent. As for the in-person and online dementia groups, these are "*extremely relevant*" for participants, "*fun*", "*engaging*", and are indeed dementia-friendly. Observations, however, have also attested that these groups usually include no personalized components, while activities are not specifically tailored to the interest, needs and differing situations of participants (e.g., various types of dementias and different cognitive abilities). Therefore, while their existence is a significant programme achievement, their person-centeredness is somewhat limited. The only exception is the Memory Café in Chisinau, which truly allowed participants to pursue their interests and make their own choices during the event.<sup>8</sup>

#### **Programme beneficiaries, their identification and follow-up**

The final point regards the differences among beneficiaries who have received WJR-funded support at the various locations. As explained above, the Heseds would usually categorise their clients by the severity of their dementia and offer their services accordingly. In Minsk and Chisinau, as well as in Kharkiv in the past, people with moderate and severe forms of dementia have greatly benefited from the programme, through specialised homecare services and/or group work. In Kyiv, however, the WJR funding has mostly been used to support people with mild/moderate dementia and to promote dementia prevention among high-risk populations (e.g., people with stroke or cardio-vascular diseases). While supporting this group is extremely important, they seem to be somewhat less relevant to the WJR programme goals.<sup>9</sup>

In the absence of sufficient medical diagnostic capacities across the target countries, most Heseds used the mini-mental test (MMSE) to identify and categorise their clients and their dementia. While the MMSE is a good starting point for initial screening, using this test alone can pose issues, for a number of reasons. Being a basic test, the MMSE does not screen for a number of difficulties (e.g., it mostly looks at cognitive functions, but disregards many important behavioural changes). Moreover, the test is significantly less effective among certain populations, such as highly educated people. In addition, due to the high levels of stigma attached to dementia in society at large, when tested in groups (a common practice in some of the Heseds), older people do not always give honest answers to the questions. Finally, even with the MMSE, some Heseds only tested their clients once, in the early years of the Dementia Programme, and since then, have been largely relying on reports by homecare

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<sup>8</sup> The Memory Café in Chisinau is attended by a large number of Hesed social workers and volunteers who are there to assist participants throughout the event. This makes it possible to tailor the event to the various needs and interests of participants making the event truly person-centered.

<sup>9</sup> Note, however, that most people with severe forms of dementia in Kyiv likely receive homecare support from the JDC's Saving Memory project. They are mostly Nazi victims though.

workers (see below in section 3.3). Some Heseds have recognised these shortcomings and introduced additional criteria in their testing. Others, however, followed the practice cited.

The current identification system does not produce reliable results, despite the fact that the allocation of Hesed services is dependent on it. Moreover, without a standardised follow-up system, it is impossible to objectively keep track on the changes in the clients' situation (changes in their capabilities, behaviour and everyday functioning). In the absence of a more accurate identification and follow-up system, it is in turn difficult to offer truly person-centred dementia services. WJR could assist the Heseds to improve their operations in this regard.

### 3.2.3 Assistance to family members caring for their relatives with dementia

The WJR assistance not only gave an impetus to staff capacity building and dementia-specific services at the Heseds, but also drew their attention to the importance of supporting family caregivers. The literature reveals – and the qualitative inquiry indeed confirms – that a majority of people with dementia in the target countries are looked after by family members. The main responsibility of care is often shouldered by a single relative, mostly women who are older themselves, with health conditions on their own. Survey results have confirmed this trend, showing that nearly 70% of family caregivers who look after relatives with dementia are 61+ years old (in fact, more than half of the respondents were 71+ years old). Interviews and FGDs also shed light on the significant challenges faced by family caregivers, including tending to their loved ones around the clock, their struggles to act and communicate attentively when relatives with dementia exhibit difficult behaviours, the constant resistance on the part of their loved ones and their inability to address their own personal needs. WJR training courses included testimonies of relatives, in order to sensitise Hesed staff to their needs. Moreover, WJR has encouraged the Heseds to develop their own assistance packages. One of the Dementia Coordinators comments on this support:

*"The WJR approach was really helpful, because it made us understand the importance of supporting family members. We've understood that working with family caregivers is essential if we are to provide our clients with dementia with a decent and dignified life."*

#### Awareness-raising lectures for family caregivers

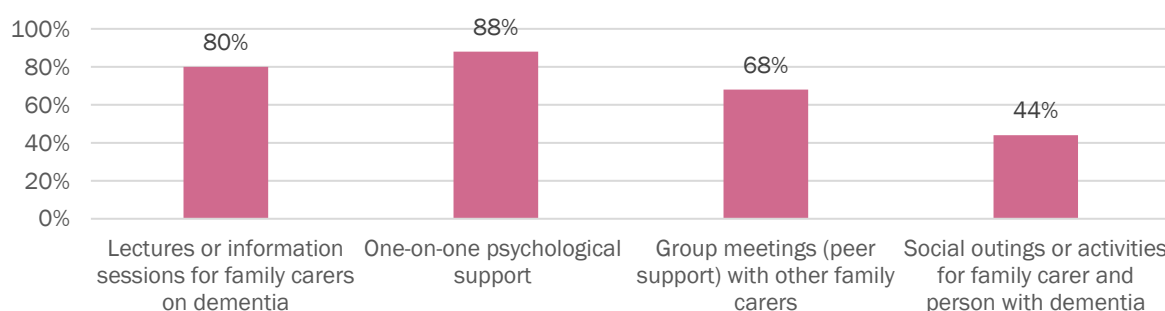
Family caregivers at each location were invited to take part in awareness lectures at the Heseds, where dementia and dementia care were explored. The lectures were mostly intended to help relatives understand the reasons behind the behaviour of their loved ones and equip them with practical tips on how to handle certain challenging situations. Some Heseds also attempted to build a supportive community of caregivers. In Kharkiv, for instance, a group of 16 relatives attended monthly lectures and met informally to exchange information. In Chisinau, family caregivers meet on a monthly basis as part of the Memory Café. However, the Covid-19 pandemic, coupled with the deep-seated stigma surrounding dementia in the wider communities and family caregivers' shame, have all hindered the development of a systematic support system. Today, family caregivers in Minsk, Chisinau and Kyiv are invited to partake in public lectures, but there are no regular support group activities exclusively for them. In Kharkiv, support to family caregivers has largely ceased, alongside other dementia activities.

## Psychological support

Individual psychological consultation has also formed part of the assistance offered to family caregivers by the Heseds. Consultations usually included five-ten meetings but were mostly available in acute cases. Individual psychosocial support was found to be an extremely relevant and effective caregiver support. Family members normally reluctant to join group activities (such as lectures or support groups) were usually more willing to accept help on a one-on-one basis. Therefore, relatives would have liked to have more such consultations in place, not only in acute cases.

## Other forms of support

As revealed by survey results, family members may also have benefited from other forms of support (see Figure 2 below).



**Figure 2. Different forms of Hesed support to family carers of people with dementia**

In Minsk, Kharkiv and Chisinau, for instance, some caregivers of people with severe dementia may have benefitted from additional homecare support, allowing them to take some time off for themselves. In Kharkiv, prior to the Covid-19 pandemic, family members would receive four-five hours of such support a month, including on weekends. This made it possible for them to visit other relatives, attend their own medical appointments or just get away from their daily routine. Still in Kharkiv, the Hesed prepared a manual for family caregivers, instructing them on how to care for their loved ones during the Covid-19 period. In Minsk, family members received regular accompaniment by a social worker (including monthly follow-up calls and practical advice on how to resolve some challenging situations at home) and participated in occasional multiday outdoor excursions. In Kyiv too, family caregivers may have been invited to take part in outdoor excursions or cultural events on specific occasions. All these initiatives aimed at easing the burden shouldered by relatives, while allowing them some time to relax and recharge.

The introduction of some form of caregiver support into the Heseds is an important achievement for the WJR programme. Findings also reveal that the Heseds tried to roll out multicomponent support systems that offered various complementary forms of assistance (including education, psychological support, peer interaction and self-care). However, in most places (particularly in Kyiv), caregiver support remained limited relative to needs on the ground, and insufficiently systematic. Therefore, WJR may want to increase its support for family caregiver interventions in the future. Strengthening family caregiver support is also to become more relevant in the future, as Nazi victims are passing away, while increasing numbers of the old older people at the Heseds (people at high risk of developing dementia) are non-Nazi victims. This beneficiary group is not eligible for the same level of social support, and their reliance on family caregivers is therefore likely to increase in the future.

### 3.2.4 Public awareness raising and advocacy activities

The last component of the local dementia programmes involved public awareness-raising and advocacy activities. Prior to the Covid-19 pandemic, Dementia Coordinators had held a variety of awareness-raising activities, some of which targeting Hesed clients and/or the general public, with other activities targeting social work professionals at other Heseds/in state institutions, as well as policy implementers and decision makers. Prior to the WJR programme, none of the Heseds had engaged in similar awareness-raising work on dementia (having neither the knowledge nor the capacity to do so), so the results below can be largely attributed to the Dementia Programme.

In order to raise awareness among their clients and/or the general public, the Heseds organised a range of activities: for example, inspired by experiences of the WJR-supported exchange visit in London, the Dementia Coordinator and other Hesed staff in Minsk organised in 2019-2020 a "*Friends of Dementia*" training of trainers (ToT) for Jewish activists, NGO representatives, volunteers, students and anybody interested in the topic. The ToT involved a series of offline and online learning events and was attended by 40 people. The online courses were later uploaded to the Internet and made publicly available. Hesed staff have noted that some ToT participants later organised their own awareness-raising activities and passed their knowledge on to other people. In Chisinau, the Hesed would mark World Alzheimer's Day each year and organise a whole-day training course for volunteers/the general public. Public awareness raising in Kyiv included the creation of a Facebook group designed to distribute relevant information. Moreover, in the early years of the programme, the Dementia Coordinator would hold regular (monthly) dementia lectures at warm houses, targeting Hesed clients in general. Finally, in 2023, the Dementia Coordinator was asked to facilitate a series of learning activities on dementia and dementia care in and around Lviv. Learning activities were organised in cooperation with other civil society organisations and targeted older internally displaced people and their family caregivers. About 150 people attended these training courses.

The four Heseds were also active in passing their new knowledge on to counterparts in the target countries. The Dementia Coordinator in Minsk, for instance, facilitated dementia workshops to Directors of all Belarusian Heseds and held awareness-raising sessions for homecare workers in Brest, Baranovichi and Mozyr. Similarly, the Coordinator in Kyiv passed her knowledge down to Hesed homecare workers in the Kyiv region, while the Coordinator in Kharkiv facilitated sessions for Hesed workers in Sumy and Poltava.

Finally, the Dementia Coordinators conducted awareness-raising and advocacy activities among social work professionals, policy implementers and decision makers at various state institutions. In Minsk, for example, Hesed staff members established important connections with representatives of the Ministry of Labor and Social Care and the territorial centres. In 2018, the Dementia Coordinator held a series of training courses for territorial centre representatives, in order to contribute to the establishment of dementia-friendly day centres across Belarus. The Covid-19 pandemic, however, hindered state efforts and the plans remained unfulfilled. Hesed employees in Minsk also put together and published a guidebook on dementia care, then distributed it among various professional bodies. The Belarusian Ministry of Labor and Social Care in turn issued its own recommendations to social workers with state facilities, largely based on this Hesed guidebook. This is a significant achievement for the advocacy work, precipitating the institutionalisation of the knowledge generated by the WJR programme and contributing towards larger-scale (policy-level) changes.

In Kyiv, the Dementia Coordinator also held a series of lectures for representatives of territorial centres and state nursing homes. Moreover, she facilitated professional development lectures at several higher-learning institutions, targeting students of various fields, including social work. Finally, in 2018, staff members at Hesed Bnei Azriel organised the first-ever international dementia conference in Ukraine, inviting more than 250 practitioners from across Ukraine, Moldova, Belarus, Georgia and the UK. Finally, as Coordinators share, the WJR-supported conference and other awareness-raising activities facilitated the formation of a dementia expert group in Ukraine. The group now includes more than 60 dementia experts – social work, mental health and health professionals – who are regularly in touch and share related information. The formation of such an expert group is another key achievement of the advocacy work, contributing towards higher-level results.

In Kharkiv and Chisinau, advocacy efforts were less intensive. In Kharkiv city council, representatives regularly attended the Hesed's dementia training courses, but further cooperation did not evolve. In Chisinau, during the early years of the programme, Hesed staff would organise their own roundtable on dementia with representatives of various state institutions in attendance. Cooperation, however, did not advance further, due to the unstable political situation that marked the country at the time.

Through various examples, this section has demonstrated the significant transformation experienced by the Heseds thanks to the WJR programme. In places where dementia was largely unheard of just a couple of years ago, where no dementia-friendly services existed, a knowledgeable workforce is now in place (see results below in section 3.3), with a range of dementia-specific services available to older people and their caregivers (when circumstances allow, naturally). Each Hesed has established ownership and developed their locally led dementia interventions according to needs and possibilities on the ground. Due to the countless, immense challenges of the implementation period (such as the Covid-19 pandemic, the Russian invasion of Ukraine, unstable and/or deteriorating political regimes and more), some results did not last, and unfulfilled potentials remain in each local programme. Nevertheless, and despite the countless challenges, most Heseds have managed to transform their operations, accumulate significant expertise in dementia care and gone from mere recipients to leading experts in the field. The WJR programme has served as a catalyst for many of these positive results and contributed to the formation of a strong foundation for the local programmes.

