DIARY Project

Disability Inclusive Action and disaster risk Reduction surveY project

Development of Guidance for Mental Health and Welfare Systems in Disasters Based on Collaboration with People with Psychosocial Disabilities [Technical report]

Department of Community Mental Health and Law,
National Institute of Mental Health, National Center of Neurology and Psychiatry

Porque, the Organisation of Persons with Psychosocial Disabilities

Introduction

This guidance document is an output of the collaborative research project, “Development of Guidance on the Mental Health and Welfare System During Disasters Based on Collaboration with Persons with Psychosocial Disabilities” (Subproject Investigator: Takayuki Kawaguchi). The research was conducted as part of the Mental and Neurological Disorders Research and Development Program funded by the National Center of Neurology and Psychiatry, under the project titled “Research on Collaboration and Workforce Development for Comprehensive Mental Health Services” (Project No. 4-2; Principal Investigator: Chiyo Fujii; Period: April 1, 2022, to March 31, 2025). It is based on the disaster risk reduction approach for inclusively addressing the needs of persons with disabilities as clearly stated in the outcome document “Sendai Framework for Disaster Risk Reduction 2015–2030”[1)] adopted at the Third United Nations World Conference on Disaster Risk Reduction. Notably, the guidance uniquely compiles essential measures for disaster management from the perspective of persons with psychosocial disabilities who have experienced natural disasters.

This research adopts an internationally rare user-led/controlled research approach in which persons with lived experience take the lead in all stages of a project (from planning to data collection, analysis, evaluation, and dissemination), while researchers participate by providing expertise and support. The project was implemented in collaboration with Porque, the organisation of persons with psychosocial disabilities (Representative Director: Yuhei Yamada), and it was conducted as the “DIARY Project” (Disability Inclusive Action and disaster risk Reduction surveY project) focusing on investigating disaster experiences via interview surveys with persons with psychosocial disabilities and service providers. We hope this guidance will contribute to the further development of disability-inclusive disaster management and the promotion of user-led/controlled and co-creative initiatives in the mental health field.

In conclusion, we sincerely thank the many stakeholders whose cooperation made this project possible.

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1. Background for Creating the Guidance

As society increasingly recognises the need for inclusive disaster management systems, there is growing awareness that persons with disabilities encounter particular challenges in accessing information, evacuating promptly, and securing adequate living conditions in shelters during natural disasters. Evidence of these challenges has been provided through investigations after such disasters. For example, a report by the Japan Broadcasting Corporation (NHK) following the 2011 Great East Japan Earthquake highlighted that the mortality rate among persons with disabilities was nearly twice that of the general population. Such evidence raises concerns that persons with psychosocial disabilities (including those with developmental disabilities) may have reduced crisis recognition that prevents them from taking appropriate evacuation measures.

The previous study[2)] contained draft guidelines for the general mental health, medical, and welfare systems in disaster situations. However, these guidelines, which were created through consensus surveys conducted by psychiatric experts, did not specifically address support for persons with psychosocial disabilities. Furthermore, systematic research to consolidate guidance based on the disaster experiences of persons with psychosocial disabilities has been very limited, with existing literature primarily comprising case studies or personal accounts.

Consequently, the needs of persons with disabilities have not been adequately addressed in Japan's disaster management plans. In fact, Japan received the following recommendations in the 2022 concluding observations of the Committee on the Rights of Persons with Disabilities on Japan's initial report under the Convention on the Rights of Persons with Disabilities[3)]:

> (Paragraph 26) In accordance with the Sendai Framework for Disaster Risk Reduction 2015–2030, ensure that disaster prevention plans and strategies (at national, prefectural, and municipal levels) as well as climate change policies are formulated together with persons with disabilities and explicitly address their specific needs in all hazardous situations.

Against this backdrop, Porque—the organisation of persons with psychosocial disabilities—has been actively promoting initiatives centred on "mental health and disasters," using the experiential knowledge gained from support activities in disaster areas during the 2011 Great East Japan Earthquake and the 2016 Kumamoto Earthquake. The association has organised symposia on disaster preparedness and risk reduction in various parts of Japan. Drawing on experiences of the damage caused by Typhoon No. 19 in 2019 (the 2019 East Japan Typhoon), it also conducted a questionnaire survey of people with disabilities in Ota Ward, Tokyo, where the association is based, and interviews with local government officials and disability service facilities. Based on these activities, it produced the report and recommendations entitled "Future Approaches to Disaster Preparedness and Risk Reduction in Light of Typhoon No. 19 in 2019—Research Report and Recommendations"[4)].

In transforming observations and insights into concrete issues recognised as "our problems" in the current project, we conducted an interview survey with persons with psychosocial

disabilities who have disaster experience and service providers. Their responses allowed us to compile a thorough analysis of the specific challenges faced by persons with psychosocial disabilities during disasters in the Japanese archipelago, where earthquakes occur particularly frequently. This led to the development of practical guidance on concrete and effective disaster preparedness and risk reduction measures, considering the motivation of persons with psychosocial disabilities and service providers to engage in disaster preparedness and risk reduction.

2. Research Roadmap

This guidance document was created based on a user-led/controlled research approach—whereby persons with lived experience lead all stages of the research—in conjunction with examining the disaster experiences of persons with psychosocial disabilities and service providers during the Great East Japan Earthquake and the Kumamoto Earthquake from the perspective of inclusive disaster management. The research process is illustrated in Figure 1.

Based on previous studies[5-7] on patient and public involvement (PPI) that advocate flexible and joint engagement across different research phases, discussions began among research members in November 2021 during the preparatory phase to determine the research themes and plan. Actual research activities commenced in April 2022. A period was set aside from December 2022 to March 2023—illustrated in Figure 1—to reach a consensus on qualitative analysis methods and overall procedures. During this period, the team dedicated significant effort to developing mutual understanding and refining their ideas and received supervision from an expert in qualitative analysis.

This extended preparatory period was essential to respect the diversity of perspectives among participants and to progress jointly through each phase of the research project.

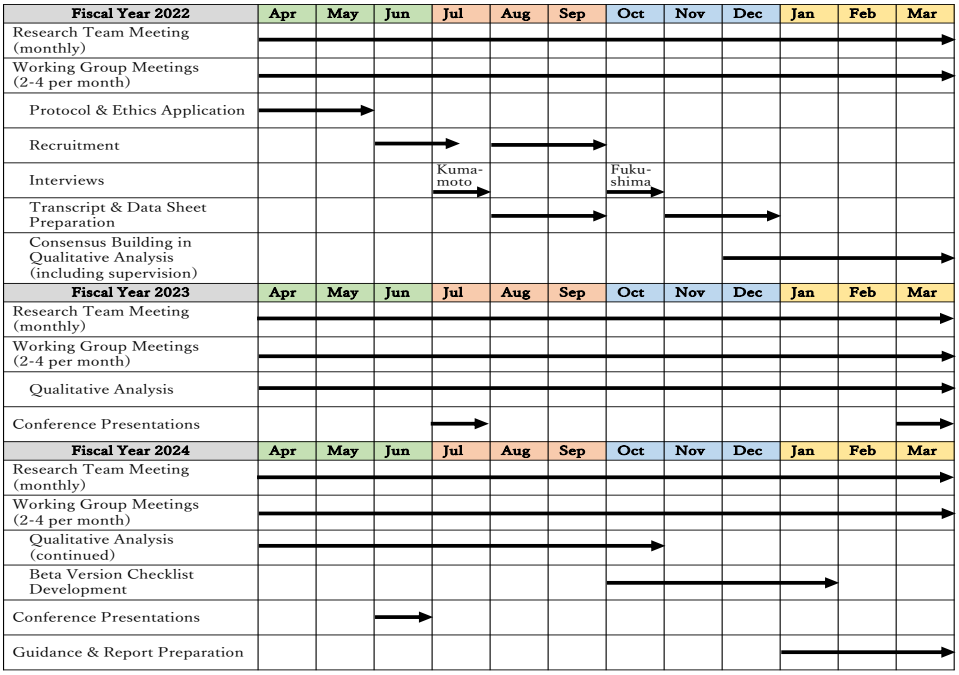


Figure 1: Research Roadmap [2022.4–2025.3]

3. Process of User-Led/Controlled Research

Since the turn of the 21st century, PPI in research—which features patients and citizens participating alongside researchers—has been internationally encouraged[8]. In the field of mental health, this paradigm shift was prompted by recognition that treatments developed solely by experts (such as pharmacotherapy or psychological methods) can have limited effectiveness[9].

The United Kingdom has led the way for PPI, stating that "no funding will be provided for research without patient and public involvement" and thus making it a standard requirement in research[10]. The Mental Health Research Network (MHRN) actively promotes involving persons with lived experience as full research collaborators, engaging in tasks from planning and data analysis to manuscript writing[11]. The momentum for "experts by experience" is growing across the field worldwide.

Patient and public involvement is seen as a crucial measure for generating academic value and driving a paradigm shift in research[12]. In essence, user-led/controlled research can be considered an evolved form of PPI: In this approach, persons with lived experience lead every step of the project—including conceptualisation and implementation—while researchers provide guidance and flexible support.

Our research activities have also led to the publication of papers detailing the challenges that arise in involving persons with psychosocial disabilities through a series of research phases. We have also undertaken conference presentations comparing the process of conducting research in collaboration with persons with psychosocial disabilities with the process of traditional researcher-led/controlled research[13].

Moreover, insights from the current study have been applied to public disaster preparedness workshops held in regions such as Kumamoto and Hokkaido. These workshops have been featured on media outlets including NHK (e.g., "Ashita wo Mamoru Navi" aired on November 26, 2023, and a special program on NHK Kumamoto NEWS on June 13, 2024) and TBS Radio ("Jinken TODAY" on October 12, 2024).

Table 1: Comparison of User-Led/Controlled Research and Patient/Public Involvement Research

Item	*User-Led/Controlled Research*	*Patient and Public Involvement Research*
Role of users involved	Take responsibility for research design, data collection and analysis, and dissemination.	Engage in the planning phase of the research and data interpretation, providing input and opinions.
Research ownership	Persons with lived experience design and conduct the research themselves.	Researchers lead the study with patients/citizens serving as advisors or collaborators.
Implementation structure	Led by persons with lived experience, with experts providing support as needed.	Researchers lead, while patients/citizens participate in advisory roles.

Item	*User-Led/Controlled Research*	*Patient and Public Involvement Research*
Funding acquisition	Persons with lived experience take the lead, including applying for external grants.	Researchers secure funding from institutional budgets.
Significance	Empower persons with lived experience and ensure research addresses real issues.	Enhance research utility by integrating patient/citizen perspectives.
Research objectives	Resolve issues that the persons themselves care about.	Elevate research quality by incorporating patient/citizen input.
Research direction	Driven by the perspectives of persons with lived experience directly impacting their lives and societal issues.	Predominantly researcher-driven while incorporating patient/citizen insights.