	Hesed Rakhamim (Minsk)	Hesed Bnei Azriel (Kyiv)	Hesed Shaare Tikva (Kharkiv)	Hesed Yehuda (Chisinau)
<b>Main funders of the local dementia programmes</b>	<p>Three organisations funding dementia activities:</p> <ul style="list-style-type: none"> <li>• WJR (Dementia Programme)</li> <li>• JDC (Saving Memory)</li> <li>• Mutual Understanding</li> <li>• In 2018-2019 the German government provided additional funding, some of which was used for dementia work</li> </ul> <p>WJR and Mutual Understanding fund similar though complementing activities, e.g. group activities for clients with severe dementia at the day centre</p>	<p>Two organisations funding dementia activities:</p> <ul style="list-style-type: none"> <li>• WJR (Dementia Programme)</li> <li>• JDC (<i>Saving Memory</i>)</li> </ul>	<p>Two organisations funding dementia activities:</p> <ul style="list-style-type: none"> <li>• WJR (Dementia Programme)</li> <li>• JDC (<i>Saving Memory</i>)</li> </ul>	<p>Two organisations funding dementia activities:</p> <ul style="list-style-type: none"> <li>• WJR (Dementia Programme)</li> <li>• JDC (<i>Saving Memory</i>)</li> </ul>
<b>1. Awareness raising training courses for Hesed staff members/volunteers</b>	<ul style="list-style-type: none"> <li>• Regular training courses for Hesed employees, co-workers and volunteers</li> </ul>	<ul style="list-style-type: none"> <li>• Regular training courses for Hesed employees, co-workers and volunteers (since the Covid-19 pandemic, training courses for Hesed staff are organised by the Coordinator of the Saving Memory project)</li> </ul>	<ul style="list-style-type: none"> <li>• Regular training courses for Hesed employees, co-workers and volunteers (since the Covid-19 pandemic, training courses have shifted online and their numbers have significantly decreased)</li> </ul>	<ul style="list-style-type: none"> <li>• Regular training courses for Hesed employees, co-workers and volunteers</li> </ul>
<b>2. Assistance to people with or at high risk of dementia</b>	<b>1. Some form of homecare support for clients with severe dementia</b>			
	<ul style="list-style-type: none"> <li>• Cognitive stimulation by a specialist at the client's home for people with the most severe forms of</li> </ul>	<ul style="list-style-type: none"> <li>• No specific homecare support under the WJR funding</li> </ul>	<ul style="list-style-type: none"> <li>• Cognitive stimulation by specialists at the client's home for people with the most severe forms of</li> </ul>	<ul style="list-style-type: none"> <li>• Cognitive stimulation by a homecare worker at the client's home, for people with the most severe forms</li> </ul>

	<p>dementia (weekly one-hour sessions)</p> <ul style="list-style-type: none"> <li>Regular homecare may be provided to people with dementia under a different WJR project</li> </ul>		<p>dementia (weekly two-hour sessions)</p> <ul style="list-style-type: none"> <li>Regular homecare may be provided to people with dementia under a different WJR project</li> </ul>	<p>of dementia (weekly two-hour sessions)</p> <ul style="list-style-type: none"> <li>Regular homecare may be provided to people with dementia, under a different WJR project</li> </ul>	
	<p><b>2. Group activities for clients with mild, moderate or severe forms of dementia (in-person at the Hesed day centres and/or online)</b></p>				
	<ul style="list-style-type: none"> <li>Regular (weekly) group sessions for people with moderate and severe forms of dementia at the Hesed day centre (the group is co-financed by WJR and Mutual Understanding. Each funder finances two monthly meetings, so the group can meet on a weekly basis.)</li> </ul>	<ul style="list-style-type: none"> <li>Regular (weekly) in-person group activities for residents of the Eurodom residential home (12-15 clients)</li> <li>Regular (bi-weekly) cognitive stimulation, dance and art therapy sessions at the Hesed day centres (prior to the Covid-19 pandemic, about 100 clients would attend)</li> <li>Regular online group activities for clients with mild and moderate dementia (since the Covid-19 pandemic)</li> </ul>	<ul style="list-style-type: none"> <li>Regular group sessions for people with mild/moderate and severe forms of the dementia at the Hesed day centre (three groups were formed, each numbering 15 clients)</li> </ul>	<ul style="list-style-type: none"> <li>Regular (weekly) group sessions for people with mild and moderate forms of dementia at the Hesed day centre</li> </ul>	
	<p><b>3. Other forms of support</b></p>				
<ul style="list-style-type: none"> <li>Outdoor excursions for clients, their caregivers and relatives</li> <li>During the Covid-19 period: distributing laptops for clients to attend online activities</li> </ul>	<ul style="list-style-type: none"> <li>Outdoor excursion for clients, their caregivers and relatives</li> <li>During the Covid-19 period: distributing laptops for clients to attend online activities</li> </ul>	<ul style="list-style-type: none"> <li>Clients marking Jewish holidays together (e.g., Rosh-ha-Shana)</li> <li>Signposting the apartments of people with severe dementia</li> </ul>	<ul style="list-style-type: none"> <li>Social visits by volunteers</li> <li>Memory Café (monthly meetings of people with dementia, their caregivers and Hesed staff/volunteers)</li> <li>Visits to cultural events and beauty salons for people with dementia</li> </ul>		

				<ul style="list-style-type: none"> <li>• Signposting the apartments of people with severe dementia</li> </ul>
3. Assistance to family members caring for their relatives with dementia	<ul style="list-style-type: none"> <li>• Awareness lectures for family caregivers (as part of public lectures)</li> <li>• Individual consultation with a psychologist (upon request)</li> <li>• Regular monthly follow up calls to family caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• There was a limited number of awareness lectures and support group meetings for family members only</li> <li>• Individual consultation with a psychologist in acute cases</li> <li>• Family member may have also participated in the online group activities for people with dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Regular awareness lectures for family caregivers</li> <li>• Support group meetings on a monthly basis</li> <li>• Individual consultation with a psychologist for a limited number of caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Regular awareness lectures for family caregivers (as part of public lectures)</li> <li>• Individual consultation with a psychologist (irregular)</li> <li>• Participation in the Memory Café</li> </ul>
4. Public awareness raising and advocacy activities	3. Public lectures to raise awareness to dementia among Hesed clients			
	<ul style="list-style-type: none"> <li>• Marking World Alzheimer's Day and the Day of Persons with Disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Creation of the public Facebook group Friends of Dementia. As of today, the group has 450 members.</li> <li>• Awareness-raising lectures on dementia for Hesed clients at warm houses (prior to the Covid-19 pandemic)</li> </ul>	<ul style="list-style-type: none"> <li>• Marking World Alzheimer's Day</li> </ul>	<ul style="list-style-type: none"> <li>• Marking World Alzheimer's Day</li> </ul>
	2. Awareness raising activities on dementia targeting other Heseds, social care professionals and the general public			
<ul style="list-style-type: none"> <li>• Workshop for the Directors of all Belarusian Heseds</li> <li>• Awareness sessions for homecare workers in Brest, Baranovichi, Mozyr</li> <li>• Training of trainers (online) for Friends of Dementia,</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness sessions for homecare workers at Heseds in the Kyiv region</li> <li>• Liaison with representatives of social policy department at the Kyiv municipal administration</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness sessions for Hesed homecare workers in Odessa, Sumy and Poltava</li> <li>• Organizing a roundtable discussion on dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness sessions for Hesed homecare workers across Moldova</li> <li>• Organising a roundtable discussion on dementia</li> <li>• Awareness lectures for social workers with nursing</li> </ul>	

	<p>offered to the general public, family caregivers and representatives of various NGOs and other social care institutions</p> <ul style="list-style-type: none"> <li>• Involvement in the inter-sectoral collaboration on dementia that took place between the Ministry of Health and the Ministry of Labour and Social Protection</li> <li>• Awareness lectures for representatives of territorial centres</li> <li>• Contribution to the "National Strategy for Active Longevity"</li> <li>• Awareness lectures at higher-learning institutions (among them at the Republican Institute for Advanced Training of Social Workers)</li> <li>• Participation in various local conferences, roundtable discussions</li> <li>• Brochures on dementia distributed widely</li> </ul>	<ul style="list-style-type: none"> <li>• Awareness lectures for representatives of territorial centres and nursing homes in Kyiv</li> <li>• Awareness lectures at higher-learning institutions targeting students of various fields, among them social workers</li> <li>• International Conference on Dementia</li> <li>• Participation in various local conferences</li> <li>• Training sessions on dementia to IDPs and their caregivers in the Lviv region</li> <li>• Brochures on dementia were distributed widely</li> </ul>	<p>homes, the municipal social assistance offices and NGO representatives</p> <ul style="list-style-type: none"> <li>• Participation in various local conferences, roundtable discussions</li> </ul>
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**Table 4. The main components and detailed activities of the local dementia programmes implemented at the Heseds, per location**

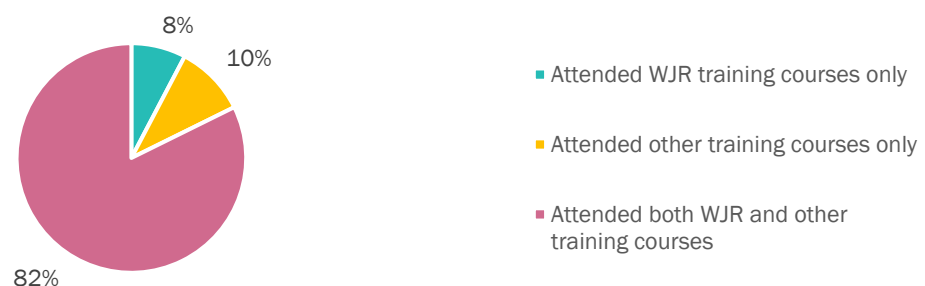
### 3.3 Results among Hesed workers

#### 3.3.1 Participation in awareness raising activities

This section presents results among Hesed workers. As noted above, knowledge on dementia had been largely non-existent at the Heseds prior to WJR programme. WJR-organized and later on locally developed awareness-raising seminars therefore formed a major part in the programme's early years. As section 3.2 reveals, local training courses were organised regularly, on a monthly/bi-monthly basis. Thanks to this impetus, the previously overlooked issue of dementia became a frequently discussed topic and an integral part of the professional development of social work professionals at the Heseds.

*"We realised how little we knew," explained one Dementia Coordinator. "We took initiative, organised our own seminars and asked for help from other organisations, to send their dementia experts, from Israel, for example. Today, homecare workers who join the Hesed must complete a 40-hour introductory course on dementia."*

Prior to the Covid-19 pandemic, the Dementia Coordinators had held their training sessions for close to 1,000 Hesed workers (curators, homecare and daycare workers, psychologists and more) and volunteers at their own Heseds, as well as others'. The Coordinator at Hesed Bnei Azriel, for instance, had facilitated dementia seminars for nearly 600 Hesed co-workers in the Kyiv region, while the Coordinator in Kharkiv had trained nearly 250 homecare workers in her city, as well as in Sumy and Poltava. Similarly, the Dementia Leads in Minsk and Chisinau too had trained hundreds of Hesed workers in their organisations and in other Heseds. In addition, hundreds of Hesed volunteers had attended locally developed awareness-raising seminars. Survey results among Hesed staff/volunteers strengthen qualitative findings and show that a majority of respondents (82%) attended several dementia seminars, of various providers (see Figure 3).



**Figure 3. Share of Hesed staff members/volunteers who attended dementia training seminars, per provider.**

Hesed interviewees who had attended the various training courses were usually highly satisfied. Interviewees at all four locations remembered their courses as "very good", "accessible", "professional", "practical" learning activities that provided a lot of "new", "hands-on" and "important" information. In addition, some interviewees felt that the courses had provided a much-needed theoretical background, which supported their intuitions on dementia and dementia care.

Due to the diversity in their training courses and providers, interviewees were usually unable to tell them apart. While programme staff at WJR and Jewish Care felt that their focus on the person-

centred approach was significantly different than the messages of other organisations, most Hased interviewees could not tell this difference. In fact, many interviewees felt that their training courses had complemented each other and offered knowledge on complementary topics. One Hased employee in Kyiv, for instance, remembers the various seminars she attended as such:

*"Our dementia training courses were not separate from each other, but rather complemented one another. Each of the courses presented a different piece of information and each helped us better understand the world of people with dementia."*

The variety of awareness-raising seminars on the ground meant that the evaluation team was unable to attribute results to WJR's learning activities exclusively. However, since WJR financed most of the in-house training courses delivered by the Dementia Coordinators, the organisation's contribution to the achievements below is unequivocal.

### 3.3.2 Contribution to new knowledge

#### Knowledge on dementia, with its signs, symptoms, underlying causes and consequences

Qualitative and quantitative results indicate that Hased workers and volunteers benefitted extensively from their training courses, personally and professionally alike. For instance, nearly all interviewees have noted that the seminars helped them understand that dementia was a disease with identifiable signs and symptoms, underlying causes and consequences. The following quotes from Hased homecare workers and volunteers of various locations demonstrate this learning process:

*"I've realised that dementia is a disease triggered by various factors. There's no cure, but the client's condition can be managed. For this to happen, it is important to create a positive and calm atmosphere."*

*"The training courses were very helpful. They explained why my client gets so aggressive at times. I've understood that this is not his fault, that he can't control his emotions. He cries a lot, then laughs or can suddenly become aggressive."*

*"I didn't have many conflicts with my clients in the past. But before the Hased courses, I would take it very personally when they'd become angry. Now I know that it's their dementia influencing their behaviour... I've become more empathic towards my clients and their situation."*

Finally, one of the Dementia Coordinators notes: *"In our Hased, we had had a lot of experiences in the past on how to work with people who suffered a stroke or head trauma. We'd wanted to see an improvement in their condition, skills and abilities as a result of our actions. But thanks to the WJR programme, we've understood that this approach would not work vis-à-vis people with dementia. The disease is progressive and it just behaves differently. The WJR seminars have completely changed our expectations and we've shifted our attention to slowing the disease and creating a comfortable and engaging environment for our clients. This was a transformative change."*

Following their training courses, several Hesed interviewees profess their new ability to recognise if their loved ones, relatives, friends and/or neighbours have some form of dementia. A volunteer in Minsk shares the following story:

*"My friend had started showing signs of dementia even before my becoming a volunteer in this project. Back then, I'd had no knowledge on dementia and no idea what to do about her strange behaviour. Neither I nor her relatives could make sense of what she was going through. Soon after attending my introductory course at the Hesed, however, I realised that she probably had dementia. I immediately shared this information with the family."*