4. Overview and Method of Creating the Guidance

This guidance was prepared based on the results of an interview survey involving 23 persons with psychosocial disabilities who had experienced disasters (targeting those affected by the Great East Japan Earthquake and the Kumamoto Earthquake) and 15 service providers and administrative personnel (see Appendix). In addition, a questionnaire survey[14)] was administered to 161 persons with psychosocial disabilities regarding their views on “daily disaster preparedness” (see [Activity 2] in Reference Materials). The qualitative analysis of the interview data generated five main themes:

- Difficulties experienced due to the disaster
- Support received during the disaster
- Pre-disaster disaster preparedness measures
- Post-disaster changes in disaster preparedness
- Challenges and hopes regarding disaster support for the future

Notably, many persons with psychosocial disabilities reported concerns related to the interruption of regular support, difficulties in securing medication, issues with the setup and operation of evacuation shelters, and experiences of stigma and discrimination. The questionnaire further highlighted that 34.8% of respondents carried medication with them in preparation for disasters and 53.5% had their medication records. In addition, many respondents indicated that they faced difficulties in determining quantities for stockpiling and maintaining supplies. These responses underscored the need for enhanced disaster education.

The insights gained from these surveys were compiled into the “Checklist for Inclusive Disaster Management (Beta Version)” and proposals to promote inclusive disaster management in mental health, both of which were included in this guidance document.

5. Intended Users of the Guidance

The guidance in this document is provided along with checklists tailored to persons with psychosocial disabilities and to service providers. The version for persons with lived experience focuses on concrete disaster preparedness measures, with the goal of encouraging self-checks regarding daily preparedness, evacuation readiness, and preparations for life in evacuation settings. The version for service providers is designed to support the establishment of organisational systems in disaster support and to guide direct support measures that consider psychological safety during disasters. These checklists are intended to be used to develop individual evacuation plans and business continuity plans during disasters.

Furthermore, by utilising video materials developed as part of the DIARY Project—titled "Everyday Disaster Preparedness—Learning from the Experiences of Persons with Psychosocial Disabilities"—users can deepen their understanding of disaster preparedness measures through visual reinforcement. Although the checklist on disaster stockpiling and related measures was developed from the perspectives of persons with psychosocial disabilities, its contents are also applicable to general disaster preparedness. Thus, addressing the issues raised by persons with psychosocial disabilities is expected to contribute to improving safety and reassurance among all evacuees during disasters.

The Proposals for Inclusive Disaster Management in the Field of Mental Health were compiled through the DIARY project after examining the issues that are considered necessary from the perspective of promoting future disaster preparation measures in the disability field.

6. Checklist for Inclusive Disaster Management—Persons with Psychosocial Disabilities Version (Beta)

Checklist for Inclusive Disaster Management—Persons with Psychosocial Disabilities Version (Beta)

For each item below, mark the corresponding checkbox if you are already engaged in the activity.

No	Items	✓
Category 1: Daily Preparedness		
1	Do you regularly talk about disaster preparedness and evacuation methods in your daily life?	
2	Do you consult with your medical or welfare service providers regarding disaster preparedness?	
3	Do you discuss your medications with your primary doctor in preparation for disasters?	
4	How do you manage any leftover medications in your daily life?	
5	Do you carry your medication with you when you are out?	
Category 2: Preparedness for Evacuation		
6	Have you taken measures—such as fixing furniture, securing fragile items, and keeping your home tidy—in anticipation of needing to evacuate suddenly?	
7	Have you prepared for a situation in which you must escape immediately following a disaster?	
8	Where do you keep your medication so that you can take it with you quickly if you need to evacuate?	
9	Do you store your medication record safely?	
10	Do you have specific evacuation locations, routes, or methods in mind?	
11	Who would you like to contact immediately after the disaster?	
12	How do you plan to communicate with others immediately after a disaster?	
Category 3: Preparedness for Life during Evacuation		
13	Have you stockpiled drinking water and water for other daily needs in an evacuation?	
14	Have you prepared food supplies in anticipation of an evacuation?	
15	Do you have essential disaster-preparedness items ready for use during an evacuation?	
16	Have you prepared personal items suited to your preferences and specific needs due to disability characteristics during a disaster?	
17	Have you checked the emergency alert settings on your smartphone?	
18	In your opinion, what special measures are necessary for information gathering during an evacuation?	
19	Have you considered informing others about your disability or the reasonable adjustments you might require during an evacuation?	
20	Have you thought about how to secure some time or space for yourself during evacuation?	
21	If you were to participate in future disaster drills, what would you expect from them?	

7. Explanation of the Checklist (Persons with Psychosocial Disabilities Version)

Through self-checks using this checklist, let's consider our efforts for daily preparedness, evacuation preparation, and preparation for life during evacuation. Here are some clarifications regarding each section:



【Daily Preparedness】

Item 1: Do you regularly talk about disaster preparedness and evacuation methods in your daily life?

Although the necessity of disaster preparedness is recognised, the reality is that we have few opportunities to talk about the necessary measures in our daily lives. People who have gone through disasters have shared their experiences, noting that discussions about disaster preparedness with family and friends temporarily increased after a disaster. When a natural disaster strikes, people may not remember the previous one. Let's create opportunities to be aware of necessary disaster preparedness measures without feeling burdened.

Item 2: Do you consult with your medical or welfare service providers regarding disaster preparedness?

During evacuation drills at welfare facilities, disaster preparedness is sometimes discussed, such as when checking routes to evacuation shelters together. However, some people have shared that this topic rarely comes up with home-based or medical service providers.

Item 3: Do you discuss your medications with your primary doctor in preparation for disasters?

There are many cases in which people felt anxious when they did not have their medication available during a disaster. We have also received stories of people who, after a disaster, regularly consult with their doctor about their amount of prescribed medication in preparation for a disaster.

Item 4: How do you manage any leftover medications in your daily life?

In relation to the above, people who have experienced disasters have shared what they have done, such as, "I save any medication I forget to take for emergencies." It may be worth discussing this with your doctor during your next appointment.

Item 5: Do you carry your medication with you when you are out?

In relation to the above, some people who have experienced disasters have shared what they have done, saying, "When I go out, I carry a few days' worth of medication in my bag." Earthquakes are a natural disaster that can occur at any time, so it's important to think about what to do in case of a disaster while you're out and about.



【Preparation for Evacuation】

Item 6: Have you taken measures—such as fixing furniture, securing fragile items, and keeping your home tidy—in anticipation of needing to evacuate suddenly?

It's important to make it a habit to avoid storing heavy items in high places. One disaster survivor said, "If you tend to keep your room messy, tidying up as much as you can on a regular basis is important as a disaster preparedness measure."

Item 7: Have you prepared for a situation in which you must escape immediately following a disaster?

It's also a good idea to develop good habits in case you need to escape suddenly. Some disaster survivors have said, "Glass was flying when we left our bed, so it was good to have slippers," and "I've decided where to put my glasses when I go to bed."

Item 8: Where do you keep your medication so that you can take it with you quickly if you need to evacuate?

Disaster survivors have taken various measures to protect the medications they take regularly. We received responses such as "I store my medication not only at home but also at work," and "It's safer to store medication in multiple locations rather than just one."

Item 9: Do you store your medication record safely?

It is possible that you may not be able to see a doctor immediately after a disaster. In such cases, having your medication record with you can be an effective solution. One example was, "Thanks to having my medication record with me at the evacuation site, I was able to get my regular medication prescribed."

Item 10: Do you have specific evacuation locations, routes, or methods in mind?

It is important to check the locations of evacuation shelters in case of a disaster at your home, welfare facility, or workplace. In some cases, a planned route may become inaccessible because of the disaster. One disaster survivor said, "I check hazard maps and confirm multiple evacuation routes."

Item 11: Who would you like to contact immediately after the disaster?

It is a good idea to have multiple ways of checking on the safety of others immediately after a disaster. One experience was, "It was a relief to be able to contact the people who usually provide support."

Item 12: How do you plan to communicate with others immediately after a disaster?

There may be times when telephones and the internet are not available. Smartphones may be damaged due to the disaster. It is also important to write down the phone numbers of people you would particularly need to contact in your notebook.

【Preparation for Life during Evacuation】

Item 13: Have you stockpiled drinking water and water for other daily needs in an evacuation?

Securing water is very important in the event of a disaster. We have received stories of people saying, “I had side effects from medication, so I needed more drinking water than others.” If your disability or medication means that you need more drinking water or water for daily use, you should take this into account when preparing for disasters.

Item 14: Have you prepared food supplies in anticipation of an evacuation?

People who tend to be picky eaters or have difficulty swallowing because of side effects from medication should also consider the possibility that rationed food may not be suitable for them. People with allergies should also be especially conscious of stocking up on food for themselves.

Item 15: Do you have essential disaster-preparedness items ready for use during an evacuation?

Try to gather disaster preparedness supplies that you think you will especially need. People reported that it would be especially helpful to have cold weather protection such as blankets, wet wipes to keep the body clean, and dry shampoo.

Item 16: Have you prepared personal items suited to your preferences and specific needs due to disability characteristics during a disaster?

Based on their experiences, some people have suggested preparing items such as masks, sunglasses, and earplugs to accommodate sensory sensitivities. Surrounding noises can be particularly stressful when living in an evacuation shelter. It’s also a good idea to include calming items like stuffed toys, soft towels, bubble wrap, and games in your disaster preparedness kit.

Item 17: Have you checked the emergency alert settings on your smartphone?

You can change the emergency alert settings on your smartphone. Some people have reported that the alert sounds they received with each aftershock after a disaster increased their anxiety. Some people have also shared their experiences of lowering the volume of notification sounds as needed.

Item 18: In your opinion, what special measures are necessary for information gathering during an evacuation?

Gathering information is extremely important when living in an evacuation shelter. However, information of unknown veracity or the information gathering process itself can be extremely stressful. It’s sometimes necessary to exercise restraint when watching television or obtaining information from social media. It may also be worth limiting the information you receive to information from people you trust.



Item 19: Have you considered informing others about your disability or the reasonable adjustments you might require during an evacuation?

One disaster survivor said, “It was difficult to explain the necessary accommodations verbally, and I felt a sense of burden.” While everyone faces great difficulties during a disaster, it’s important to regularly communicate about your disability and gain experience in requesting reasonable accommodations.

Item 20: Have you thought about how to secure some time or space for yourself during evacuation?

People who live with their families will likely spend more time with their families than usual during evacuation after a disaster. This situation can sometimes lead to stress. People who have experienced disasters have said things like, “It would have been nice to have a place to relax and spend time.”

Item 21: If you were to participate in future disaster drills, what would you expect from them?