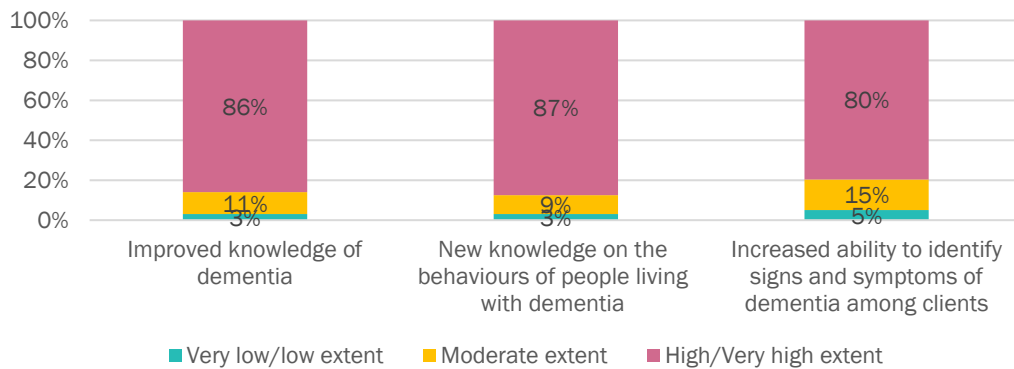
Another interviewee shares a similar story: thanks to the information at the training courses, *"I was able to recognise the initial signs of dementia in a friend. Together with her children, we persuaded her to see a specialist. She started dementia-specific care, which in turn stabilised her condition."*

At the professional level, Hesed employees understood how to identify signs and symptoms of dementia in their clients. Most interviewees made their assessments based on their communication with the clients, having observed their mood and behaviour. Some interviewees also looked out for other signs, such as memory loss or disorientation in space. Accordingly, two homecare workers in Minsk and Kyiv describe the contribution of the training courses to their knowledge:

*"After attending the training courses, I was able to recognise the signs and symptoms of dementia in my client. I could tell it simply by communicating with her."*

*"Well, I can recognise the early signs of dementia when, for example, I visit a client and see that things are scattered around in their otherwise tidy apartment. But I also look at their mood, if they get very angry out of the blue: that's usually a sign."*

Quantitative results support qualitative findings and show that a majority of survey respondents (above 80%) assess the contribution of their training courses to their knowledge on dementia, and the reasons behind the behaviours of people with dementia, as high/very high (see below in Figure 4). Moreover, 80% of survey respondents feel that the seminars have highly/very highly increased their ability to identify the signs and symptoms of dementia among their clients. The quantitative analysis, however, also revealed that respondents who had only attended the WJR training courses tended to report lower levels of contribution to their knowledge than people who had attended courses of various providers. This finding supports the importance of continuous, varied training on the ground.



**Figure 4. Contribution of training courses to Hesed workers/volunteers' knowledge on dementia, with its signs, symptoms and consequences.**

### Knowledge on dementia care and the person-centred approach

Several interviewees report learning new information at the Hesed training courses on *"how to behave appropriately with people who have dementia."* One volunteer in a day centre explains the contribution of her ongoing training as such:

*The Dementia Coordinator "always explains how to address some challenging situations we might encounter at the day centre vis-à-vis people with dementia. For example, there's this woman in one of the groups who regularly accuses Hesed staff and fellow participants of theft. We have learnt how to respond to her, how to avoid getting into confrontation to divert her attention and calm her down. It works well."*

Another day centre volunteer also mentions acquiring good practices at the Hesed courses, on how to interact with people with dementia and assist them during group activities:

*"The training sessions were very helpful and provided a lot of practical information. For instance, I now know that you can always diffuse a tense situation with a smile. There is no need to get into arguments. Or if someone repeats the same thing over and over again, it's important to ask other participants in the group if they've had a similar experience in life. Our goal should be to gently refocus the group's attention, away from the person to something else."*

Attentive communication, a better understanding of the person with dementia and customising care experience are key components of the person-centred dementia care approach. Findings suggest that Hesed workers and volunteers have received plenty of new information in this regard. For instance, thanks to their training courses, a great majority of interviewees understood how best to communicate with people with dementia. Psychologists, day centre volunteers, curators and homecare workers all report learning new ways of communication. As an interviewee explains:

*"I've really come to understand which approach works best for communicating with people with dementia: a calm and quiet approach, where you mostly listen and don't argue."*

Several interviewees also feel that in order to succeed in their communication with people with dementia, it is imperative better to understand their clients, their needs and interests. Accordingly, one interviewee, who was responsible for some learning activities at the Hesed, explicitly promoted this approach in her training courses:

*"In the seminars I hold to homecare workers, I talk a lot about the biographical approach in dementia care. I first heard about this approach at the WJR seminar. How important it is to get to know our clients, their life stories, hobbies, interests, then plan our work accordingly. I teach the homecare workers how to make use of this information in order to better connect with their clients and help vulnerable older people better preserve their dignity."*

Other interviewees also cite the importance of knowing the needs and interests of their clients for a positive care experience. As one homecare worker explains:

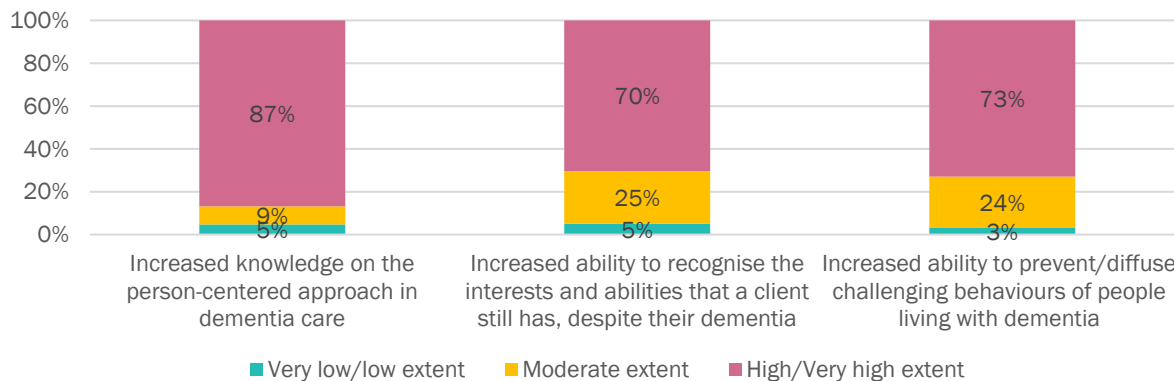
*"During the training and later on, in practice, I've realised how important it is to support my client in their hobbies, so that they can practice some of them. If they have none, you should just come up with one by yourself. Read them a book, do some crosswords together, watch a movie and have a discussion about it, or look at old photographs so they can remember familiar faces."*

Several homecare workers mention that *"each client requires a different approach"* and a set of activities relevant and enjoyable particularly for them. Understanding their clients' needs and interests has also helped Hesed interviewees better respond to challenging situations and reassure people with dementia more effectively. A homecare worker shares:

*"I've realised that it's not an issue of character but a disease. If so, then you can always find a way to communicate with a person. You can make them interested in things they used to be passionate about in the past and use that to distract them in situations when unpleasant communication is brewing."*

Another interviewee shares similar thoughts: *"Participation in such awareness-raising activities is helpful, as they expose the essence of dementia. They also teach you how to support and help people with this condition. People with dementia are very vulnerable. They often don't understand what we really want from them. They require constant attention and care. You always need to keep them engaged, find a hobby for them or distract their negative thoughts."*

The numerous quotes above demonstrate that a majority of Hesed workers/volunteers interviewed for this evaluation were indeed proficient in the basic principles of dementia care and the person-centred approach. Quantitative results strengthen qualitative findings and show the high/very high contribution of Hesed training courses for people's knowledge on dementia care, the person-centred approach and how to handle challenging situations/behaviours by people with dementia (see below in Figure 5).



**Figure 5. Contribution of training courses to Hesed workers/volunteers' knowledge on dementia care and their person-centred approach.**

### Increased ability to support family members

The final point regards Hesed staff members' ability to support family members of people with dementia. As noted above, prior to the WJR programme, the Heseds would not offer any assistance to family caregivers. By now, this has largely changed. Today, family members may attend awareness lectures, receive psychological or other forms of support, but more importantly, they are being listened to and supported by Hesed workers throughout their interaction with the organisation. Regardless of their position, Hesed curators, psychologists, homecare workers and volunteers interviewed for this evaluation have all understood the importance of being attentive to family caregivers and support them in their difficulties. As one curator explains:

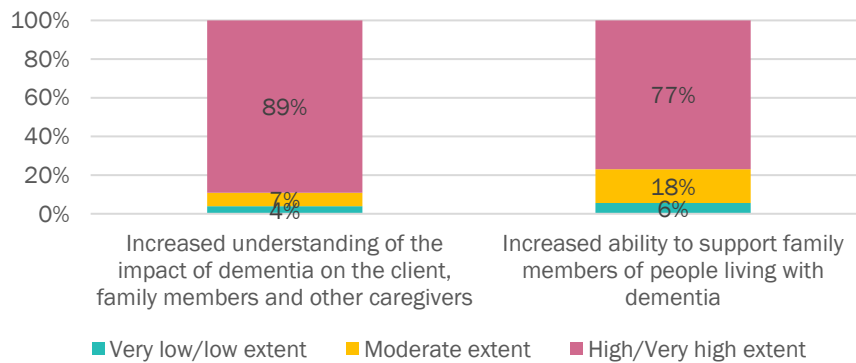
*"Family caregivers often panic over the behaviour of their loved ones and then call us. I mean, when their relatives harm themselves or are harmful to others. When this happens, we need to listen to them, calm them down and give them strength."*

Homecare workers at various locations have also confirmed that they get a lot of questions from family members, mostly on how to react when a person with dementia exhibits unusual behaviour. Interviewees used their knowledge confidently in such situations and were able to provide advice and relief to relatives. As one homecare worker recounts:

*"I always explain to them [family caregivers] how they shouldn't react aggressively with their relatives and how to avoid shaming and interfering when relatives act strangely, and redirect them instead."*

Another homecare worker also shares: *"Some family members are more accepting of their loved ones' condition, while others are in denial. These people are usually sceptical and suspicious. I am in direct contact with them and it is my mission to empower them with information."*

Quantitative results support qualitative findings and show that the training courses have highly/very highly contributed to Hesed workers' understanding of family caregivers and their ability to support them, as seen in Figure 6 below.



**Figure 6. Contribution of training courses to Hesed workers/volunteers' understanding of family caregivers and their ability to support them.**

### 3.3.3 Contribution to perception change

#### Shift in Hesed workers'/volunteers' views on dementia and people with dementia

As the data collection reveals, initial knowledge on dementia at the Heseds included several misconceptions, while degrading attitudes prevailed. Some Hesed workers, for example, used to think that "dementia was a mental illness" or "an issue of bad character". Findings suggest that WJR-facilitated as well as locally developed awareness-raising activities have succeeded in dismantling many such beliefs and contributed to a positive change in people's views. As a personal benefit of the seminars, some interviewees have realised that "although dementia was a disease, they could live with it." Other interviewees mention that they are "no longer afraid of growing old and losing their mind".

Others yet have started better to understand loved ones and/or clients with dementia and developed more accepting, tolerant attitudes towards them. As a Hesed worker shares:

*"The training courses help us look at our clients as they are. I've realised that my client's behaviour is completely unconscious, that he has no control over his actions. He simply cannot understand that what he's doing is wrong."*

One Dementia Coordinator cites significant change in the language used by Hesed employees in addressing their clients: "Curators and homecare workers started referring to people with dementia as the 'partners' of our homecare services, rather than as clients or sheer recipients." Another Coordinator shares a transformative perception change she has witnessed in her organisation:

*"Curators used to gossip about people with dementia and laugh about their 'strange' behaviours. Today, they are more attentive, kinder and respectful. In our organisation, there is no talking behind the clients' back anymore."*

Quantitative results strengthen qualitative findings and reveal that nearly 90% of survey respondents at the Heseds have become more empathetic towards people with dementia, thanks to the awareness-raising activities.

### Increased confidence in dementia care

Previous sections show that Hesus workers and volunteers received plenty of new information on how to support people with dementia and create a positive, person-centred care experience. The new knowledge has also made Hesus staff more confident in their abilities and actions. Moreover, several interviewees (Coordinators, as well as curators and homecare workers) started viewing themselves as experts of dementia care. This was an empowering process that positively influenced their views on their professional roles and responsibilities. One Coordinator explains:

*"Participating in the WJR programme was a very significant personal and professional journey for me. Not only did I become more informed about the field, but I've also learnt how to pass my knowledge on and train others."*

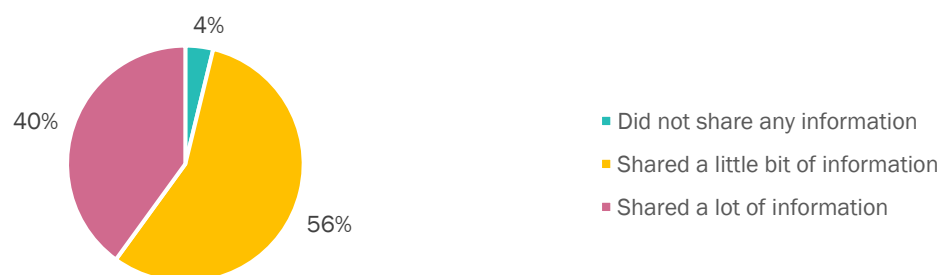
Another interviewee, a homecare worker, describes her professional development process:

*"The Dementia Coordinator usually talks about the psychological aspects of communicating with clients with dementia and points out where you can find more information. But it's then down to us to plan and prepare for the visits. We need to be resourceful and innovative and make adjustments to accommodate the particular situation of our clients. It's not always easy, but to me, this has been an empowering experience."*

### 3.3.4 Contribution to behaviour change

#### Sharing about dementia

The sections above demonstrate that dementia has become a frequently discussed issue in the Hesus. Findings also show that knowledge sharing does not stop within the organisations, as Hesus workers and volunteers have also talked about the issue with others. According to survey results, most Hesus workers and volunteers shared a little bit (56%) or a lot (40%) of their new knowledge on dementia with others, like family members, friends or colleagues, thereby creating a steady flow of information into the wider community (see Figure 7).



**Figure 7. Percentage of Hesus staff members/volunteers who shared information on dementia with others.**

#### Implementing a person-centred approach in dementia care

The sections above reveal that Hesus workers and volunteers have received a lot of new information on the person-centred approach in dementia care. This part considers whether they have been able

to put their knowledge into practice and create a more personalised care experience for clients with dementia.

### **Improved communication with clients with dementia**

Nearly all Hesed workers and volunteers interviewed for this evaluation have reported making some changes to their communication with people with dementia. Responses to an open-ended question in our survey suggest that about 25% of Hesed staff members and volunteers have made changes to their communication with loved ones, thanks to the information received at the training courses. As a Hesed worker recounts:

*"I began to understand my husband better. He is an older man who suffered a mild stroke. He doesn't show significant signs of dementia, but after attending the training courses at the Hesed, it became easier for me to communicate with him."*

Another Hesed worker shares a similar experience: *"I have a friend with dementia. After the training courses, I started to communicate with her differently, and was able to calm her down."*

Yet another survey respondent talks about some concrete changes she has made in her interaction with older people: *"I've become more attentive to older people on the public transportation and out on the street.... I also react more calmly to the 'peculiarities' of my neighbours and patiently repeat the answers to their repetitive questions."*

Hesed workers have also made adjustments to their communication with clients living with dementia. Several quotes in this report show that care workers have started using a calmer, more attentive tone, trying their best to deescalate/avoid conflicts. Such positive changes have been observed among curators, homecare and daycare workers, as well as in volunteers.

### **Individualisation of the care experience**

Another key element of the person-centred approach is the personalisation of the care experience. The evaluation has uncovered several examples at all four locations that confirm the implementation of a more personalised approach in care practices of the Heseds. Most examples were gathered among homecare workers, while dementia group activities were almost never personalised, except for the Memory Café in Chisinau. Results among homecare workers, however, were significant and widespread. One of the Dementia Coordinators, for instance, explains the numerous changes she has introduced in her organisation:

*"We started to focus our work on the clients' emotional memory, their feelings. I've seen this approach during the WJR visit in the UK and decided to implement it in our homecare work. For instance, after the training courses, I accompanied homecare workers and made sure that they put into practice what we'd talked about, that they kept the clients busy with activities that the older people enjoyed. The homecare workers understood that any activity could be turned into a cognitive and emotional stimulus. We also taught them how to be more patient, willing and able to slow down with their work for the benefit of their clients. We taught them, for instance, not to rush*

*with folding the clothes, but rather to invite clients to participate, even if it meant the task took longer... Finally, we encouraged homecare workers to prepare 'memory boxes' with the clients, a collection of items that generate pleasant feelings and remind the older people of their lives before dementia. I've seen the homecare staff using these boxes in real life when they had to reassure an anxious client."*

Homecare worker interviewees also brought many examples for personalising their care, at least to some extent. For instance, various interviewees in Ukraine and Minsk share the following experiences:

*"I had a client with dementia, she was 92 and died last year. She used to spend her time sitting and playing the piano. She didn't remember many melodies, but whenever she played, she seemed to come to life. So I always encouraged her to play."*

Another interviewee recounts: *"It was difficult when I just started tending to clients with dementia. I introduced some cognitive exercises and they found them too easy. Later on, I mapped their life stories and interests and designed the activities accordingly. I always prepare for each visit separately, look for crosswords, art and craft exercises, whatever the client enjoys. They've become more engaged, and they now look forward to my visits."*

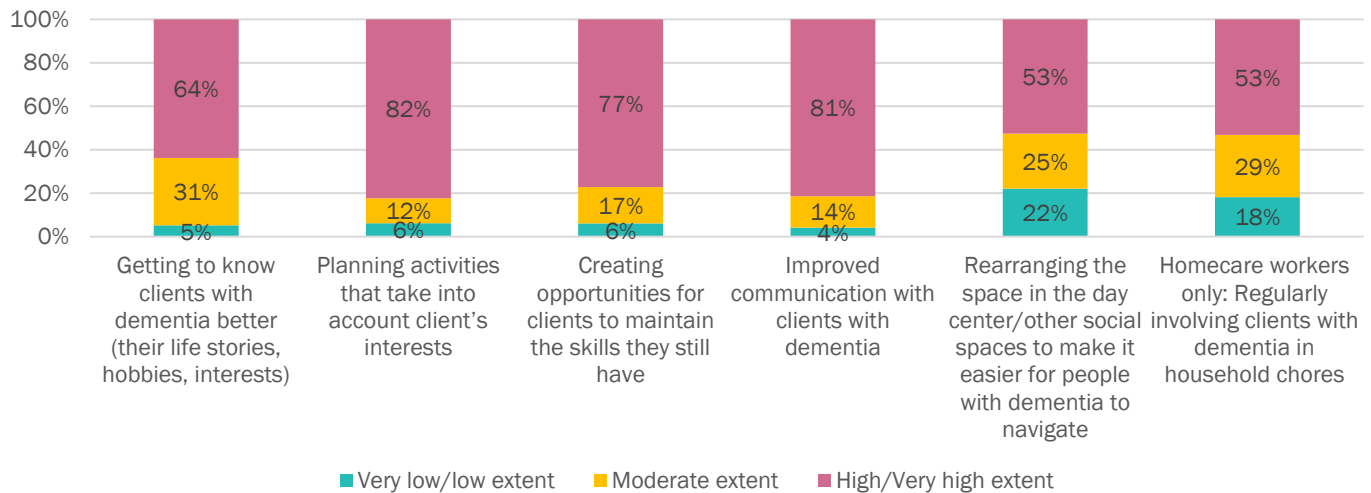
One social worker who no longer works with the Hesed remembers her visits to clients with dementia: *"Visiting clients with dementia was not just about cooking and cleaning, but also about sensing their mood on that particular day and seeing what they were interested in."*

Finally, a homecare worker who delivers both regular and communication homecare explains: *"Following the training courses, I've shifted my attention to the mental stimulation of my clients. This is a more important part of my job than cleaning their houses... I always offer some exercises, because then clients are more independent and willing to engage in other tasks. Afterwards I might ask them to help me peel the potatoes or do some of the dishes, if their condition and mood allows... I now spend two-thirds of my time communicating with my clients and engaging them in different tasks, and the rest is about house chores. In the past it used to be the other way around."*

As this last quote reveals, some homecare workers have tried to involve their clients in light house chores. However, interviewees also note that many clients were simply unable to participate in such activities, due to the severity of their dementia or other health conditions. Cognitive stimulation exercises, various games, art and craft work were widely used during home visits, but in most cases, their goal was to keep the clients' engaged and *"in good spirits"*. Finally, in some Heseds, homecare staff have also started to consider the clients' living environment, as part of their care plan. In Kharkiv and Chisinau, for instance, homecare staff signposted apartments of people with severe dementia, in order to motivate them and help them better navigate their living space.

The survey has gathered some additional information on Hesed workers' care practices. As Figure 8 shows below, most Hesed employees and volunteers responded positively when asked about the

implementation of person-centred practices in their daily work with people with dementia. It seems that today, most trained homecare workers who look after people with dementia indeed take into consideration their clients' interests, plan their visits accordingly and emphasise client engagement one way or another during their visits.<sup>10</sup>



**Figure 8. Person-centred activities implemented by Hesed workers/volunteers in their care for people with dementia.**

### Challenges for implementing a person-centred approach in dementia care

Finally, Hesed workers and volunteers who filled the survey were asked to share challenges that prevented them from implementing a person-centred approach in their care. While most respondents did not experience difficulties, those who did cited three main issues. When a client with dementia had additional health conditions (such as chronic diseases, disability, hearing or vision impairment), it was significantly more difficult to implement a person-centred approach. Moreover, when a client was generally aggressive or experienced severe depression/significant mood swings, it was also more difficult for care workers to implement a person-centred approach. As interviewees note, future capacity-building activities could focus on these specific challenges and offer more hands-on knowledge on how to handle them.

All in all, results in this section show that the WJR programme has made a significant contribution to the professionalisation of dementia caregivers across the Heseds. Hesed workers and volunteers had the opportunity to attend several locally developed awareness-raising seminars; they received new and important knowledge on dementia, its signs and symptoms, consequences and how better to care for people with the condition. Increased knowledge has led to positive perception changes on the disease, as well as on people who live with dementia and care workers' own abilities, roles and responsibilities. As demonstrated above, most Hesed workers have succeeded in putting their

<sup>10</sup> Note, however, that where there was a high turnover in homecare staff, e.g., mostly in Ukraine and especially in Kharkiv, newly recruited homecare workers likely lack the necessary knowledge and experience to implement a person-centered approach in their care.

new knowledge into practice, changed the tone of their communication with clients and started taking their clients' needs and interest into consideration; homecare staff have created more engaging care experiences for people with dementia. Finally, the knowledge received at the Heseds has also proved meaningful in their personal lives, helping them better understand their loved ones and improving their interactions with relatives, friends and neighbours.

### 3.4 Results among family caregivers

This section presents results among family caregivers who have benefitted from some form of support at the Heseds. Interviews and FGDs reveal that many family members have been caring for relatives with dementia for several years (three-seven years or more), while most of them have been shouldering this task without much help from other family members. Over the years, caregivers have faced many difficulties, accumulated a lot of stress and often felt angry and helpless in difficult situations. *"You just don't know what to do and how to handle certain situations,"* shares an interviewee. Another interviewee says that the most difficult part in caring for his wife is *"her constant mood swings. She can get angry out of the blue, then she doesn't want to engage in anything and I cannot force her. It was difficult to make sense of her behaviour."* Other family members complain about the constant care required by relatives with dementia. To cite one interviewee:

*"We have to take care of my mum almost 24/7; perform basic hygiene tasks, feed her, change her clothes, talk to her and so on. We can't leave her alone even for half an hour, because she may harm herself."*

Therefore, the Hesed assistance proves crucial for family members.

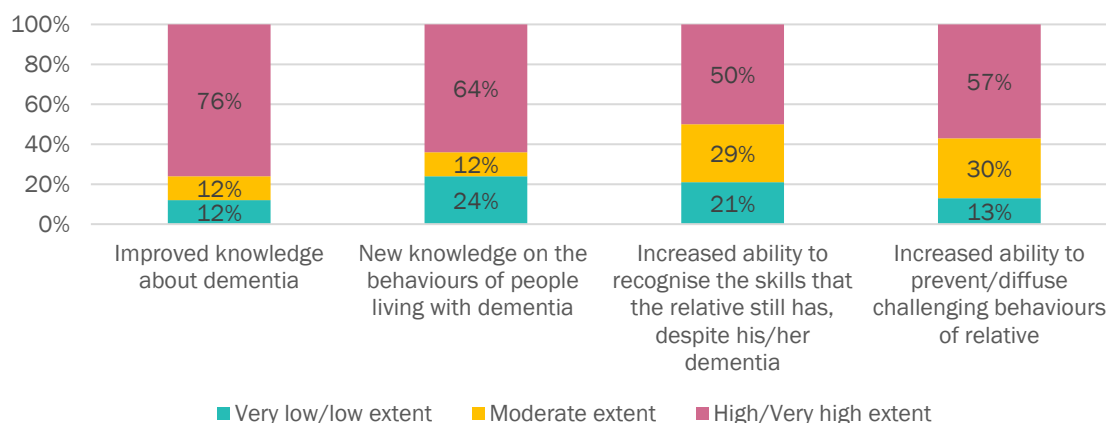
#### 3.4.1 Contribution to new knowledge

##### Knowledge on dementia and how to make everyday life with a person with dementia easier

Qualitative findings reveal that family caregivers have learnt about dementia on their own, as well as during the local Hesed training courses. Learning from Hesed training courses was rarer in Kyiv, and more common in other locations. Those attending the Hesed training courses usually found them *"helpful"*. One interviewee, for instance, remembers the lectures he attended as *"useful"*. *"They helped me better understand my wife's behaviour,"* he adds.

More importantly, most family caregiver interviewees have received at the Heseds practical ideas on how to better manage the day-to-day life of their loved ones. Some family members, for instance, have learnt that *"it's best to hide their relatives' keys"* and *"make sure they carry an address somewhere in their clothes"*, in order to prevent relatives with dementia from getting lost. Others have learnt *"to lock some parts of their fridge in order to avoid obsessive eating"*, *"unplug the stove"* or *"rearrange the rooms"* so that their relatives couldn't cause damage or harm themselves.

Survey results show that thanks to the Hesed assistance, most family caregivers have increased their knowledge on dementia to a high/very high extent (76%) and received new information on the behaviours of their loved ones (64%). More than half of them have also increased their ability to prevent/diffuse challenging situations (57%) (see Figure 9 below).



**Figure 9. Contribution of the Hesed support to family caregivers' knowledge.**

### Importance of spending quality time with people with dementia

Interviews and FGDs reveal that an effective way of learning new and practical information was when family members attended the visits of Hesed homecare workers and observed them engage their loved ones in various tasks. By observing how homecare workers cared for their loved ones, some family members learned about various forms of stimulation (like word games, art and craft exercises), while others witnessed the value of targeting the emotional memory of people with dementia when they were anxious or in a bad mood (e.g., by looking at old photographs together). One interviewee, for instance, shares: *"A homecare worker visited us and told me what activities I could do with my husband. Then I did them with him in my free time."* Some, though not all, family member interviewees understood the importance of spending meaningful time with their loved ones in order to *"make people feel good"* and *"slow the progression of this condition"*. In the future, such hands-on learning from care workers could be emphasised in the local dementia programmes. For instance, even when a person with dementia is not eligible for regular homecare support, their family member could benefit from such visits for a period of time, for learning purposes (accompaniment).