Even though people understand the importance of disaster preparedness efforts, not many have actually participated in a disaster response drill. Some people have reported that they “participated in a local government disaster response drill and were able to interact with their neighbours.” It might be a good idea to take this opportunity to participate in a disaster response drill held in a place close to you. It might also be worth considering holding a disaster preparedness workshop at a workplace or welfare facility with familiar acquaintances.



8. Checklist for Inclusive Disaster Management—Service Provider Version (Beta)

Checklist for Inclusive Disaster Management—Service Provider Version (Beta)

For each of the following items, check off the corresponding box if you have verified or taken the indicated action with your service users or in your organisation.

No	Items	✓
Category 1: Points to Confirm with Service Users		
1	Have you confirmed with service users the details of disaster stockpiling as part of disaster preparedness?	
2	Have you discussed medication with service users in preparation for a disaster?	
3	Have you discussed with service users how to request understanding of their disability in preparation for a disaster?	
4	Have you reviewed and confirmed evacuation methods (including those for home settings) with service users?	
5	Have you confirmed with service users the people they wish to contact and how to reach them in an emergency?	
6	Have you discussed with service users how to filter and select reliable information during disasters?	
Category 2: Knowledge for Advocacy		
7	Are you aware of the importance of providing disaster support that safeguards the psychological safety of service users?	
8	Do you understand that service users may exhibit a range of physical and mental responses during a disaster, requiring tailored support?	
9	Are you aware that service users might require special support during a disaster?	
10	Do you know that service users might need assistance in navigating systems and applying for benefits during a disaster?	
11	Do you understand the importance of safeguarding the rights of service users while living in evacuation settings?	
Category 3: Support System for Disaster Preparedness		
12	Do you routinely update and maintain service users' essential information (including medication details and emergency contacts) with their consent?	
13	Is there an established communication network (e.g., within your organisation or with external agencies) for disaster situations?	
14	Have you ensured that the necessary supplies (water, food, and disaster-preparedness items) are available for disaster support?	
15	Have you secured an evacuation space that can accommodate service users during disasters?	
16	Is there a system in place for creating individual evacuation plans that consider each service user's needs during evacuation?	
17	Have you established a support system for your own staff during disaster response situations?	
18	Do you conduct disaster drills that consider the unique needs of your service users owing to their disability characteristics?	
19	Do you share information about each service user's medical and welfare service status with relevant agencies, with their consent?	
20	Are you in discussions with other agencies regarding potential issues with medication supply during disasters?	
21	Have you developed relationships with nationwide disaster support organisations so that appropriate support can be mobilised during a disaster?	
22	Have you established networks with organisations representing persons with disabilities to enhance disaster support?	

9. Explanation of the Checklist (Service Provider Version)

When you look over this checklist, let's reflect on your daily support activities and check what you should confirm with your service users, knowledge for advocacy, and the status of awareness-raising and system development efforts regarding support systems for disaster preparedness and mitigation. Please note that [Category 1. Points to Confirm with Service Users] is not intended to assess whether users (service users) are taking disaster preparedness measures; it is a checklist for joint confirmation. Furthermore, because reminding service users of disasters may incite anxiety or fear, before discussing disaster preparedness and mitigation with service users, be sure to obtain their consent for the discussion. [Category 3. Support System for Disaster Preparedness] cannot be completed by your facility alone; it requires active relationship building and collaboration with other facilities and the local community. Use this guidance to communicate and establish a community-wide disaster preparedness and mitigation system.



【Points to Confirm with Service Users】

Item 1: Have you confirmed with service users the details of disaster stockpiling as part of disaster preparedness?

Some service users need support in imagining what kind of supplies and the quantities they should prepare to safely and securely remain at home or live in an evacuation shelter. For example, more drinking water than the average amount will be needed, considering water for medication. It is also important to prepare disaster response supplies and reassuring items tailored to the service user's disability characteristics.

Item 2: Have you discussed medication with service users in preparation for a disaster?

It is important to confirm where medication is stored so that service users can quickly take it with them in the event of a disaster. It is also a good idea to confirm regularly how to store surplus medication in case scheduled hospital visits are not possible. In some cases, you may need to support the service user in discussing prescription amounts with their doctor in anticipation of a disaster.

Item 3: Have you discussed with service users how to request understanding of their disability in preparation for a disaster?

Considering ways for service users to ask those around them for understanding of their disability and for necessary support can be reassuring, assuming they will have to evacuate or live in an evacuation shelter after a disaster.



Item 4: Have you reviewed and confirmed evacuation methods (including those for home settings) with service users?

Consider where and how to evacuate safely after a disaster and which route to take, accounting for the service users' habits, schedules, and locations. Note that disasters can occur even when they are not at home.

Item 5: Have you confirmed with service users the people they wish to contact and how to reach them in an emergency?

Consider who to contact and how to contact them after evacuating to safety, taking into account the service users' habits, schedules, and locations. Consider carrying a written copy of contact information with you.

Item 6: Have you discussed with service users how to filter and select reliable information during disasters?

When a disaster occurs, a variety of information will be circulating online and through word of mouth. It is important to identify reliable sources and confirm that the information you obtain is accurate.



【Knowledge for Advocacy】

Item 7: Are you aware of the importance of providing disaster support that safeguards the psychological safety of service users?

When providing disaster preparedness and mitigation support, simply reminding service users of a potential disaster poses the risk of being invasive and evoking anxiety and fear in them. When providing disaster preparedness and mitigation support, it is important to consider the service users' psychological safety.

Item 8: Do you understand that service users may exhibit a range of physical and mental responses during a disaster, requiring tailored support?

During a disaster, changes in the physical condition of those receiving support manifest in various ways. It is essential to understand their support needs, including care for any symptoms that may arise, by leveraging support relationships established during ordinary times.

Item 9: Are you aware that service users might require special support during a disaster?

During a disaster, in addition to aiming to quickly restore and resume normal services, special support such as safety confirmation, mobile consultations, and communication and coordination with related organisations is required. A support system for this purpose must be established.

Item 10: Do you know that service users might need assistance in navigating systems and applying for benefits during a disaster?

When a disaster requires the use of temporary housing or the relocation of residence, various application procedures are required. Furthermore, in some cases, receiving the insurance or subsidy that the recipient of support had enrolled in may result in the suspension of welfare payments. Support recipients may need support to navigate the system, and service providers are required to understand this.

Item 11: Do you understand the importance of safeguarding the rights of service users while living in evacuation settings?

In previous disasters, there have been cases of violations of the rights of support recipients at evacuation centres, including discriminatory treatment based on disabilities and exposure to media coverage. Furthermore, support recipients sometimes face difficulties living in evacuation centres owing to a combination of factors. It is important to be fully aware of the need to protect the rights of support recipients during evacuation.



【Support System for Disaster Preparedness】

Item 12: Do you routinely update and maintain service users' essential information (including medication details and emergency contacts) with their consent?

With disaster preparedness in mind, it is especially important to update users' pharmaceutical information and emergency contact information. With the consent of service users, a system for regularly updating their information must be established.

Item 13: Is there an established communication network (e.g., within your organisation or with external agencies) for disaster situations?

In preparation for disasters, you should establish a communication system, such as a communication network or mailing list, among service providers within the facility. It is also important to consider a system for reaching those in need of support and their emergency contacts in the event of a disaster.

Item 14: Have you ensured that the necessary supplies (water, food, and disaster-preparedness items) are available for disaster support?

In the event of a disaster, lifeline supplies could be cut off. To continue providing services in such a situation, it is necessary to stockpile water, food, and disaster preparedness supplies.

Item 15: Have you secured an evacuation space that can accommodate service users during disasters?

In the event of a disaster, your business may need to evacuate your clients and their families temporarily or for the short term. This possibility applies to all service providers. In addition to continuing services, you need to consider your evacuation arrangements.

Item 16: Is there a system in place for creating individual evacuation plans that consider each service user's needs during evacuation?

Local governments are currently developing individual evacuation plans, particularly for people who require assistance with evacuation. By creating practical individual evacuation plans that address the various challenges posed by psychosocial disabilities, you can ensure the safety and security of your clients.

Item 17: Have you established a support system for your own staff during disaster response situations?

In the event of a disaster, service providers will also be affected. Therefore, it is necessary to consider support and follow-up systems that consider the possibility that service providers may become exhausted, experience anxiety and stress, or have difficulty with self-regulation.

Item 18: Do you conduct disaster drills that consider the unique needs of your service users owing to their disability characteristics?

In Japan, we need to anticipate all types of disasters. Fire evacuation drills are often conducted, but those are not enough. Considering the regional characteristics of your facility, you should plan and conduct disaster response drills tailored to various types of disasters. When doing so, it's important to carefully consider how you need to support evacuation actions based on the specific disabilities of those you support and then have them participate in the drills.

Item 19: Do you share information about each service user's medical and welfare service status with relevant agencies, with their consent?

Do you know what services your clients use beyond those provided by your facility and to what extent? In the event of a disaster, if a client falls ill, crisis intervention through collaboration with other organisations or medical and welfare collaboration may be required. In anticipation of a disaster, it is important to share information with other organisations, with the client's consent.



Item 20: Are you in discussions with other agencies regarding potential issues with medication supply during disasters?

Many people with psychosocial disabilities have shared their experiences of securing medication during a disaster. In anticipation of situations in which support recipients are unable to make scheduled medical visits during a disaster, establish a coordination and communication system to discuss with other organisations, focusing on the wishes of the support recipient, actions such as how to stockpile medication and store surplus medication.

Item 21: Have you developed relationships with nationwide disaster support organisations so that appropriate support can be mobilised during a disaster?

Is there a communication system with nationwide disaster support organisations, affiliated organisations of the support facility, professional associations, and so forth that can be used in the event of a disaster? Consider what kind of support you can receive (or provide) in the event of a disaster and establish a communication system.

Item 22: Have you established networks with organisations representing persons with disabilities to enhance disaster support?

Connections with disability organisations are expected to function as a support network. Some organisations provide financial support and personnel support in the event of a disaster. It is important to build and maintain these relationships in everyday life.

10. Proposals for Inclusive Disaster Management in the Field of Mental Health

Promoting a Cohesive Society through Inclusive Disaster Response

- Inclusive disaster response is a concept that aims to “leave no one behind” in the event of a disaster, regardless of age, disability, nationality, language, or gender. People with disabilities, including those with psychosocial disabilities, often require additional support during disasters and therefore require support in disaster response measures.
- From this perspective, promoting disaster response efforts that address diverse needs, including those of persons with psychosocial disabilities, will ultimately lead to the creation of an accessible and safe environment for everyone. In other words, inclusive disaster preparedness promotes the realisation of universal design for disaster response. For example, considerations for reducing stress during disasters (such as adjusting sound and lighting and allowing sufficient personal space) are effective not only for people with psychosocial disabilities, but also for a wide range of people. These measures are therefore highly valued within the framework of universal design.
- Promoting inclusive disaster preparedness that takes psychosocial disabilities into account can deepen understanding of disability more broadly and foster community building through collaboration with people with lived experience. These efforts are expected to be a crucial step toward realising an inclusive society.