### 3.4.2 Contribution to perception change

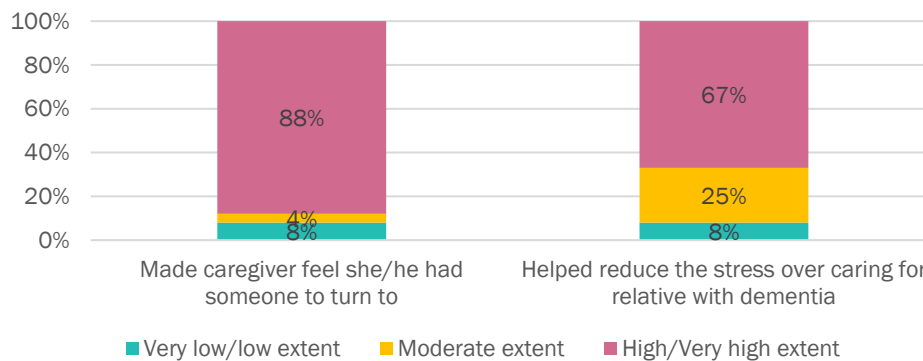
#### Increased confidence in dementia care

Survey results show that thanks to the new information and practical advice, a majority of family members (68%) have felt a high/very high increase in their confidence when caring for loved ones with dementia. As an interviewee in Chisinau notes, *"we are doing what we are doing because of the Hesed. Without them we would not be caregivers. We simply did not view ourselves as care providers in the past."*

#### Feeling of being supported and not being alone

Curators and homecare workers report being in frequent touch with family caregivers: inquiring about their situation, providing them with practical advice or just listening to their difficulties. Family members in most locations confirmed this and very much appreciated the availability of Hesed workers, while many of them noted that this interaction made them *"feel they were not alone in their struggles"*. Survey results strengthen qualitative findings and show that a majority of family

caregivers (88%) attribute high/very high levels of contribution to the Heseds, in making them feel they have someone to turn to (see below in Figure 10).



**Figure 10. Contribution of the Hesed support to family caregivers' perceptions.**

Moreover, the Hesed assistance, specifically its psychological advice and homecare visits, have helped family members feel emotionally supported; they felt they had more time for themselves and allowed them to experience reduced stress. One interviewee notes that caring for her relative *"became easier emotionally. The homecare worker took up some of my responsibilities and her visits really helped me."* Other interviewees too are grateful for the homecare support, as it allows them to have some Me time. Accordingly, one family member says that the home visits are very important to her, because *"usually this is when I get out of the house, off to the city to do some shopping or go to the pharmacy to get our medication."* Another interviewee shares similar thoughts:

*"Thanks to the Hesed homecare services, I now have some time for myself. I don't have to constantly sit with my relative. I know that the homecare worker will come and take good care of her, which makes everyone happy."*

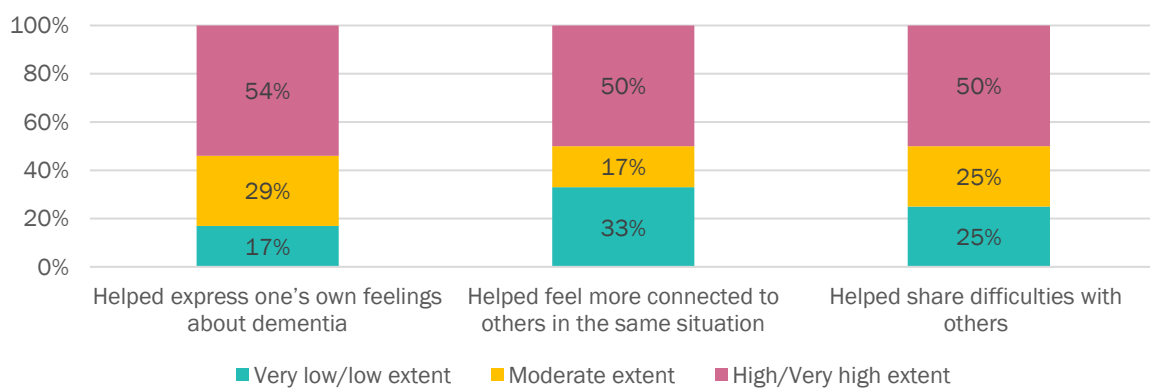
At the same time, certain family caregiver interviewees also felt that they did not receive significant support at the Hesed. As one interviewee says, *"whenever a problem occurred, I usually solved it on my own."* Similar reports were more frequently recorded in Kyiv, while family caregivers elsewhere attributed higher levels of contribution to their Hesed assistance. As for the quantitative findings, the low number of survey respondents did not allow for comparative statistical tests to be carried out. However, it was noted during the analysis that respondents from Kyiv tended to assess the contribution of their Hesed assistance as lower (usually as low/very low), while respondents at the other three locations tended to rank it higher (especially in Chisinau). The triangulation of qualitative and quantitative findings therefore indicates a general trend. Assistance to family members was less systematic in Kyiv, with only a few activities specifically aimed at this beneficiary group, while homecare support in the WJR programme was also limited to none. The limited support is likely the reason behind the lower results.

### 3.4.3 Contribution to behaviour change

#### Sharing about dementia

As noted above in section 3.2, many of the Heseds tried to establish peer support groups for family caregivers, with mixed results. In Minsk and Kyiv, support groups were not sustainable. *"The group*

*work was difficult for family caregivers,”* notes one Coordinator. Deep-seated stigma surrounding dementia in the wider communities, alongside family caregivers’ shame and reluctance to open up to each other, were the main reasons. In Kharkiv, peer-group activities had been more successful initially and taken place regularly. But when the Covid-19 pandemic hit and activities shifted online, family members lost interest. The most successful peer-group encounter was observed in Chisinau, at the Memory Café, which provided a regular opportunity for family members to meet in a friendly environment and interact freely. Survey results also show that the local dementia programmes have been somewhat less (all in all, moderately) successful in connecting family members with fellow caregivers. Figure 11 below shows that half of the survey respondents feel the Hesed support has helped them to a high/very high extent in sharing their difficulties with others and connecting with other caregivers of a similar situation. The rest of the respondents find the Hesed support moderately or even less helpful in this regard. Individual support (such as consultation with a psychologist or a social worker) has proven more effective and better appreciated by family caregivers. It is highly recommended to offer more such support in future programmes.



**Figure 11. Contribution of the Hesed support to family caregivers’ ability to share about dementia with others.**

### Improved communication with loved ones with dementia

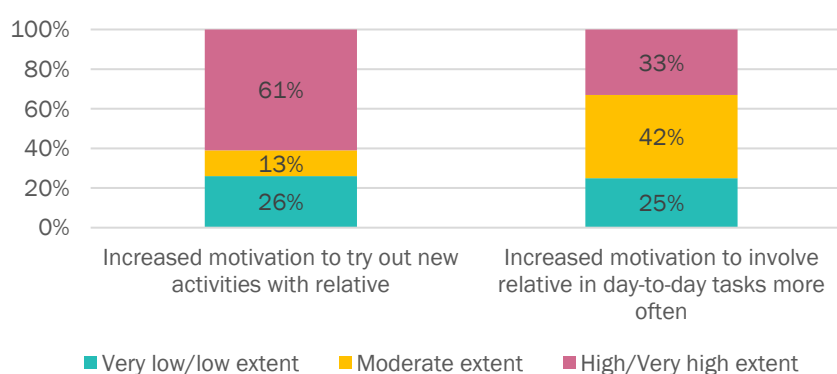
Qualitative and quantitative findings suggest that the Hesed support (particularly its practical advice from curators, homecare workers and consultation with the psychologist) has made a significant contribution to family caregivers’ communication with their loved ones. *“I’ve learnt how to control my emotions, accept my relative and not to be angry with him,”* recounts one interviewee. Another interviewee shares a similar contribution:

*“Suddenly my mother took a photograph and started eating it. It was shocking... but over at the Hesed, they explained why and how I shouldn’t get cross with her.”*

In their survey responses, 64% of family caregivers agree to a high/very high extent that the Hesed support has improved their communication with their relatives. Interviews also reveal that in some specific cases, improved communication has then led to significant improvements in the overall relationship between family caregivers and their relatives with dementia.

## Changes in family members' care for their loved ones with dementia

Survey results show that some family caregivers have tried to implement changes in their care for loved ones (see below in Figure 12). Few interviewees also mention that they have learnt some new stimulating exercises, which they have started practicing with their loved ones. However, results also suggest that a more person-centred care is not widely exercised among family members. While they have learnt how better to navigate day-to-day challenges and improve their communication, providing people with dementia more choices or creating a more engaging environment for them remains a challenge for many family caregivers. Moreover, Hesed homecare worker interviewees also note that certain family members continue to resent their relatives with dementia and show very little willingness to take any advice on board or modify their interaction or care. It is likely that for more significant changes to occur, family members should have a more systematic support from the Heseds.



**Figure 12. Hesed support's contribution to changes in family members' care for loved ones with dementia.**

All in all, family caregivers very much appreciate the assistance received at the Heseds. Nearly all survey respondents (96%) are highly/very highly satisfied with their Hesed support. The Hesed assistance has been most effective in equipping caregivers with practical knowledge on how to manage the day-to-day life of their loved ones and embrace a more attentive communication with them. Moreover, the support has also made family members feel they are not alone in their struggles, thereby contributing to positive changes in their mental health and well-being. These are significant achievements for the local dementia programmes. Meanwhile, results also suggest some room for improvement in this component. The Heseds could better systematise their family caregiver interventions and prioritise one-on-one support, such as consultation with a psychologist or accompaniment by a social worker. Moreover, learning new ways of dementia care has been most effective at home, in front of family caregivers' eyes. This approach could receive more emphasis in the local dementia programmes, even when a client with dementia is not eligible for homecare support.

### 3.5 Results among people with dementia

This section lays out the results that emerged among people with dementia, the ultimate beneficiaries of the WJR programme. Findings below present the culmination of data gathered from various sources, including interviews and FGDs with people who are at high risk of, or live with, dementia, observations of Hesed day centre activities (in Kyiv and Chisinau), interviews and survey

results among Hesed workers and interviews and survey results among family caregivers. Some of these beneficiary groups vary significantly in their assessment of the programme's contribution. Recognising that the care experience can be somewhat subjective, we will present various views below. Moreover, some of these groups spend more time with people with dementia, while others less. This may also affect their views.

### 3.5.1 Satisfaction

Information regarding satisfaction with the Hesed support was mostly gathered from people who had attended dementia group activities at the day centres. Interviewees and FGD participants all said they "*looked forward to their day centre activities*" and prepared for their meetings, for example, by sprucing up ahead. Observations also reveal that dementia groups enjoyed a positive and friendly atmosphere (including the online meetings), while participants were eager to attend, chatted with each other and actively engaged in exercises.

### 3.5.2 Contribution to knowledge

#### Knowledge on dementia and what it means to live with it

WJR programme staff expected that the various activities and support at the Heseds would lead to higher levels of dementia awareness among older people. Findings, however, show limited progress in this regard. Dementia and how to live with the condition were not a frequently discussed topics with clients who attended day centre activities and/or benefitted from home-based care. These issues were not addressed during group activities; nor did Hesed homecare workers talk about them with their clients. Interviews also reveal that most clients were not familiar with the term '*dementia*', though many of them admitted to having some degree of memory problems. Participants of day centre activities usually considered attending their groups as a preventive measure. One interviewee, for instance, notes that "*I really don't like the memory exercises in the group, whether with words or numbers. But I understand that it's important that I practice them, in order to avoid future problems.*" Some specific interviewees had higher knowledge on dementia, and even cited knowing some people with dementia. Nevertheless, even these interviewees did not believe they had the condition, or they did not feel comfortable to disclose it to the evaluation team. This finding suggests that despite the many positive programme achievements, there remains a lack of understanding when it comes to dementia, notably among the very people who live with the condition.

Information gathered from family caregivers also indicates that Hesed activities and support have moderately influenced their relatives' dementia awareness. In their survey responses, 30% of family caregivers agreed to a very low/low extent that the Hesed assistance had increased their relatives' dementia awareness, while 30% agreed to a moderate extent and 40% agreed to a high/very high extent. All in all, results suggest some room for improvement in this regard.

### 3.5.3 Contribution to perception and behaviour changes

#### Increased acceptance of one's own condition, but not necessarily of dementia

Interviews with clients, their family caregivers and homecare workers suggest that the Hesed support has helped some older people accept that they "*do not remember certain things*". In the absence of open discussion on dementia, however, people tended to attribute their memory losses to a

normal aging process rather than to the condition. Therefore, the evaluation has found no evidence of increased acceptance of dementia among older people.

### Positive changes in the mood of people with dementia

Positive changes in the mood of people with dementia have been widely reported by all beneficiary groups. People with mild/moderate dementia (usually participants of the Hesed day centre activities) note that their meetings have helped them psychologically, for example, *"improved their emotional state"*. As a family caregiver explains, positive changes in the mood of her loved one had far-reaching positive consequences:

*"He very much liked attending the group meetings at the Hesed day centre. I mean, the meetings somehow uplifted his spirit. And of course, his good mood always had a positive effect on everything else: his communication, thoughts and memory."*

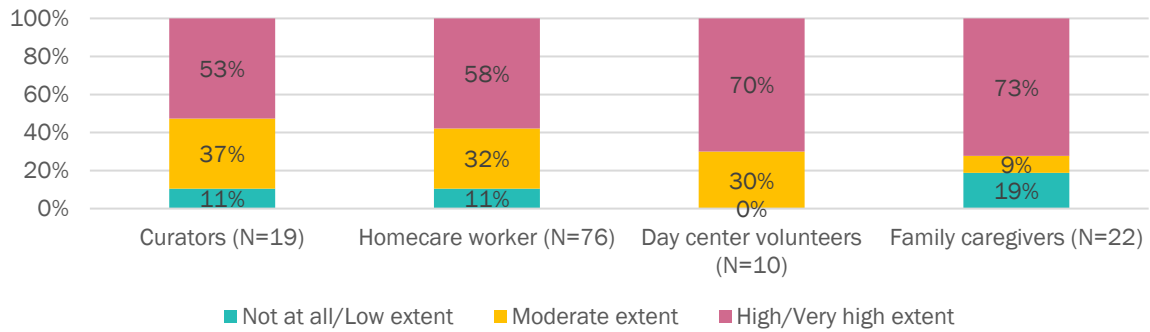
Interviewees also note that during their group meetings, they feel supported by Hesed staff and/or fellow participants. An interviewee shares:

*"Communication with fellow participants helps me emotionally. I always look forward to our meetings, because we joke a lot and cheer each other up."*

In Ukraine, the Russian invasion has introduced a lot of additional stress to the lives of older people. Group activities have been found to be helpful in reducing some of it. In Minsk, group activities were attended by people with more severe dementia. According to Hesed staff involved in these meetings, participants in Minsk also benefitted from improved well-being. One of the volunteers assisting the group notes that *"the clients get to interact with each other and they enjoy it very much. Otherwise, they would just sit at home."*

Homecare workers caring for people with severe dementia too widely report positive changes in their clients' mood. A majority of interviewees have said that their clients wait for their visits, and are happy when the homecare workers are around. One interviewee notes that *"whenever I come by my client immediately smiles and recognises me"*. Another homecare worker says that her client has an *"improved outlook on life"* thanks to her visits, while others mention that their clients *"do not feel lonely, and are more active, sociable and cheerful"*. The following quotes by various Hesed workers in our survey all refer to the positive contribution of their care to the well-being of older people with dementia. One Hesed worker, for instance, reports that her client *"has understood that he is not alone, that someone needs him, and that he can still do some things on his own."* Another respondent mentions that her client *"feels protected"* in her presence. Some homecare workers, however, report no improvements in their clients' mood, but said that the older people were frequently angry, *"behaved strangely"* and often tried to argue with them. While present on the ground, such reports were not widespread.

Survey results also show that most Hesed workers, volunteers and family caregivers have seen positive changes in the mood of people with dementia as a result of the Hesed assistance. Results, however, vary by different respondent groups. Day centre volunteers and family caregivers were significantly more optimistic and reported higher levels of positive changes, while curators and homecare workers reported somewhat lower results, as shown in Figure 13 below.



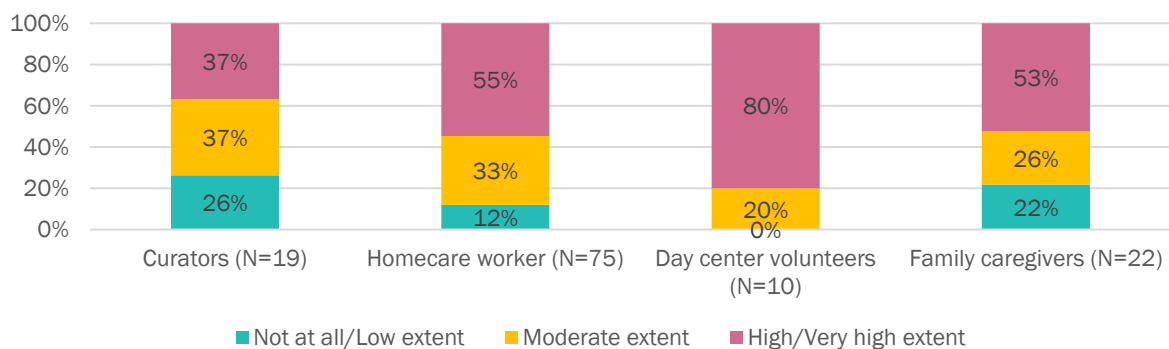
**Figure 13. Influence of the Hesed support on the mood of people with dementia, as seen by Hesed workers, volunteers and family caregivers.**

### Active engagement in hobbies/favourite activities and other joyful tasks

Interviews, FGDs and observations confirm that attendants of Hesed day centre activities are usually actively involved and enjoy most of the tasks. At the same time, findings also indicate that participants of day centre activities do not have much say on the content of their group work and have limited power to decide which activities to undertake.

Homecare workers caring for people with severe dementia in their homes had more opportunities to take into consideration their clients' personal preferences and abilities. As various quotes show above, several homecare workers encouraged their clients to get involved in activities they enjoyed and were still within their power, like playing the piano, reading books or doing crosswords together, art and craft exercises, light housework and more.

Quantitative findings among Hesed workers, volunteers and family caregivers show different results. Curators assessed the level of engagement of people with dementia to be lowest in joyful tasks, while Hesed volunteers (usually assisting day centre activities) assessed it as significantly higher (overall as high/very high). Homecare workers and family caregivers reported similar results. Nearly half of them assessed the level of people's engagement as high/very high; 25-30% assess it as moderate, while the rest assessed it as very low/low, as shown in Figure 14.

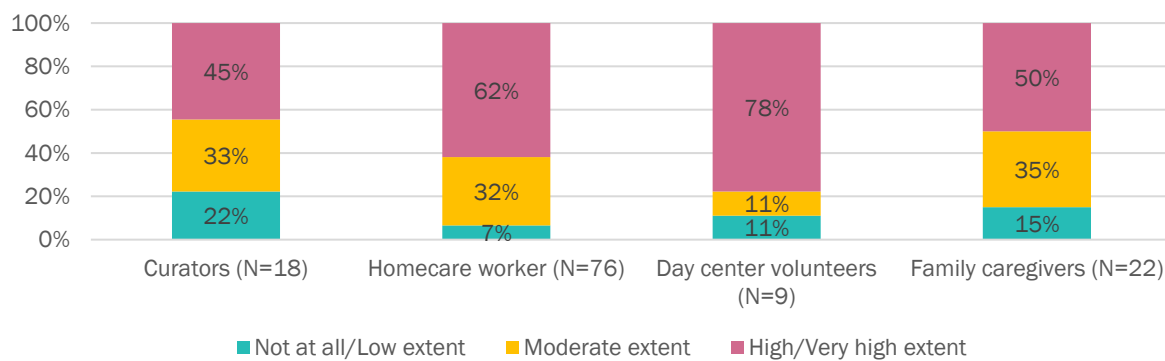


**Figure 14. Influence of the Hesed support on the engagement level of people with dementia with joyful activities, as seen by Hesed workers, volunteers and family caregivers.**

## Improved communication and social relationships

Several interviewees (clients, Hesus workers and family caregivers) report that the Hesus assistance has helped people with dementia improve their communication and relationships. Various quotes presented above show that participants of day centre activities enjoy meeting each other and communicating with fellow group members. Some homecare workers have also reported positive results among people with more severe dementia: a homecare worker says that her clients have *"become more open to communicate. Even people with whom I no longer work call me and want to remain in touch."* Another homecare worker mentions that her client *"has become more sociable with others and even started calling his friends over the phone."* Similar positive results vis-à-vis the communication among people with dementia have been reported by a number of homecare workers and at various locations.

Quantitative results of various respondent groups vary greatly, with curators being the least optimistic; day centre volunteers stand as the most optimistic, reporting the highest-level positive changes in the social relationships of people with dementia. Once again, homecare workers and family caregivers responded similarly, reporting a moderate positive change (see Figure 15 below).



**Figure 15. Influence of the Hesus support on the social relationships of people with dementia, as viewed by Hesus workers, volunteers and family caregivers.**

## Maintaining the skills and abilities of people with mild/moderate dementia

As dementia is a progressive condition, maintaining the skills and abilities of clients with the condition was not a general expectation of WJR staff *per se*. Some participants of the Hesus day centre activities (usually people with mild/moderate dementia), however, have praised their groups for helping them preserve their physical strength and cognitive functions – benefits they attribute to the local dementia programmes. For instance, physical exercises are thought to invigorate people's *"muscle function and blood circulation"* and contribute to their improved well-being. One interviewee highlights the positive influence of physical exercises:

*"Before the group meetings, you wake up and it's hard to walk, to move yourself... But then you come to class, warm up and immediately get better, physically speaking. You stretch your muscles and your health improves."*

Other interviewees note that group exercises on brain neuroplasticity stimulate some of their cognitive functions. *"Your brain starts working, you start remembering things,"* says one interviewee.

Facilitators and volunteers with day centre activities also cite the positive effect of continuous participation in the dementia group activities on clients' abilities. As one day centre interviewee explains:

*"When a client misses out on a series of group meetings, due to an illness, for example, the next time they attend, they do everything slower. We notice that they have more difficulties and require more of our help."*

This last quote signifies the importance of continuity in dementia care. Some Hesed interviewees working in the day centres also find that the positive effects of the dementia groups could be maximised if meetings took place more often or if clients continued practicing at home, assisted by their family members or Hesed homecare workers.

### **Maintaining a daily/weekly routine for people with severe dementia**

Hesed homecare workers report that maintaining a different form of continuity, a daily/weekly routine, had a significant positive effect on people with severe dementia. A regular routine *"made clients feel better and helped preserve their dignity."* Clients with a regular routine became more willing to engage in daily hygiene and other tasks, such as light housework or other meaningful activities. When a homecare worker fell ill for more than two weeks, however, and the Hesed could not replace her, the interviewee saw a deterioration in her clients' situation.

This finding too signifies the importance of continuous dementia care, in home-based settings as well as across day centres. The Heseds should do their best to ensure such continuity. If resources allow, day centre group meetings could be more frequent (at least once a week). Moreover, family caregivers could be taught and encouraged to follow up on some of the day centre activities back at their loved ones' homes. Homecare for people with severe dementia should be provided on a regular basis, as irregular care can negatively affect the overall condition of clients in the most vulnerable situation. When possible, day care should be combined with some form of homecare, to maximise their contribution.

Finally, the evaluation team has gathered some examples of good practices that demonstrate the achievements of the WJR programme, particularly the high levels of care provided by the Heseds to people with dementia, and their contribution.

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**About the client:** A. is a 92-year-old widow with severe Alzheimer's disease. A. lives alone with no family support.

**Hesed support:** A. used to attend dementia group activities at the Hesed day centre, but is no longer able to leave her home. Today, she participates in online group activities. A. also receives regular homecare support by a social worker (10 hours a week) and is occasionally visited by Hesed volunteers, who chat and socialise with her. The homecare worker regularly introduces some cognitive exercises and keeps A. engaged in other joyful tasks, such as art and craft work and physical exercises. She also helps A. with house chores.

**Influence of Hesed support:** A. has heard of dementia and knows that she often forgets stuff but is not aware of having dementia. A. recognises her Hesed homecare worker and the two share a warm relationship. Their communication is positive, attentive and respectful. A. enjoys it whenever the social worker comes around, and very much likes the activities she engages in. A.

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actively uses her smartphone in order to attend online group activities and communicate with other people.

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**About the client:** B. is an 80-year-old woman with severe dementia. B. repeatedly tried to harm herself in the past and was institutionalised, but ran away.

**Hesed support:** Once a week, B. attends the Hesed day centre activities. Moreover, she receives regular homecare support, and Hesed volunteers visit her to chat and socialise with her.

**Influence of Hesed support:** B. appears to be a very well-cared for person. She has heard of dementia and understands that the condition has to do with memory loss. B. knows people around her who live with the condition; however, she does not believe that she herself has dementia. B. very much enjoys the day centre activities and loves meeting fellow group members. She remembers them and considers them to be her friends. B. has a good relationship with her homecare worker. The two women learn Romanian together and play various games. B. very much enjoys their time together. The homecare worker also signposted B's apartment with positive affirmations, such as *"I love to..."* or *"things that I used to like..."*. The two women regularly look at the signs and share their memories. B. feels that the various activities she undertakes at the day centre and at home help her *"be more focused and sharper"* in her mind and give her *"something to look forward to"*.

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**About the client:** C. is an 85-year-old woman with severe dementia. C. has advanced memory loss and suffers hallucinations. C. lives alone but is regularly visited by her daughter, whom she does not recognise.

**Hesed support:** C. receives regular homecare support at the Hesed. Due to her condition, three social workers care for her. C. does not recognise any of them. C.'s apartment has been signposted, to help her better navigate her space.

**Influence of Hesed support:** Despite her difficult condition, C.'s relationship with her homecare workers is mostly good. They keep her engaged in various activities and tasks. Whenever she is involved in something, she participates actively, pays attention and communicates well. When not engaged in any tasks, she reverts back to a severe condition.

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This section reveals the many positive effects of the local programmes in the lives of people with dementia. Thanks to their Hesed support, several older people have experienced improvements in their mental health and well-being. Moreover, many older people also note the positive changes in their communication and social relationships. Such positive results have been frequently reported by clients with mild/moderate dementia, as well as by those living with severe forms of the condition. Thanks to their Hesed assistance, clients have also been actively involved in various dementia-friendly activities that they enjoy, in the day centres as well as at home. Clients have had little say on their day care activities, but homecare workers would usually take into consideration their clients' preferences and abilities and plan their activities accordingly. Continuity was found to be a key factor in effective dementia care. Continuous engagement in group activities has helped some clients with mild/moderate dementia to maintain their physical strengths and some abilities. A regular routine in home care (another form of continuity) has significantly contributed to people with severe dementia:

it has made them more open for certain tasks, allowed them to feel better and helped them preserve their dignity. Despite the many positive achievements, there is one issue in which the local programmes have made limited progress.

### 3.6 Results among other organisations, partners

This last section provides a brief summary of the results revealed by the evaluation team among other organisations and partners who had attended WJR awareness-raising training courses. Some of these partners were representatives of other Heseds, while others hailed from local civil society organisations and/or state institutions. Partners arrived at their WJR learning activities with varying levels of initial knowledge on dementia. Some had heard about the condition before, but a majority of partners learnt about dementia for the first time at their WJR seminars. Partners found their WJR seminars very practical, with hands-on knowledge provided. For instance, some interviewees came to realise that dementia was a condition and also recognised *"the urgent need of supporting people with the condition as well as their family caregivers"*. Other interviewees say that the WJR seminars helped them *"get inside the mind of people with dementia"* and better understand their challenging situation. Others again highlight the person-centred approach in dementia care as their main takeaway from the learning events. From among the various partners interviewed for this evaluation, representatives of one organisation report making some concrete changes in their programming as a result of the WJR seminars. The interviewee summarise the changes as such:

*"We've implemented a lot of changes in our work: for instance, we organised a dementia-friendly support group for 10-15 people. We also trained 120 social workers, raised their awareness on dementia and taught them how to personalise their care. Finally, we dedicated additional homecare hours to the stimulation and engagement of older people with various joyful activities."*

Following their WJR seminars, some partners have remained in touch with the Heseds across the four main locations. Those usually continued their learning curve and attended other awareness-raising sessions on dementia, organised by the Heseds. Actual implementation of the knowledge, however, remained scarce.