Strengthening the Position of Disaster Preparedness in Community-Based Integrated Care Systems, Including Mental Health

- It is essential to conduct community disaster response drills and hold regular coordination meetings during non-disaster periods, as well as to strengthen the role of disaster preparedness within community-based integrated care systems, including support for psychosocial disabilities.
- A key priority is to establish a one-stop system that provides seamless access to essential medical, health, welfare, and reconstruction support in the event of a disaster.
- In addition, to prevent medication discontinuation caused by distribution disruptions, it is urgent to establish a support system as part of disaster preparedness, such as a system for sharing medication-related information in accordance with each person's wishes.

Promoting the Creation of Individual Evacuation Plans that Account for the Characteristics of Psychosocial Disabilities

- During large-scale disasters, uniform responses and the implicit assumption of personal responsibility are often seen in evacuation centres, making people with psychosocial disabilities more likely to experience psychological distress. In many cases, characteristics such as sensory hypersensitivity make living in communal evacuation settings difficult.
- The May 2021 amendment to the Basic Act on Disaster Management Measures made it mandatory for municipalities to develop individual evacuation plans. However, according to a

survey by the Ministry of Internal Affairs and Communications (as of April 1, 2024)[15], only 16.8% of municipalities conduct drills related to individual evacuation plans. Therefore, it is necessary to develop effective individual evacuation plans tailored to the characteristics of psychosocial disabilities.

- In doing so, the "Checklist for Inclusive Disaster Management" in this guidance and the video resource "Everyday Disaster Preparedness—Learning from the Experiences of Persons with Psychosocial Disabilities" should be used to develop plans covering the period from immediately after a disaster through to life during evacuation.

Establishing Guidelines in Psychiatric Services in Anticipation of Disasters

- While pharmacotherapy is one of the important treatments in psychiatric care, medication use in anticipation of disasters is rarely discussed during routine clinical consultations. In fact, many people with psychosocial disabilities who have experienced disasters have reported difficulties related to medication discontinuation, including its risks and serious consequences.
- It is therefore necessary to establish disaster-preparedness prescription guidelines for psychiatric care, considering the specific characteristics of antipsychotic medications, among other considerations. For example, such guidelines could include longer-term prescriptions tailored to individual needs, as well as clear advice on carrying essential medications even in non-emergency situations.

Introducing Additional Reimbursements in Mental Health, Medical, and Welfare Fields for Disaster Preparedness Efforts

- For medical and welfare institutions engaged in disaster preparedness, such as supporting the creation of individual evacuation plans and establishing psychiatric consultation systems in anticipation of disasters, it is desirable to introduce additional remuneration measures for medical, nursing care, and disability welfare services. This action is expected to facilitate continuous disaster preparedness efforts in the field.

Promoting Cross-Sectoral Networking in Disaster Preparedness Awareness Activities

- By establishing a "Disaster Preparedness Awareness Alliance (tentative name: Inclusive D-Alliance)," a nationwide coalition of patient groups, support groups, local governments, disaster response NPOs, medical and welfare professionals, and others, it is possible to promote networking beyond the mental health, medical, and welfare sectors.
- Such collaborative awareness-raising activities will also promote understanding of psychosocial disabilities and eliminate stigma. Furthermore, while referring to this guidance and other documents, it is expected that specific awareness-raising and educational activities will be strengthened, such as sharing disaster preparedness measures in various regions and introducing disaster response kit models to people with psychosocial disabilities.

Promoting Disaster Preparedness Measures Through the Participation of Persons with Lived Experience

- The Sendai Framework for Disaster Risk Reduction (2015–2030) (1), adopted at the United Nations World Conference on Disaster Risk Reduction, for the first time positioned disability inclusion as a priority issue for disaster risk reduction and emphasised the importance of stakeholder participation. Specifically, it calls for the participation of people with disabilities in the formulation and implementation of policies, plans, and standards based on the principles of universal design; data collection that includes disaggregation by disability status in addition to age and gender; investment in disability-related technological innovation and development; and promotion of the empowerment of people with disabilities at each stage of disaster response, recovery, and reconstruction.
- In light of these developments, Japan must also actively promote the participation of people with psychosocial disabilities and their organisations in the formulation of various disaster preparedness policies, including municipal disaster risk reduction plans. In particular, the voices of people with psychosocial disabilities have tended to be left out of existing policies, so it is essential to reflect their voices to build an inclusive disaster response system.

11. Appendix: Outline of the Interview Survey for Persons with Psychosocial Disabilities and Service Providers Who Have Experienced Disasters

1. Project Title

“Examining the Disaster-Response Mental Health and Welfare System Inclusive of Persons with Psychosocial Disabilities: An Interview Survey of Persons with Psychosocial Disabilities and Service Providers Who Have Experienced Disasters”

2. Research Objectives

The study was based on interview surveys with persons with psychosocial disabilities and service providers who had disaster experiences. The primary objectives were to elucidate the challenges faced by persons with psychosocial disabilities during disasters, identify the issues in the mental health and welfare system in disaster contexts, and propose necessary disaster management measures and system improvements.

3. Methods

1) Research Setting

The focus group interviews included persons with psychosocial disabilities and service providers (including administrative staff) who had experienced a natural disaster, either the Great East Japan Earthquake or the Kumamoto Earthquake.

2) Research Team

The team comprised seven members (two persons with psychosocial disabilities and five researchers). For each focus group, paired facilitators (one person with lived experience and one researcher) conducted the semi-structured interviews.

3) Participants

Criteria for participation included:

- ✓ Individuals with psychosocial disabilities living in the community, or service providers in community mental health and welfare (including administrative staff).
- ✓ Aged 20 years or older.
- ✓ Having disaster experience during the Great East Japan Earthquake or the Kumamoto Earthquake while residing in Fukushima or Kumamoto Prefecture.

4) Recruitment Method

Participants were recruited via announcements on the Porque email list, Facebook, and notices posted by public institutions, support groups, and service organisations. A total of 38 candidates applied (Fukushima: 13 persons with lived experience, nine support professionals; Kumamoto: 10 persons with lived experience, six support professionals). All applicants were briefed on the study and ethical considerations, and participants provided written consent.

5) Data Collection

Focus group interviews were conducted as follows:

- In Kumamoto between July 28 and 31, 2022, and in Fukushima between October 14 and 17, 2022.
- Participants were divided into groups based on their roles (six groups for persons with lived experience and five groups for support professionals), with each group interview lasting approximately 120 minutes (including breaks), recorded on a Sony IC recorder, and fully transcribed.

Before each interview, a set of interview themes (see Box 1) was provided. Facilitators used an interview guide to conduct semi-structured discussions.

For Persons with Lived Experience

1. What challenges or support needs did you experience as a result of the disaster?
2. What disaster preparedness measures did you have in place before the disaster, and how have these changed after the disaster?

For Support Professionals

1. What difficulties did the persons you support face during the disaster, and what support did you provide?
2. Were there any differences in the support provided before and after the disaster?

Box 1: Interview Themes

6) Data Analysis

Transcriptions of the interviews were analysed using qualitative descriptive analysis. The content was thoroughly discussed by the research team—including two persons with lived experience and one researcher—to generate codes, subcategories, and broader categories.

7) Ethical Considerations

Written consent was obtained from all participants, and the study was approved by the National Center of Neurology and Psychiatry Research Ethics Committee (Approval No. A2022-022).

4. Results

1) Participant Attributes

Persons with lived experience (n = 23)

- Gender: 12 females [52.2%]
- Average age: 50.2 ± 12.8 years
- Diagnoses: 12 schizophrenia, 2 bipolar disorder, 2 depression, 7 other

Support professionals (n = 15)

- Gender: Six women [40.0%]
- Average age: 51.1 ± 10.0 years
- Service types: five from employment support agencies, four from counselling support agencies, two administrative staff, one home-visiting nurse, and three others

2) Findings from the Interview Analysis

For the theme of disaster experiences, five major themes emerged from the interviews with persons with lived experience:

Difficulties experienced during the disaster (see Table 1)

Support received during the disaster (see Table 2)

Disaster preparedness measures prior to the disaster (see Table 3)

Changes in disaster preparedness following the disaster (see Table 4)

Issues and expectations for future disaster support (see Table 5)

For support professionals, seven major themes were identified:

Difficulties perceived among persons with lived experience during the disaster (see Table 6)

Support provided during the disaster (see Table 7)

Challenges in providing support (see Table 8)

Positive aspects of the support provided (see Table 9)

Pre-disaster preparedness measures (see Table 10)

Post-disaster changes in preparedness (see Table 11)

Issues and expectations for future disaster support (see Table 12)

5. Discussion

- The influence of regional characteristics and the limited number of support professionals with medical service experience (only one, with three having past experience in medical services) on the findings remains unclear.
- The study results provide foundational data that can be used to identify issues in the disaster-response mental health and welfare system and to propose concrete disaster preparedness measures tailored to the challenges that persons with psychosocial disabilities face during disasters.

Table 1　Difficulties Experienced as a Result of the Disaster
(Based on Interviews with People with Psychosocial Disabilities)

Category	*Subcategory*	*Representative Statements*
Effects on physical and mental health		
Changes in physical and mental health	Disrupted sleep and daily rhythm	“My sleep schedule got reversed.” “I couldn’t sleep no matter what.”
	Disrupted routine	“My usual routine was disturbed, and it caused me stress.”
	Self-harm	“I ended up hitting myself so hard that I got bruises.”
	Loss of appetite	“I lost my appetite and couldn’t eat.”
	Worsening symptoms	“I felt worse.” “I even heard voices.”
	Disaster-related anxiety and fear	“I was really scared during the earthquake.” “I felt uneasy when I saw a bent gas pipe.”
	Overactivity and exhaustion	“I became overactive and then completely exhausted.”
Disruption of regular medical and welfare support	Difficulty accessing medication	“I couldn’t take my medication because there wasn’t enough available.” “I had to adjust my doses myself.”
	Difficulty accessing medical care	“I had to change my doctor.” “I couldn’t see a doctor regularly, so I lost access to support.”
	Difficulty accessing welfare support	“I found it difficult to ask for help about my welfare needs.”
Impact on daily life during a disaster		
Difficulties in daily life	Lack of water	“I needed more drinking water because of the side effects of my medication.” “I had difficulty securing water to flush the toilet.” “I couldn’t buy water.” “I couldn’t use the tap water.” “The water distribution did not reach us.”
	Lack of food	“I couldn’t get food that I could eat.” “There was nothing I could eat.”
	Poor hygiene	“I couldn’t wash my hands or bathe.” “I felt uncomfortable because of the smell.” “I also had issues during my period.”
	Disruption of communication services	“My mobile phone didn’t work.” “I had to queue for a public phone.”
	Transportation difficulties	“I couldn’t get fuel, and I lived far from the town centre.”

		“I couldn’t drive.”
	Disruption of essential utilities	“The electricity, gas, and water were all cut off.”
	Damage to living space	“Furniture toppled over and my home was a mess.”
	Overexposure to disaster news	“Watching the earthquake news on TV scared me.”
	Incorrect information	“False news spread on social media.” “There were disparities in access to information.”
	Financial hardship	“I lost my job and had no money.” “I had no insurance or other financial protection.”
	Complicated paperwork	“It was very difficult to get a disaster certificate and complete insurance procedures.”
	Family separation	“My family ended up in different shelters, leaving me feeling lonely and anxious.”
Difficulties in evacuation shelters	Extreme temperature	“It was extremely cold.”
	Distress caused by noise and emergency alerts	“I was distressed by the footsteps of people going to the toilet.” “The earthquake early warning alerts made me panic.”
	Lack of privacy	“I felt uncomfortable because I had no privacy.”
	Risk of infection	“There was an outbreak of flu around me.”
	Lack of supplies	“People with cars gathered and soon supplies ran out.”
	Difficulty transporting supplies	“Moving supplies was really painful for my legs.”
	Difficulties evacuating with pets	“I couldn’t take my pet into the shelter.” “I was worried about disturbing others, so I had to sleep in my car.”
	Stress from group living	“The shelter was noisy all the time, making it hard to feel comfortable.” “It was difficult to make others understand my situation.”
Changes in family and community relationships		
Family relationships	Worsening family relations	“I ended up having more fights with my parents.”
Influence from others	Conflicts among residents and neighbours	“There were conflicts among neighbours in our community.”
	Stigma or prejudice	“My disability became known.” “People started talking about me, which I hated.”
	Feeling isolated	“I felt very lonely.” “I didn’t get the support I needed.”

Table 2 Support Received During the Disaster

(Based on Interviews with People with Psychosocial Disabilities)

Category	*Subcategory*	*Representative Statements*
Mental health and welfare services		
Medical services	Sharing and coordinating medical information	"I was given a referral letter, which made it easier for me to see a doctor."
	Counselling and listening	"I felt comfortable talking to a friendly day-care worker."
	Prescription of medication	"My medication was prescribed based on my medication record, and I was given an additional supply."
	Consultation on medication management	"They allowed me to keep any leftover medication."
	Adjusting the frequency of medical visits	"They told me I could come in any time, and they shortened the intervals between my check-ups."
Welfare and administrative services	Use of a care taxi	"I was able to take a care taxi to the supermarket."
	Use of a consultation hotline	"I felt reassured knowing I could always get through to someone when I called for help."
	Outreach by support staff	"Someone called to check on me because of the earthquake."
	Contact from public health nurses and commissioned welfare volunteers	"A public health nurse helped me start looking for a hospital." "A commissioned welfare volunteer visited me at home."
	Leisure programmes	"I found comfort in games and recreational activities at the day-care."
Support during disasters		
Daily life	Food distribution	"I did not have any trouble getting food."
	Volunteer support	"A volunteer helped me obtain a disaster damage certificate."
	Access to temporary transport	"A temporary bus stop was set up for us."
	Waiver of medical and utility fees	"My medical costs were waived."
Life in evacuation shelters	Sharing and lending supplies	"We borrowed and lent chargers among ourselves."
	Provision of medication	"I received medication from a Red Cross worker."
	Posting information	"Information about available housing was posted."

	about available housing	
	Support for people with pets	“A tent provided by the Boy Scouts was used as a shelter for people with pets.”
	Toilet and bath facilities	“The Japan Self-Defence Forces set up toilet and shower facilities.”
Mutual support within families, peers and communities		
Family	Understanding within the family	“My family understood that I couldn’t go to the shelter.”
Neighbours and community associations	Checking on safety and making contact	“My neighbour was the first to call and check on me.”
	Providing space or lending a bathroom	“I was able to use a bathroom.” “I was able to rest at a church when I needed to.”
	Sharing information on public bath facilities	“I received information that bathing facilities had been made available at a certain location.”
	Supplying water and food	“A local farmer brought supplies, and I even received well water.”
	Evacuating together with neighbours	“I was helped by neighbours who evacuated with me.”
	Helping with cleanup	“Volunteers from our housing complex helped move furniture after the disaster.”
Peer connections	Support through comfortable peer relationships	“Connecting with people who understood my situation was a great source of support.”
	Mutual understanding and empathy	“We know each other and understand one another.”
	Providing a place to stay	“I was able to stay overnight with a peer.”
Friends and social media connections	Sharing medication information	“I consulted an acquaintance who was a pharmacist and was able to obtain some medication from them.”
	Sharing food	“My friend and I shared food together.”

Table 3 Disaster Prevention Measures Taken Before the Disaster (Based on Interviews with People with Psychosocial Disabilities)

Category	*Subcategory*	*Representative Statements*
Measures to protect physical and mental health	Keeping a supply of medication	“I kept about two days’ worth of medication in my bag.”
	Keeping medication in a designated place	“I always kept my medication in the same designated place.”

	Remembering medication names	“I remembered the names of my medications.”
Preparing for evacuation and daily life during a disaster	Securing furniture	“I only secured my bookshelf.”
	Stockpiling water and food	“I kept a stockpile of water and food.”
	Preparing camping equipment	“I had a complete set of camping gear.”
	Discussing where to evacuate	“We discussed which shelter we would meet at.”
	Having earthquake insurance	“I had earthquake insurance, just in case.”
	Registering on a list of people requiring evacuation assistance	“I remember registering on a list of people who needed assistance with evacuation before the earthquake.”
	Participating in disaster drills	“I participated in fire drills four times a year.”
Building community relationships	Communicating with peers online	“I created a LINE group chat with my peers.”
	Building relationships with neighbours	“We agreed to help each other if anything happened.”

Table 4　Disaster Preparedness Measures Taken After the Disaster (Based on Interviews with People with Psychosocial Disabilities)

Category	*Subcategory*	*Representative Statements*
Measures to prepare for physical and mental health impacts		
Ensuring access to medication	Keeping medication and medication records ready to take quickly	“I keep them in the living room so I can grab them immediately.”
	Always carrying medication	“I always keep my medication in my bag.”
	Carrying medication records, prescriptions and medical cards together	“I carry these items with my medication.”
	Deciding where and how to store medication	“I keep my medication in a specific drawer.”
	Maintaining an emergency supply of medication through regular rotation	“I arrange an earlier medical appointment to replenish and rotate my medication supply.”
	Discussing medication supplies with a doctor	“I talked with my doctor about getting extra medication for emergencies.”

	Leaving a copy of a prescription or medication record with a support agency	“I gave a copy of my prescription or medication record to the support agency.”
Use of medical and welfare services	Consultation with medical support staff	“I frequently called the day-care staff for advice.”
	Using welfare or consultation helplines	“I used the consultation helpline and felt reassured knowing someone was there.”
Preparing for evacuation and daily life during a disaster		
Self-initiated measures	Increasing awareness of disaster preparedness through television	“I started watching TV specials about disaster preparedness.”
	Gathering information through television, brochures and social media	“I collect news and updates from the internet and social media.”
	Setting up earthquake early warning alerts	“I enabled earthquake early warning alerts on my phone.”
	Securing furniture and preventing glassware from breaking	“I secured my chest of drawers and switched to plastic items.”
	Preparing an emergency grab bag	Emergency grab bags containing items such as slippers, headphones, comfort items, pet supplies, earplugs, blankets and important documents.
	Keeping essential items in designated places	“I decided on a fixed place for my glasses.”
	Keeping cash readily accessible	“I need to keep some cash at home for emergencies.”
	Maintaining a rotating supply of water	“I buy extra water.” “I fill the bath with water in advance.”
	Maintaining a rotating supply of food	“I keep a supply of instant food and snacks on hand.”
	Ensuring access to reliable communication methods	“I checked where public telephones were located, and I use a mobile phone from a major network provider.”
	Deciding where to evacuate	Choosing to shelter at home, checking evacuation shelter locations, and considering staying at a business hotel.
	Checking evacuation routes and methods	“I reviewed the evacuation routes using a hazard map.”
	Keeping living spaces tidy	“I make sure to keep things organised every day.”

	Ensuring fuel supplies and transport readiness	“I always keep my car’s fuel tank at least half full.” “I carry my car keys with me.”
	Writing down individual support needs	“I wrote down the support I need because I find it difficult to explain verbally.”
Use of public services and resources	Participating in disaster preparedness activities	“I attended disaster meetings at my day-care centre.”
	Registering on a list of people requiring evacuation assistance	“I registered on the list, hoping someone would contact me if needed.”
	Developing an individual evacuation plan	“Individual evacuation plans are beginning to be developed.”
Building community relationships		
Developing community connections	Building relationships with neighbours and community groups	“I regularly talk with my neighbours and am a member of the local community group.”
	Building peer networks	“I have made friends who understand my disability and health issues.”
Establishing ways to stay in contact	Checking on one another in shared housing	“We call each other to check if everyone is safe.”
	Keeping a written list of emergency contacts	“I keep a written list of emergency contacts.”

Table 5 Future Support Needs and Hopes for Disaster Assistance (Based on Interviews with People with Psychosocial Disabilities)

Category	*Subcategory*	*Representative Statements*
Challenges and expectations for services during disasters		
Medical services	Access to counselling	“I wish there was professional counselling available in the shelter.”
	Compassionate and understanding doctors	“I hope for a doctor who truly understands my feelings rather than a strict, task-based approach.”
	Sharing medical information and ensuring access to prescriptions	“It would be great if I could get my prescriptions even without my insurance card or medication record.”
	Outreach to check on health and medication needs	“I’d like someone to check on me if I get sick or can’t contact anyone during a disaster.”
	Access to familiar hospitals during evacuation	“It would be very helpful if I could evacuate to the hospital I usually visit.”