## Chapter 4. Conclusions and Recommendations

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### 4.1 Main conclusions

As Chapter 3 demonstrated, WJR's Dementia Programme has made clear advancements towards its goals and contributed to significant results, thereby laying down a strong foundation for the local dementia programmes. Hesed workers/volunteers have become more professional as they received high/very high levels of new knowledge on dementia and dementia care. Increased knowledge has led to positive perception changes, and most Hesed workers (especially curators and homecare workers) have put their new knowledge into practice and made some significant changes in their care for people with dementia.

Thanks to the WJR financial support, the Heseds locally developed and then rolled out a range of specialized services, such as dementia-friendly group activities at their day centres and home-based care that energized and stimulated people with the condition. While most of the dementia-friendly homecare services were person-centred, group activities were not specifically tailored to participants' interests and situations. This could be improved in the future.

The WJR assistance also drew the Heseds's attention to the importance of supporting family caregivers. The Hesed assistance has proven most effective in equipping family caregivers with practical knowledge on how to manage the day-to-day life of their loved ones and communicate more attentively. Moreover, the support has also made family members feel they are not alone in their struggles, thereby contributing to positive changes in their mental health and well-being. Despite these important achievements, caregiver support has remained limited relative to needs on the ground and insufficiently systematic. In the future, this component should be prioritized and further developed in the local programmes.

Thanks to their Hesed support, several older people with dementia have experienced improvements in their mental health and well-being. Many older people also cite positive changes in their communication and social relationships. In addition, clients have been actively involved in various dementia-friendly activities that give them joy, in the day centres and/or at homes. Continuity was a key factor for effective dementia care, and as such it should be promoted in future programmes as much as possible.

Finally, thanks to the WJR support, most Heseds have managed to transform their operations, gain significant expertise in dementia care and go from mere recipients to leading experts in the field. Dementia Coordinators have held a variety of locally developed awareness-raising activities, targeting Hesed clients and/or the general public, social work professionals at other Heseds/in state institutions, policy implementers and decision makers. Advocacy efforts were particularly successful in Minsk and Kyiv, contributing to the institutionalization of the knowledge generated by the programme and some larger-scale changes.

## 4.2 Ways for improvement

Despite the significant positive results listed above, some unfulfilled potentials remain. Moreover, due to the immense challenges of the implementation period (Covid-19 pandemic and the Russian invasion of Ukraine) some results failed to last. The following sections offer some key recommendations that could help further increase the impact of WJR's Dementia Programme thereby strengthening the local dementia initiatives.

### Continue investing in the capacity building of Hesed workers/volunteers

During and after the Covid-19 pandemic, professional development activities for Hesed workers/volunteers became less frequent, including their local dementia training. Most Coordinators agree about the importance of relaunching their seminars, refreshing and deepening knowledge on the ground. Coordinators have also suggested the organisation of another round of training for trainers in order to increase the number of qualified professionals at the Heseds who can educate others. Moreover, the facilitation of cross-border knowledge sharing and experience exchange has also been widely requested. Future capacity-building activities could focus on particularly challenging issues, such as supporting older people with dementia who have additional health conditions, supporting clients with a high level of aggression and/or depression, personalisation of dementia group activities or improved identification and follow-up on dementia cases. Practical, hands-on examples are preferable to theoretical information.

### Improvements in the identification and follow-up on people with dementia

The current system used by the Heseds to identify and categorise people and their dementias does not produce reliable results, even though the allocation of Hesed services is dependent on it. Moreover, the Heseds also lack a standardised follow-up system, which could help them keep track of changes in the clients' situation (their capabilities, behaviour and everyday functioning). In the absence of a more accurate identification and follow-up system, it is difficult to offer truly person-centred dementia services. WJR could assist the Heseds in improving their work in this regard.

### Improvements in dementia-specific social care services

#### Homecare support

Hesed management and Dementia Coordinators have mentioned the insufficient homecare hours currently available to their clients, specifically to non-Nazi victims. Moreover, as echoed by Hesed staff, some people with early-onset dementia (under 65 years) were not eligible to any home-based support even under the flexible WJR funding. While the current WJR programme does not explicitly include homecare, the organisation could in the future earmark funds to some specific forms of home-based care, as it has turned out to be an effective assistance. For instance, when the same trained homecare worker provided regular and communication homecare, she was able to dedicate more of her time to engaging the clients in joyful activities. Moreover, family caregivers were also better able to internalise new information on dementia care when given the chance to observe homecare workers caring for their relatives (homecare for learning purposes). In a future programme, WJR could consider financing some or more of these types of support. Finally, Hesed workers have also suggested the establishment of a flexible emergency fund that could provide funding for

homecare services in urgent and special cases, for instance, when a Hesed client presents with dementia from a younger age.

### **Daycare activities**

Homecare services have been significantly more personalised than day centre activities. Future capacity-building activities of Hesed staff could focus on this issue, while additional funding could explicitly support the personalisation of dementia group activities. A good example for a person-centred group activity was observed in Chisinau, at the Memory Cafe. This is a hugely successful endeavour of Hesed Yehuda. Similar group-based interventions could be developed elsewhere too, with additional funding and professional advice from WJR.

### **Continuity**

Continuity of dementia care should be promoted to the fullest extent. Accordingly, the Heseds should make sure that people with severe forms of dementia and in need of/entitled to the support do not remain without regular home-based care. Moreover, the positive effects of the dementia groups may be maximised if the meetings take place more often or if clients could continue practicing at home, assisted by their family members or Hesed homecare workers.

### **Improvements in family caregiver interventions**

WJR could increase its support for family caregiver interventions and help the Heseds better systematise their work in this regard. Family caregivers often preferred one-on-one support and hands-on learning with a social worker. These components could receive more emphasis in the local programmes. Strengthening family caregiver support is also to become more relevant in the future, as Nazi victims are passing away, while increasing numbers of the old older clients at the Heseds (people at high risk of developing dementia) are non-Nazi victims. This beneficiary group is not eligible for the same level of social support, and their reliance on family caregivers is therefore likely to increase in the future.

### **Promoting awareness raising among clients**

Dementia awareness has remained low among the very clients who live with the condition. According to Coordinators, many old people are not ready/willing to accept their condition, which makes it difficult openly to address it. Some WJR capacity-building activities could help Hesed staff think of gentle and culturally-appropriate ways to address dementia with their affected clients and show them how to live with the condition. Moreover, awareness raising should start well before people are most vulnerable. Prior to the Covid-19 pandemic, the Heseds were active in promoting an open discussion on the condition among their clients, as well as in the Jewish and wider communities. The pandemic, however, has impeded this awareness-raising work. WJR could help the Heseds restart their public awareness raising and adjust it to current realities on the ground.

### **Continue with a cooperative, flexible and differential approach**

The final note concerns the nature of WJR's cooperation with the Heseds. Thanks to the organisation's flexible approach, each Hesed developed their local dementia programmes according to needs and possibilities on the ground. This was key for the many successes, ensuring high levels of

ownership over the local programmes. In the future, WJR is advised to continue its flexible and differential approach, as it has proved to be highly effective.

In Minsk, the main priorities include capacity-building among Hesed workers, following the slowdown of the Covid-19 pandemic, setting up another dementia group at the day centre and/or more frequent group meetings, in order to ensure continuity. Supporting family caregivers remains challenging, but Hesed Rakhamim uphold it as a priority nevertheless. In Chisinau, the intention is to upscale the current activities: provide additional capacity-building opportunities for Hesed staff, increase homecare support and offer more frequent dementia group meetings, including Memory Cafe sessions. Due to the ongoing Russian invasion of Ukraine, the Heseds in Kyiv and Kharkiv should strengthen their family caregiver interventions, given that many people with dementia cannot be reached otherwise, due to the current war. Moreover, in Kyiv there is a need to include some form of homecare support in the local programme which is currently largely missing. Finally, the situation in Kharkiv remains challenging. Under the current circumstances, the main priority for the Hesed is to invest in capacity building among newly recruited staff. Moreover, as chances of restarting the local dementia programme as a standalone intervention are slim, the Coordinator has suggested to have it merged with another project that combats loneliness among older people. WJR is advised to take these priorities into consideration when planning the continuation of its programme.

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### Evaluation of World Jewish Relief Dementia programme

#### Background:

World Jewish Relief has been a funder of projects in support of the social cohesion and physical wellbeing of older people for over 20 years, mainly within the context of the Jewish community and predominantly in Ukraine but also in Georgia, Moldova, Belarus and Poland. Our projects are entirely implemented by local partner organisations in-country – mainly 'Heseds' which are Jewish social welfare organisations, and we support both core costs and programmatic costs of project implementation.

In 2015 we embarked on a programme aiming to improve awareness and knowledge of dementia and increase opportunities for people with dementia, and their relatives, to access appropriate support and activities more tailored to their needs.

Over a period of approximately 3 years (2015-2018) we visited numerous times, bringing along experts in dementia care from another UK organisation – Jewish Care. During this time we identified key issues and challenges, conducted training on person-centred approaches, and also brought social care professionals from our partner organisations to the UK for exchange visits. We focused on four locations where we had strong partnerships – Kyiv, Kharkiv, Minsk and Chisinau.

In brief, the following challenges were identified:

- Overall lack of understanding on the basics of dementia, leading to overemphasis on “prevention” as opposed to understanding how to live with dementia.
- Lack of person-centred approaches – at its worst form involving medication of people with advanced dementia and a purely medical/institutional approach (State system), alongside sometimes very rigid, one-size fits all approach (such as cognitive stimulation exercises) within the Hesed network.
- Frequent conflicts at home between carers and individuals with dementia, burnout of carers.
- Lack of suitable activities for people at home and in day centre settings.
- Lack of suitable residential care options.
- Misunderstanding of dementia in wider society, stigmatisation of dementia.
- Lack of timely medical diagnoses of dementia and no differentiation as to the different types of dementia which exist.
- Challenges in physical environment for older people in general, specifically dementia.

After identifying these challenges we set specific goals for the programme as follows:

- 1. To build the capacity of the Jewish community caring for older people those living with dementia and/or disability.**
- 2. To make Jewish communities more ‘dementia friendly’ and accessible for those with disabilities in the long term.**
- 3. To support the development of better social care for future Jewish generations.**

*\*A more detailed breakdown of these objectives and intended outcomes is included at the end of this ToR.*

## What we did

- Introduction trainings on person-centred approaches, covering basics on dementia, for Jewish community social workers and those from the State system.
- Train the trainer seminar for key staff members.
- Recruited dementia leads in 4 locations.
- Started funding dedicated day centre activities for people with dementia.
- Introduced dementia carer support – mainly in the form of peer support, specific training sessions for relatives, in some places social activities.
- General awareness raising – by partners and us, information dissemination.
- Exchange visits for key partners to the UK to visit dementia care programmes.

## Context in 2023

Programmes in the four initial locations have continued, albeit with moderations due to the Covid-19 pandemic and then the full-scale Russian invasion of Ukraine. These involve a combination of direct assistance to people with dementia and their families; regular training and support sessions for care staff; psychological support to family carers; day centre activities for people with dementia; home visits to people with dementia. In a further 13 locations where we work we are funding smaller scale activities – many focused on support to family carers. These activities have emerged a result of both our engagement with staff on this issue and our provision of specific funds for doing so. In some locations, staff have actively engaged with wider community structures such as State social care services to share knowledge and learning, but this has been done in an ad-hoc way.

Clearly and understandably, the war has turned attention of both Government and Civil Society in Ukraine to other pressing matters. However, we can see small signs of progress in terms of awareness raising and increased understanding of dementia in society at large. Yet, research shows that older people are less likely to evacuate or relocate, and people with dementia have experienced increased trauma and worsening of symptoms as a result of living in a war context. This means they are among the most vulnerable to be caught up in the war.

***As we look to further invest in the capacity of our partner organisations to continue to improve dementia awareness and quality of care, we are looking for someone to***

***conduct an evaluation of our work to date in this area and help guide us in developing a strategy on dementia for the next 3 years.***

Key objectives of the evaluation:

- Provide analysis of the extent to which the original issues identified are still relevant today
- Assess to what extent the programme has met its original objectives outlined above
- Provide an evidence base for demonstrating the effectiveness of the

programme methodology, specifically identifying which elements of the programme are most/least effective – with the secondary goal of producing evidence to use in communications and fundraising materials to further draw attention and funding to World Jewish Relief programmes

- Identify any unintended (positive or negative) outcomes and impacts of these activities
- Produce strategic recommendations for further investment in this area, looking at training needs and potential for other collaboration by identifying key stakeholders

## **Methodology**

- The successful candidate should plan and use a variety of methods for data collection and analysis, both quantitative (e.g. surveys) and qualitative (for example with focus groups, key informant interviews, individual interviews, etc.) as necessary.
- In undertaking this evaluation, the consultant will look at a sample of dementia projects (geography tbd – majority in Ukraine, plus one other location). The process will be guided and informed by World Jewish Relief, who will be working closely with the consultant on designing of methods and tools and providing all required information and data on relevant projects (e.g. funding applications, narrative reports and budgets, previous internal evaluation).

## **Output/Deliverables**

The following deliverables will be expected:

- 1) Evaluation methodology and tools finalised in consultation with World Jewish Relief.
- 2) A final impact evaluation report in English, containing results (quantitative and qualitative), lessons learned, conclusions and recommendations, among other information to be determined by the evaluator and World Jewish Relief.
- 3) An executive summary of the final evaluation report, containing key findings and statistics to enable us to develop relevant communications materials from the report

## **Governance**

The evaluation consultant will work independently, but will coordinate closely with World Jewish Relief via email, Skype, telephone and meetings in person as needed. World Jewish Relief will assist with logistics and administrative support, including arranging meetings with partners.