	Check-ins and listening support from staff	“I think it would be nice if support staff went around the shelter and checked in on everyone.”
Welfare/administrative services	Establishing a contact network or mailing list	“I feel reassured when there’s a good network or mailing list to check on safety.”
	An easily accessible consultation service	“I wish there was a place where I could simply drop by to ask for advice.”
	Additional daily living support during disasters	“If my day care or work centre could offer extra support during disasters, I would feel more at ease.” “I would like more respite facilities to be available.” “There needs to be somewhere that can look after children.”
	A single point of contact for support services	“It would be very helpful if one centre could connect all my services instead of having to contact several places.”
	Assistance with administrative procedures	“I would appreciate it if someone could help me with all the paperwork during a disaster.”
	Clear information about available compensation	“I hope there is clear, widespread information about what compensation is available.”
	Financial support for people who fall through gaps in existing support systems	“I wish there were benefits for those who fall through the gaps in the support systems.”
Challenges and expectations for daily life during disasters		
For daily activities	Usefulness of a “help sign” (like a Help Mark*)	“I don’t use it regularly, but I’d really need one when I require help.”
	Less distressing earthquake warning sounds	“I wish the alarm sounds during an earthquake were less jarring.”
	More accessible and user-friendly emergency supplies	“It would be better if there were simpler, more user-friendly emergency kits available.”
	Volunteer assistance with daily tasks and clean-up	“I need volunteer help for things like fetching water and moving furniture after a disaster.”
For life in evacuation shelters	Provision of water storage and bathing facilities	“It would be helpful to have somewhere to store water.”
	Adequate and good-quality food provision	“I hope the food provided in the shelter is enough and of good quality.”
	Quiet spaces and items to support sleep	“It would be nice if there were quiet spaces and sleep aids so I could rest well at a shelter.”
	Infection prevention and	“I need strong precautions to prevent infections and

	measures to reduce secondary harm	other harmful effects during a disaster."
	Providing privacy through partitions or separate spaces	"I'd feel more comfortable if there were partitions or separate areas in the shelter."
	Support tailored to women's needs	"It's important that shelters provide special support for women."
	Accessible shelters for people with disabilities	"A shelter with a quiet room where people with disabilities can rest would be very helpful."
	Flexible shelter access based on individual needs	"It would be great if I could decide when to use the shelter based on my personal needs and timing."
	Pet-friendly evacuation shelters	"I hope there is a shelter that can also accommodate pets."
Challenges and expectations for social connections		
Peer and community connections	Peer support networks	"I'd love a space where people with similar experiences can gather, talk, and help each other."
	Workshops where persons with psychosocial disabilities can come together	"It would be nice if workshops were held where those of us with similar challenges could meet up."
Local community/neighbourhood links	Finding ways to connect with neighbourhood associations	"It would be helpful to have information showing where to find the contact details of the neighbourhood association chairperson."
	Mutual support within the community	"I hope neighbours share supplies and help each other out when needed."
	Greater understanding of disability-related needs among local organisations	"I wish local governments and care staff better understood the needs of people with disabilities."
Challenges and expectations for disaster preparedness		
Disaster preparedness and risk reduction efforts	Establishing a contact network or mailing list	"I feel reassured when a contact network or mailing list is in place for disaster updates."
	Using a list of people requiring evacuation assistance	"I hope that the list of people who need evacuation support is shared with those who can help."
	Difficulties in developing individual evacuation plans	"I think progress in developing individual evacuation plans for people with psychosocial disabilities will be slow."
Disaster preparedness	Sharing disaster preparedness information	"I wish there was more information on evacuation tips and the essential items for disaster preparedness."

education and training	Regular and accessible disaster drills	“I would like disaster drills to be held regularly by organisations that understand my needs.”
Expectations for government support	Providing clear information about evacuation shelter locations	“I want clear and widespread information about where shelters are located.”
	Government provision of emergency supplies	“It would be great if the government provided disaster supplies.”
	Information about welfare evacuation shelters	“I want to know exactly where the welfare shelters are.”

*Help Mark: a symbol used in Japan to indicate that a person may need assistance or consideration, even if their needs are not immediately visible.

Table 6 Difficulties Experienced by People with Psychosocial Disabilities Following the Disaster (Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Difficulties in maintaining physical and mental health		
Changes in physical and mental health	Disrupted sleep and daily rhythm	“I received reports that some people couldn’t sleep at night, making it hard for them to wake up and go to work in the morning.”
	Difficulty recognising stress	“They later realised their collapse was due to severe stress.”
	Self-harm	“One person became so overwhelmed that they started hitting themselves and ended up with many bruises.”
	Restlessness	“People were noticeably agitated and restless, wandering around without settling.”
	Anxiety and fear following the disaster	“A significant number of people experienced intense fear, especially of earthquakes.”
	Sensory sensitivities and distress	“Some were so sensitive that they could not take a bath because the smell was unbearable.”
	Substance dependence	“There was an increase in alcohol dependence among those staying in shelters or sleeping in their cars.”
	Overdose	“I heard one person took around 50 tablets of Depas.”
Inability to access medical and welfare	Difficulty maintaining access to medication	“Some people didn’t even think about running out of medicine until it was too late.”
	Reluctance to take	“At several evacuation shelters, it was only when

services	medication due to fear of discrimination	psychiatric symptoms began to emerge that people realised some evacuees had not been taking their medication."
	Closure of medical facilities	"Many medical facilities were closed after the disaster."
	Delays in accessing support	"Those who were not already connected to medical services had their support postponed."
	Loss of access to support and consultation services	"People returned to areas with no hospitals, shops, or workshops, leaving them unsure where to seek help."
Difficulties in daily life following evacuation		
Challenges in daily life	Access to water	"For about three days, there was only one 500 ml bottle of water available from morning until evening."
	Lack of a safe living space	"The house was badly damaged, making it too frightening to stay there."
	Lack of employment opportunities	"Some wanted to work, but no jobs were available."
	Financial hardship	"Many couldn't take their wallets with them, so they had no money."
	Difficulty moving from temporary housing	"Once someone moved into temporary housing, it became very hard to get permission to move to a new place."
Disruption to relationships and familiar surroundings	Deterioration in family relationships	"Some people experienced a decline in family relationships."
	Lack of familiar or trusted people to talk to	"There was no one I knew among the people around me at the evacuation site."
	Leaving a familiar area	"They had to leave their neighbourhoods and could no longer live as they did before."
	Being misled by false information	"False information spread easily and was sometimes even shared by those affected."
	Loss of a sense of belonging	"Many felt they had lost their sense of belonging."
	Difficulty adjusting to new environments	"Even after several attempts to adapt, some still could not fit into the new environment."
Difficulties in evacuation shelters	Difficulty feeling comfortable in shelters	"Some individuals simply couldn't settle or feel comfortable in the shelter."
	Strict or unclear shelter rules	"People followed the rules but were still scolded, and they couldn't understand why."
	Lack of understanding of disability-related needs	"Hidden disabilities became obvious, and affected individuals were told to fit in as if everyone were the

		same."
	Difficulty disclosing a disability	"Many found it hard to reveal their disability due to fear of prejudice and discrimination."
	Discrimination in shelters	"At the evacuation shelter, there was a sense that certain people were being grouped together in one area and told, 'You should stay here."

Table 7 Support Provided During a Disaster
(Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Maintaining continuity of mental health and welfare services		
Medical services	Arranging hospital admission	"When a client needed to be hospitalised, we called the hospital and arranged for them to be admitted."
	Ensuring access to prescribed medication	"When our usual clinic ran out of medication, we contacted another medical provider. We supported the client during the day and delivered their medication to their home at night."
Welfare/administrative services	Providing a safe and supportive space	"We organised time-limited sessions for small groups to provide a safe and supportive environment."
	Arranging work opportunities	"Since there was little to do after the disaster, we organised work opportunities for those affected."
	Providing overnight accommodation at the facility	"For clients who couldn't return home, we provided overnight stays at our facility."
	Providing advice and referrals	"We received many phone calls asking what to do if someone ran out of medication or couldn't visit the doctor."
	Assistance with welfare applications and administrative procedures	"We helped clients navigate and complete public assistance applications and other paperwork."
	Coordinating with employers	"We worked with companies so that when the situation improved, they could explain the next steps to our clients."
	Coordinating accommodation through local welfare services	"We worked with the prefectural government to establish a matching programme for people who could be discharged from hospital, involving other hospitals

		and group homes."
Support for daily life during the disaster		
Daily life assistance	Checking on people's safety	"All staff joined forces to call and check on clients at their homes and in group homes."
	Outreach through home visits	"We made home visits to check on clients' conditions and quickly connected those in need to support services."
	Gathering disaster-related information	"We gathered information from various sources, including word of mouth about where petrol might be available the following day."
	Procuring and delivering essential supplies	"We transported essential supplies, including food and boxed lunches, to the shelters."
	Assistance with bathing	"Once the gas supply was restored, we helped clients bathe in turn."
	Preparing and distributing meals	"Our team worked together to prepare and distribute hot meals."
	Cleaning and tidying up	"Residents at group homes even helped with cleaning while we organised the space."
Coordination and communication		
Coordination within and between organisations	Coordinating evacuation and accommodation across facilities	"Even when one group home lost water, we grouped the clients in facilities with stable utilities."
	Collaboration with external support teams	"Local staff dealt with immediate tasks, while supporters in the Tokyo metropolitan area took on planning and coordination work."
Supporting daily life in evacuation shelters	Creating visual signs to request assistance	"We made simple signs and pictures for people with developmental disabilities to signal when they need help."
	Volunteering to gain acceptance in evacuation shelters	"Our director even helped clean the shelter in the morning to set a good example."
	Adapting the shelter environment to individual needs	"We arranged special spaces or separate rooms for people who needed additional support."

Table 8 Difficulties in Providing Support
(Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Personal challenges faced by support staff	Disaster impacts on staff and their families	"Many staff members were unable to work because of the disaster, and almost all those with young children had to evacuate."
	Exhaustion	"I heard a public health nurse, completely worn out, still cheerfully saying, 'I'm fine.'"
	Anxiety and stress	"Many said they felt caught between not knowing whether to start work or wait for things to settle."
	Difficulty with self-regulation	"With so many supporters coming and going, I sometimes found it difficult to keep my spirits up while having to explain things repeatedly."
	Distress caused by repeated disaster-related messages and images	"I was repeatedly exposed to distressing tsunami footage." "I found constant messages such as 'Stay strong, stay strong' exhausting."
Difficulties in maintaining routine support services	Staff shortages	"Because of the tsunami damage, there weren't enough staff members, and the facility had to close the next day."
	Difficulties identifying clients who need support	"Some clients didn't speak up about their difficulties, so they did not receive the support they needed."
Difficulties in accessing medical services	Disruption of medical services	"We received calls from hospitals saying to handle things ourselves because they couldn't accept more patients."
	Shortages of medication	"There were cases where clients could not obtain their medication."
	Limited experience in responding to medical emergencies	"Some staff at the welfare centre had never seen an epileptic seizure and didn't know how to help."
	Low priority in accessing medical care	"Clients with developmental disorders were often given low priority, and their medication supplies were sometimes insufficient."
Difficulties in providing support in evacuation shelters	Lack of suitable spaces for people in distress	"With so many people crowded into the school gymnasium, there was nowhere to provide support to those who were beginning to show signs of mental health deterioration."
	Limited understanding of disability-related needs	"Many people in the shelter did not understand disabilities, which created many challenges."

	Discrimination and prejudice	“Negative comments, such as calling someone ‘crazy,’ were common because people did not understand mental or developmental disabilities.”
	Intrusive media coverage	“Clients were upset because reporters took pictures of them while they were sleeping or crying, focusing only on their distress.”
Difficulties in supporting daily life during evacuation	Difficulty confirming people's safety	“When people evacuated to different places, we couldn’t keep track of who went where.”
	Uncertainty about evacuation decisions when safety could not be assured	“We were unsure if our facility was safe, so we ended up wandering through shelters with our clients.”
	Fuel shortages	“Petrol did not arrive for 10 days to two weeks.”
	Disruption to supply deliveries	“No supplies were delivered at all during the disaster.”
	Difficulty accessing essential supplies	“There was no way for clients to go out and get food or other resources.”
	Disruption to essential utilities	“Water, gas, and electricity were all completely turned off.”
	Rumours and misinformation	“Rumours and false information spread quickly, leaving us confused about what was actually happening.”
	Difficulty finding housing that meets individual needs	“The available public housing was old, and the rooms were on upper floors, making it difficult to find accommodation that met clients’ needs.”
	Lack of a coordinated disaster support network	“When our centre couldn’t operate well, we didn’t know where to refer our clients for support.”
	Difficulties coordinating with other support organisations	“When many support groups arrived at shelters, we became confused about how to coordinate our efforts, which led to even more chaos.”

Table 9 What Went Well in Providing Support During the Disaster (Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Flexible responses to changing needs	Flexible access to prescriptions	“The healthcare professionals used the records kept at the facility to prescribe the necessary medication. Their flexible approach was very helpful.”
	Local government	“For clients who came to the facility, the public health

	response and welfare checks	nurse and welfare department already knew them and kept track of their situation."
	Providing meals	"When the power went out, staff quickly prepared meals using food from the refrigerator, and having a meal on the first day helped everyone feel reassured."
Effective delivery of support	Prompt safety checks	"It was good that people connected with welfare service providers had many people looking out for them."
	Continuity of support	"For people living in group homes, the support continued without any break."
Support through collaborative networks	Support from national and external organisations	"They provided direct support to us and reinforced the network among welfare centres." "When we called the national network, partner organisations quickly gathered and even provided funds."
	Effective support networks	"Through word of mouth, more people became involved, and our network became a hub for providing hot meals and other forms of assistance."
Professional growth through disaster response	Learning through experience	"I came to realise that if we could survive the first three or four days, we would somehow manage."
	A sense of fulfilment from providing disaster support	"Even though it was very hard until the end, I felt a deep sense of satisfaction from the support work we did."
Improvements in administrative responses	Media coverage prompting action	"Although the authorities did not respond to repeated requests at first, they acted quickly once the issue was reported in the media."

Table 10 Pre-Disaster Preparedness Measures
(Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Preparedness measures implemented before the disaster		
Preparedness at facilities	Preparedness for disasters other than earthquakes	"We were well prepared for floods and typhoons. Our evacuation plans and communication systems worked well."
	Stockpiling essential supplies	"We kept a large stock of food supplies."
Building support	Establishing a nationwide	"We actively visited organisations across the country

networks	support network	to establish disaster support networks."
	Participating in disaster support training	"We attended training sessions to learn about the support needed following the Great East Japan Earthquake."
	Building relationships with other organisations	"The hospital coordination team had strong connections with other agencies."
Preparedness measures not implemented before the disaster		
Gaps in disaster preparedness	Insufficient preparation for medication needs	"They had not made a habit of carrying medication with them. They kept it at home and only took it with them when they thought they would need it."
	Limited collaboration between hospitals	"Allied health professionals were collaborating with one another, but there was no comparable network among medical institutions."
	Lack of drills for earthquakes and other natural disasters	"We held fire drills, but there were no drills for earthquakes or other natural disasters."
	Limited effectiveness of mandatory disaster drills	"We only conducted a mandatory drill once a year, which was not particularly useful."
Lack of prior disaster preparedness	Lack of preparedness for disasters	"We had not prepared for a major earthquake at all. We had never discussed disaster preparedness with clients." "I was unaware of the Disaster Psychiatric Assistance Team (DPAT)."

Table 11 Post-Disaster Preparedness Measures
(Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Measures taken by support organisations		
Advice and guidance for clients	Encouraging clients to keep spare medication	"We encouraged clients to keep a supply of their medication for emergencies."
	Keeping copies of prescription records	"When a client's prescription changed, we made a copy of the updated prescription and kept it at the facility."
	Encouraging clients to carry medication records	"We advised clients to always carry their medication record with them."
	Preparing emergency information cards	"We prepared an emergency information sheet for each client, including their name, address, emergency contacts, medication details and important notes, so they could take it

		with them in an emergency.”
Establishing evacuation and communication procedures	Establishing an internal safety-check system	“We used a LINE group chat and established a rule that all staff had to respond within 30 minutes following an earthquake of seismic intensity 5 or above on the Japanese scale.” “We also created a mailing list across different facilities.”
	Recording emergency contact details for clients and families	“We registered clients’ and their family members’ phone numbers in our facility’s mobile system.”
	Planning alternative evacuation routes	“We planned three different routes to the shelter so that if one route was blocked, we would have alternatives.”
	Preparing for sheltering at the facility	“We prepared to use our facility as a safe place during heavy rain or earthquakes, assuming that going to a public shelter might not be necessary.” Preparing for evacuation outside designated shelters
	Stockpiling water	“We made sure there was enough water for both drinking and for the toilet.”
	Stockpiling food	“We stored instant meals like cup noodles.”
	Preparing emergency supplies	“We gathered a large amount of camping gear, such as tents and sleeping bags, for emergencies.”
	Maintaining fuel reserves	“We made sure to refill the petrol tank whenever it was half-empty.”
	Regularly reviewing emergency stockpiles	“We regularly reviewed our emergency supply plans to ensure that essential items, portable toilets and water were available.”
Building and strengthening networks	Providing disaster preparedness education	“We developed a personal disaster action plan called ‘My Timeline’ to help people understand what actions to take during a disaster, and shared examples of good practice.”
	Strengthening collaboration between welfare and medical services	“Welfare staff visited hospitals to speak with day-care and outpatient clients, and we started online monthly meetings to discuss challenges as equal partners.”
	Building nationwide support networks	“Groups from across the nation now quickly send help if something happens—if one location has an issue, they can immediately dispatch support.”
Learning from the experiences and	Drawing on the experiential knowledge of organisations of people with disabilities	“Information shared by organisations of persons with disabilities helped bring various issues to light.”

knowledge of organisations of people with disabilities	Learning from disaster preparedness notebooks	“I was inspired by a disaster preparedness notebook for people with developmental disabilities. It described common challenges and included sections for contact information, medication details and important precautions.”
Measures taken by public authorities		
Administrative procedures and planning	Protecting personal information	“When sending documents, the government took care to protect personal information as much as possible.”
	Incorporating disaster response into business continuity plans	“We were required to include what we would do and how we would respond in the event of a disaster in our business continuity plans (BCPs).”
Developing support infrastructure and facilities	Expanding shelters and establishing welfare areas	“Additional shelters and dedicated welfare zones were set up so that those in need could have a safe area.”
	Establishing mental health care centres	“A mental health care centre was established to support disaster victims.”
	Building networks with relevant organisations	“Local support workers were appointed to create a network with organisations related to disability welfare.”
Gaps in post-disaster preparedness		
	Insufficient preparedness	“Once the immediate sense of crisis has passed, people tend to forget, so surprisingly little has been done.”

Table 12 Future Support Needs and Hopes for Disaster Assistance (Based on Interviews with Support Staff)

Category	*Subcategory*	*Representative Statements*
Individualised support	Building an inclusive community	“We need to make sure that our community considers how to support people who require special care.”
	Disaster support tailored to individual needs	“For example, if someone’s health deteriorates, they should receive support tailored to their condition rather than the same support as everyone else.”
	Supporting people who have difficulty expressing their needs	“It is important to find ways to support people who are struggling but find it difficult to express their needs.”
	Tools for recording personal needs and difficulties	“It would be helpful to use a practical tool to record in advance the different reactions one might experience during a disaster.”
Organisational	Concerns about	“Some staff feel that registering people on the

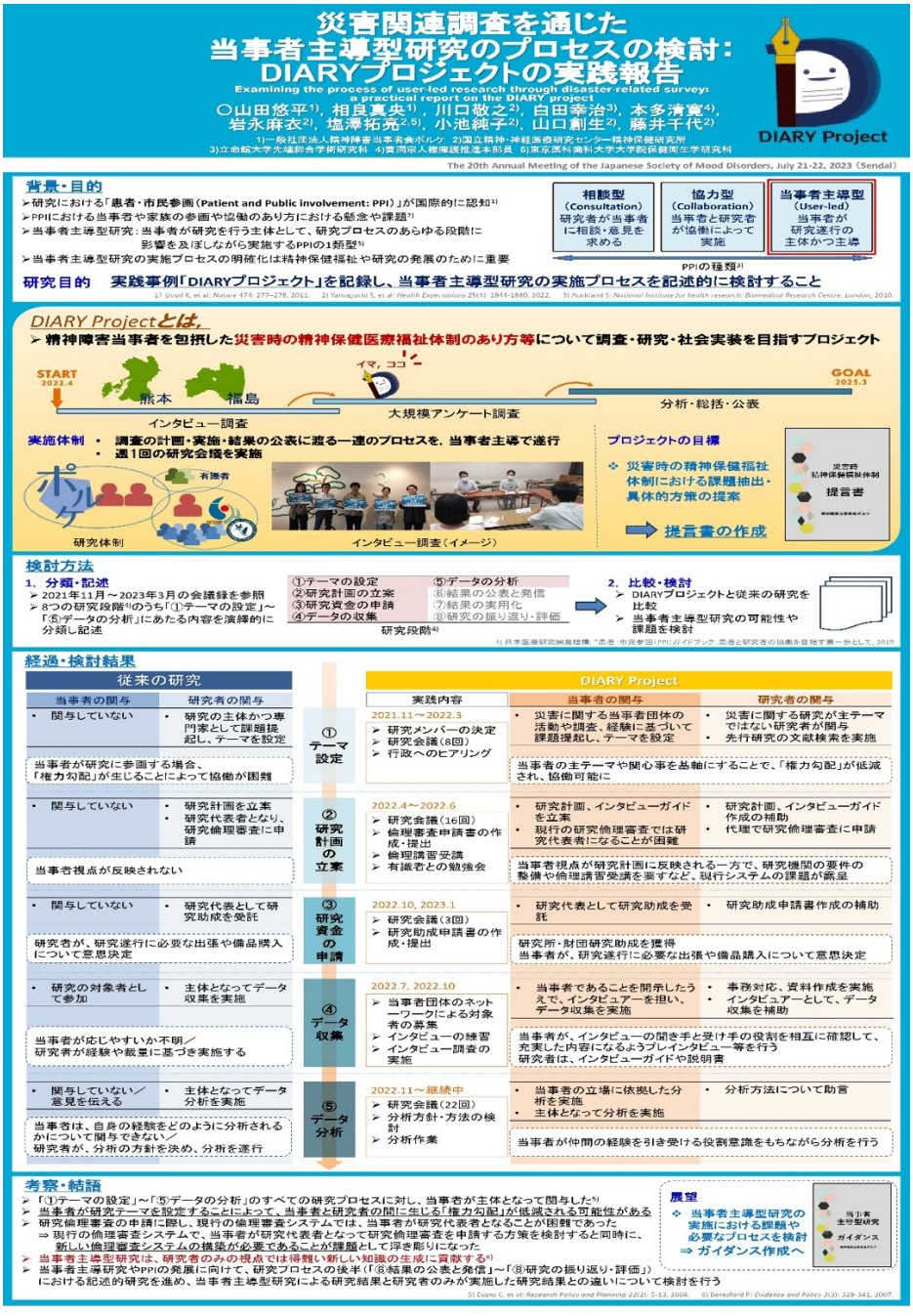
support systems	registration on evacuation support lists	evacuation support list involves too much hassle."
	Developing practical individual evacuation plans	"For people who have trouble evacuating, we need clear plans showing with whom, where, and how to leave safely."
	Reviewing arrangements for medical appointments and medication	"We still need to review how to ensure access to medication and arrange medical appointments, as these arrangements have not been adequately reviewed."
	Strengthening evacuation support systems	"We should clarify roles and establish clear procedures for providing support during evacuations."
	Keeping client information up to date	"We used to keep copies of prescriptions at the facility, but recently this has not been done as much."
	Considering alternatives to public evacuation shelters	"If a client's regular living space can be made safe, it might be better to use that instead of a public shelter."
	Allowing support staff to prioritise their own and their families' safety	"In a serious emergency, support staff should be able to prioritise their own safety and that of their families."
Building support networks	Ensuring timely access to medication for those most in need	"It's crucial that clients who need medication most urgently receive it quickly."
	Strengthening everyday community cooperation	"Local help and mutual support in the community are essential, and everyone should stay involved."
	Providing a single point of contact for advice and support	"A single, easy-to-use consultation service for all needs would be very helpful."
	Coordinating medical care and daily living support	"Medical and daily living support services should work together to address people's needs."
	Building integrated networks of medical and welfare support	"Even though we hold meetings and networking events, participation is still low—we need to encourage more people to join."
	Collaboration among local support organisations	"Local agencies should work together so that support is available right where people live."
	Including disaster-affected organisations of people with disabilities in support networks	"Since organisations led by people with disabilities who have experienced disasters have proven effective, they should be included in local support networks."