## **Timeframe and logistics**

We anticipate that the timeframe of this evaluation will be approximately divided as follows:

- Methodology and design of evaluation tools – 5 days
- Fieldwork – 15 days, plus travel time
- Analysis and report writing – 5 days
- Meetings with World Jewish Relief – 1 day (2 half-day meetings – one before fieldwork and one following submission of final report)

Travel, accommodation costs and expenses will be covered by World Jewish Relief and should be included in the evaluation budget.

The final report and executive summary should be finalised and submitted to World Jewish Relief ideally by the end of December 2023.

## **Requirements**

The successful candidate should possess the following skills and experience:

- Working knowledge of and experience in dementia and disability in Eastern European context (a medical background is not required).
- Practical experience in conducting similar research/evaluations.
- Excellent analytical and communication skills.
- Report writing skills (in English).
- Fluent proficiency in Ukrainian/Russian.
- Ability to travel to Ukraine (security depending) and/or Moldova/Georgia, including significant local travel during field work.

## **Original objectives:**

To improve the well being of older people in the Jewish community living with dementia and/or disability through enhanced quality of care and increased understanding.

## **Specific objectives are:**

***To build the capacity of the Jewish community caring for older people those living with dementia and/or disability.***

## **Actions**

1. To hire staff in each location to :
  - Participate in Jewish Care training and then share/develop skills of homecare workers and other staff
  - Arrange events for the community
  - Distribute materials
  - Raise awareness in the press and encourage a person-centered approach across Hesed programmes
2. Hire a member of staff (social/support worker) to provide support for relatives/carers of people living with dementia or other complex needs.
3. Provide companionship homecare for people living with dementia (provided by trained staff/volunteers)
4. Establish new social opportunities for people with dementia and their family members (e.g. Memory Way Cafe, Singing for the brain, reading groups)

## **Outcome/impact**

1. Jewish community has better understanding of dementia and can

- better provide for Hesedclients with dementia
2. Relatives are better able to cope and can provide better care for their relatives.
  3. People living with dementia are able to stay at home (rather than go into State care)
  4. People living with dementia are less socially isolated and have improved emotional well being.

***To make Jewish communities more 'dementia friendly' and accessible for those with disabilities in the long term.***

**Actions:**

1. Distribute information and arrange special events for community (and wider Jewishcommunity) about dementia
2. Making existing Hesed services dementia friendly, e.g. Warm Homes, Day centre activities

**Outcome/impact:**

1. Less social isolation among future generations
2. Reducing stigma associated with mental health problems
3. Community is better able to care for those with additional needs

***To support the development of better social care for future Jewish generations.***

**Actions:**

1. Discuss and inform local authorities/National Gov. on aims and results of project
2. Include local social workers/other professionals in training opportunities on dementia
3. Raise awareness in the local media and with other NGOs/social sector organisations about theproject

**Outcomes/impact**

1. Improve social services in-country for future Jewish generations
2. Increased awareness and understanding of dementia in wider community – benefits Jewishcommunity now

## Annex 2. Evaluation Surveys

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### Survey Targeting Trained Hesed Workers

Dear Sir or Madam,

The British charity World Jewish Relief (WJR) has been supporting various dementia activities at Heseds/in the wider community, and we are conducting an evaluation of these activities in order to understand what further support is needed in this area.

We are eager to hear your thoughts. Your feedback will play a crucial role in improving the dementia programme and moving forward.

**The questionnaire is entirely anonymous, and it takes about 10 minutes to fill.**

The information you provide will be aggregated and used solely for the purpose of this evaluation.

**Thank you very much for your contribution.**

The WJR team

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#### Part 1. [Control]

##### 1. Where are you based?

- 1) Belarus
- 2) Ukraine
- 3) Moldova
- 4) Georgia
- 5) Other, please specify: \_\_\_\_\_

##### 2.1 Please mark the statement that applies to you the most:

- 1) I currently work for Hesed [Condition: If Q2.1 == 1 -> Proceed to Q2.2]
- 2) I used to work for Hesed in the past, but I am no longer an employee [Condition: If Q2.1 == 2 -> Proceed to Q2.2]
- 3) I currently volunteer with the Hesed [Condition: If Q2.1 == 3 -> Proceed to Q3]
- 4) I work/volunteer in a separate organisation and have never worked at Hesed. [Condition: If Q2.1 == 4 -> Proceed to Q3]

##### 2.2 In what position are you working/did you work for Hesed?

- 1) Curator
- 2) Homecare worker
- 3) Working at the day center
- 4) Psychologist
- 5) Other, please specify: \_\_\_\_\_

**3. Between 2016 and 2018, British organisations World Jewish Relief (WJR) and Jewish Care organized a range of learning activities across the region (at Heseds, and other community spaces) that focused on dementia and the person-centered approach in dementia care.**

**Please mark the activities you participated in:**

	Yes	No	I am not sure
1) A one-off (2-3-day) seminar	1	2	3
2) A series of training courses	1	2	3

**4. Have you participated in other training courses at Hesed that focused on dementia and dementia care, such as training courses facilitated by the Dementia Coordinator, other Hesed managers or the JDC/Joint?**

- 1) Yes
- 2) No
- 3) I am not sure

[Condition: If Q3.1 & Q3.2 == 2 or 3 AND Q4 == 2 or 3 -> proceed to END of SURVEY]

**Part 2. [Knowledge]**

**5. To what extent have the Hesed learning activities on dementia and dementia care contributed to your knowledge and skills in the below fields?**

	Not at all	Low extent	Moderate extent	High extent	Very high extent	Don't remember/ Not applicable
1) Improved your knowledge of dementia, its causes, signs and symptoms, stages of development and consequences	1	2	3	4	5	99
2) Given you new knowledge on the behaviors of people living with dementia and the reasons behind them	1	2	3	4	5	99
3) Increased your ability to prevent or diffuse behaviors of older people living with dementia that you find challenging	1	2	3	4	5	99
4) Increased your knowledge on the person-centered approach in dementia care	1	2	3	4	5	99

5) Increased your understanding of the impact of dementia on the client, their family members and other caregivers	1	2	3	4	5	99
6) Increased your ability to support family members/caregivers of people living with dementia	1	2	3	4	5	99
7) Increased your professional knowledge/skills related to dementia care with information you did not know before	1	2	3	4	5	99

**6. Have you shared your new knowledge/skills on dementia and dementia care with others, such as your colleagues, family members or friends?**

- 1) I did not share any information
- 2) I shared a little bit of information
- 3) I shared a lot of information

**Part 3. [Perception]**

**7. To what extent has your participation in the Hesed learning activities on dementia and dementia care...**

	Very low extent	Low extent	Moderate extent	High extent	Very high extent	Don't know/Not applicable
1) Increased your empathy towards clients living with dementia	1	2	3	4	5	99
2) Increased your ability to identify if a client is showing the signs and symptoms of dementia	1	2	3	4	5	99
3) Increased your ability to recognize the interests, the skills and abilities that a client still has, despite their dementia	1	2	3	4	5	99
4) Improved your communication with clients living with dementia	1	2	3	4	5	99
5) Inspired you to try out new activities and personalized approaches when caring for clients living with dementia	1	2	3	4	5	99

8. Has your participation in the Hesed learning activities on dementia and dementia care contributed to you personally beyond your professional work? Please explain.

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**Part 4. [Behavior]**

9. To what extent have you been able to carry out the following activities/tasks in your daily work?

	Very low extent	Low extent	Moderate extent	High extent	Very high extent	This task is not part of my professional responsibilities
1) Getting to know clients with dementia better, for instance, mapping their life stories, hobbies and interests	1	2	3	4	5	99
2) Planning activities specifically taking into account your client's interests	1	2	3	4	5	99
3) Creating opportunities for clients to maintain the skills and abilities they still have	1	2	3	4	5	99
4) Regularly involving clients living with dementia in household chores such as cooking, cleaning, washing, shopping [Condition: Ask Q9.4 if Q2.2 == 2]	1	2	3	4	5	99
5) Rearranging the space in the day center or other social spaces to make it easier for people living with dementia to navigate/more dementia friendly [Condition: Ask Q9.6 if Q2.2 == 3]	1	2	3	4	5	99

**10. All in all, to what extent have you been able to implement a more person-centered approach in your work with clients living with dementia?**

Very low extent	Low extent	Moderate extent	High extent	Very high extent	The person-centered approach is not part of my daily work
1	2	3	4	5	99

**Part 5. [Influence on clients]**

**11. To what extent do you think this approach has affected your clients living with dementia in the below fields?**

	Not at all	Low extent	Moderate extent	High extent	Very high extent	Don't know/Not applicable
1) Their mood has improved.	1	2	3	4	5	99
2) They have become more active and engaged in tasks they enjoy.	1	2	3	4	5	99
3) They feel that somebody cares for them and they feel less lonely.	1	2	3	4	5	99
4) They have better social relationships	1	2	3	4	5	99
5) Other, please specify: _____	1	2	3	4	5	99

**Part 6. [Challenges and improvement]**

**12. Were there any challenges that limited your ability to implement a person-centered approach when caring for clients living with dementia?**

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**13. Did the HESed provide you with any of the below support when working with clients living with dementia? [Condition: If Q2.1 == 4 -> Proceed to END of SURVEY]**

	Yes	No
1) Additional learning opportunities (training courses, workshops) to learn more about dementia and how to care for people living with dementia	1	2
2) More regular supervision	1	2
3) One-on-one psychological support	1	2
4) Psychological support in a group with other carers/staff/volunteers	1	2
5) Other, please specify: _____	1	2

**14. How could Hased improve its activities to better support you in your work with clients living with dementia?**

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**You've reached the end of this survey.**

**Thank you very much for your cooperation!**

[END of SURVEY]

## Survey Targeting Family Members/Caregivers

**Interviewee to mark the following information prior to the interview:**

**Date of interview:** \_\_\_\_\_

**Gender of interviewee:**            1) male                            2) female

**Introduction**

Dear \_\_\_\_\_,

My name is \_\_\_\_\_, I am contacting from Info Sapiens, a research company and I have received your contact details from the Hesed. The Hesed would like to improve the support it gives to people living with dementia and their family members. Your feedback will play a crucial role in it.

**The questionnaire is entirely anonymous, and it takes about 10 minutes to respond.**

**Thank you very much for your contribution.**

**Part 1. [Hesed support]**

**1. Have you or your relative received any of the following support from Hesed?**

	Yes	No	I don't know/Don't remember
1) Regular home visits by a homecare worker to assist your relative with house chores (shopping, cooking, cleaning)	1	2	99
2) Regular home visits by a homecare/social worker to look after your relative and allow you to take couple of hours off	1	2	99
3) Regular home visits by a professional to conduct physical or cognitive exercises with your relative	1	2	99
4) Online group activities for your relative	1	2	99
5) In-person group activities for your relative at the Hesed day center	1	2	99
6) Lectures or information sessions for you (family members) on dementia	1	2	99
7) Social outings (such as visiting a cafe) or activities for you and/or your relative to attend together	1	2	99
8) One-on-one psychological support for you or your relative	1	2	99

9) Group meetings (peer support) with other family members who care for their relatives living with dementia (online or in-person)	1	2	99
10) Other, please specify: _____	1	2	99

**2. To what extent do you think this support affected your family member in the below fields?  
Thanks to the Hesed support...**

	Not at all	Low extent	Moderate extent	High extent	Very high extent	Don't know/Not applicable
1) Your relative is aware of their condition and what the implications are of living with dementia	1	2	3	4	5	99
2) Your relative's mood has improved.	1	2	3	4	5	99
3) Your relative has become more active and engages in tasks he/she enjoys.	1	2	3	4	5	99
4) He/she has better social relationships.	1	2	3	4	5	99
5) Other, please specify: _____	1	2	3	4	5	99

**Part 2. [Knowledge, perception, behavior]**

**3. To what extent has the support from the Hesed...**

[Knowledge, perception and behavior: Caring for family member]

	Not at all	Low extent	Moderate extent	High extent	Very high extent	Don't know/Not applicable
1) Improved your knowledge of dementia, its causes, signs and symptoms, stages of development and consequences	1	2	3	4	5	99
2) Given you new knowledge on the behaviors of people living with dementia and the reasons behind them	1	2	3	4	5	99
3) Increased your ability to better understand the situation and challenges of your relative	1	2	3	4	5	99

4) Increased your confidence in your ability to care for your relative	1	2	3	4	5	99
5) Increased your ability to recognize the skills and abilities that your relative still has, despite their dementia	1	2	3	4	5	99
6) Improved your communication with your relative	1	2	3	4	5	99
7) Motivated you to try out new activities with your relative	1	2	3	4	5	99
8) Motivated you to involve your relative in day-to-day tasks more often	1	2	3	4	5	99
9) Increased your ability to prevent or diffuse behaviors of your relative that you find challenging	1	2	3	4	5	99
10) Improved your relationship with your relative in general	1	2	3	4	5	99

**4. To what extent has the support from the Hesed contributed to the following...**

[Perception and behavior: Self-care]

	Not at all	Low extent	Moderate extent	High extent	Very high extent	Don't know/Not applicable
1) Helped you express your own feelings over dementia	1	2	3	4	5	99
2) Helped you feel more connected and supported by others in the same situation	1	2	3	4	5	99
3) Helped you share your difficulties with others	1	2	3	4	5	99
4) Made you feel you have someone to turn to	1	2	3	4	5	99
5) Helped to reduce the stress you feel over caring for your relative	1	2	3	4	5	99

**5. All in all, to what extent are you satisfied with the support you and your relative receive from the Hesed?**

Very low extent	Low extent	Moderate extent	High extent	Very high extent
1	2	3	4	5

6. Is there something else the Hesed could do to better support you and your family member?

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**Part 3. [Demographics]**

7. Where are you based now? [Interviewer: If the person is an IDP in Ukraine, please mark this under the category 'Other':]

- 1) Belarus
- 2) Moldova
- 3) Ukraine – Kyiv
- 4) Ukraine – Kharkiv
- 5) Other, please specify: \_\_\_\_\_

8. How old are you? [Interviewer: to mark one of the following categories:]

- 6) 18-30
- 7) 31-40
- 8) 41-50
- 9) 51-60
- 10) 61-70
- 11) 71 or older]

**Thank you very much for your cooperation!**

[END of SURVEY]