	Planning coordination with national and external support groups in advance	“We need to organise and plan how national and external support groups will work together before a disaster happens.”
Awareness and education	Maintaining disaster awareness through regular activities	“When life returns to normal, people tend to forget about disasters, so regular reminders are needed.”
	Promoting disability awareness and understanding through education	“It is important to help everyone better understand mental and developmental disabilities and how to support people with these disabilities.”
	Supporting the active involvement of people with psychosocial disabilities	“When they have the capacity, people with psychosocial disabilities can also take on support roles, such as listening to evacuees during outreach visits to shelters or helping to deliver supplies.”
	Raising awareness of the role of people with disabilities in education and outreach	“We should raise awareness that people with disabilities can lead workshops and training sessions, sharing their experiences and knowledge.”
	Mechanisms for sharing disaster experiences	“When considering disaster preparedness and risk reduction measures and what supplies to prepare, we should gather and bring together the knowledge and ideas of people who have experienced disasters.”
Government and administration	Providing private spaces in evacuation shelters	“It would be good if shelters could provide some private space for individuals.”
	Providing a single source of accessible disaster information	“A simple system that organises essential disaster information into clear categories would be very helpful.”
	Flexible administrative responses	“Support for benefit applications should be simplified and the process made easier during a disaster.”
Media	Improving the communication of disaster information	“During a disaster, the media should communicate essential information in ways that help reduce anxiety rather than increase it.”
	Protecting disaster survivors from intrusive media coverage	“We need to rethink our relationship with the media so that survivors are not further hurt by intrusive reporting.”

12. Reference Materials: DIARY Project-Related Activities

[Activity 1] Presentation at the 20th Annual Meeting of the Japanese Society of Mood Disorders (July 2023)

The lead speaker was Yuhei Yamada of Porque, the organisation of persons with psychosocial disabilities. The presentation was based on the records of the DIARY project, and it descriptively examined the implementation process of participant-led research, comparing it with traditional research processes.



This study was supported by the National Center of Neurology and Psychiatry, the Mental and Neurological Disorders Research and Development Program
The poster presentation was published with permission from the chair of the 20th Annual Meeting of the Japanese Society of Mood Disorders.

[Activity 2] Overview of the "Everyday Disaster Preparedness" Survey

This survey summary is an excerpt from the report "2023 Survey and Activity Report on Everyday Disaster Preparedness for People with Psychosocial Disabilities"[14], part of the Kirin Welfare Foundation's FY2023 Kirin Welfare Power Development Project, "Development of Comprehensive Disaster Preparedness Support Tools for People with Psychosocial Disabilities" (implemented by Yuhei Yamada, representative director of Porque, the organisation of persons with psychosocial disabilities).

1. Project Title

Survey on "Everyday Disaster Preparedness"

2. Research Objectives

To conduct a survey of people with psychosocial disabilities regarding their everyday disaster preparedness and mitigation efforts and identify challenges in disaster response and mitigation.

3. Method

1) Research Setting

An online survey was conducted via Google Forms, and a paper survey was also conducted.

2) Participants and Recruitment Method

- The survey was announced to approximately 2,000 Porque newsletter subscribers via the mailing list, website, and Facebook.
- The survey form and explanatory letter were sent to Porque network members and staff at disability welfare support facilities who were willing to participate in the survey. Voluntary participation was then solicited from facility users.

3) Survey Items

- The survey consisted of items 1 through 5 (Box 2).
- Some of the questions in items 2 and 3 were developed with reference to the Cabinet Office's "Public Opinion Survey on Disaster Preparedness"[16].

4) Data Collection and Analysis

- The survey was conducted online via Google Forms.
- The questionnaire forms were collected by staff at disability welfare support facilities and sent in bulk.
- Descriptive statistics were used for data analysis.

5) Ethical Considerations

This study was approved by the Porque Research Ethics Committee, a General Incorporated Association for People with Psychosocial Disabilities (Approval Number P2023-01).

1. General Information: Gender, age (generation), type of work, experience with psychiatric care, prefecture of residence, type of residence, cohabitation status, presence of anyone requiring assistance with evacuation (self or family), experience of being affected by a disaster
2. Experience of participating in/observing disaster response drills, motivation for participating in/observing disaster response drills, reason for not participating in/observing disaster response drills, deciding factor for participating in disaster preparedness events, what you would like to learn/experience at disaster preparedness events
3. Current stockpiles and disaster preparedness measures, estimated number of days of evacuation due to stockpiles and disaster preparedness measures, difficulty level in the preparation process for stockpiles and disaster response, whether you carry medications and estimated number of days, whether you carry your medication record
4. Self-evaluation of your own disaster preparedness measures
5. Current ideas for your own disaster preparedness measures and ideas you would like to share (free description)

Box 2: Questionnaire Items

4. Results (partial excerpt)

- Responses were received from 161 people with psychosocial disabilities (women: 94 [58.4%]; aged 20–39: 64 [39.8%]; aged 40–59: 82 [50.9%]; with disaster experience: 60 [37.3%]).
- Regarding participation in disaster response drills, 92 [57.1%] of the 161 valid responses were “I have never participated.”
- The most common reasons for “never participating in disaster response drills” (multiple answers allowed) were “I didn’t know they were being held” (43 people), “I don’t have the time/it doesn’t suit my schedule” (39 people), and “I don’t know the specific date, time, location, or how to apply” (39 people). Twenty-five people also answered, “I feel burdened by others knowing I have a disability.”
- Regarding the deciding factors for participating in disaster preparedness events (select two that apply), the most common reasons were “They are held on days and times that are convenient for me” (84 people), “They are held near my home” (83 people), and “I can learn about the information and preparedness measures, including those specific to people with psychosocial disabilities” (53 people).
- When participants were asked what they would like to learn at disaster preparedness events (select three items), the most common answers were “Evacuation sites and evacuation procedures” (98 people), “Special preparations for people with disabilities” (90 people), and “Emergency supplies” (72 people).
- When participants were asked about whether they carry their medication with them, 103

of 158 valid responses [65.2%] were “I don’t carry it.”

- When participants were asked about whether they carry their medication record, 85 of 159 valid responses [53.5%] were “I carry it.” (Among those who have experienced a disaster, 66.6% answered “I carry it.”)
- Self-evaluation of their own disaster preparedness measures (0: Not at all prepared, 10: Well prepared): Average 3.5±2.1

5. Discussion

- Regarding participation in disaster response drills, the 57.1% who answered, “I’ve never participated” was higher than the 50.1% who answered, “I’ve never participated or observed” or “I didn’t know that disaster response drills were being conducted” in the Cabinet Office’s “Public Opinion Survey on Disaster Preparedness.”[16)]
- To encourage participation in disaster response drills and events, it is necessary to consider “days and times that are convenient for people to participate,” “locations close to home,” and “content specific to psychosocial disabilities.” In addition, it is necessary to consider a person’s burden from having their disability revealed to others.
- The percentage of people who carry their medication records varied depending on whether they had experienced a disaster, suggesting that disaster experience is one factor related to disaster preparation and mitigation behaviour.
- These survey results can be used as basic information to encourage people with psychosocial disabilities to participate in disaster preparation and mitigation efforts and to provide support tools for creating individual evacuation plans that take medication security into account.

[Activity 3] Video Material: “Everyday Disaster Preparedness—Learning from the Experiences of Persons with Psychosocial Disabilities”

As part of the DIARY project, we produced a video resource for use in workshops to enhance disaster preparedness in local communities, learning from the “experiential knowledge” of people with psychosocial and developmental disabilities who have experienced disasters. The video resource was designed based on insights gained through group work, imagining a timeline from immediately after the disaster to life in evacuation shelters, in line with questions set forth in each chapter.

■ Video Resource Features

- Learn specific disaster preparedness measures based on the experiences of people with psychosocial and developmental disabilities who have experienced disasters.
- The content is written from the perspective of those affected, avoiding shocking disaster footage and taking psychological burden into consideration.
- It can also serve as a reference for creating individual evacuation plans while empowering people with psychosocial or developmental disabilities.
- It can also be used for evacuation drills at welfare facilities and other facilities.





■ Video Resource Structure

The video is approximately 25 minutes long and consists of the following five chapters.

1. Preparations for the Immediate Post-Disaster Period
2. How to Survive Evacuation
3. How to Communicate About Disabilities
4. Making Evacuation Sites More Comfortable
5. Preparing on a Regular Basis



As a special feature, this program features a conversation between Chiyo Fujii of the National Center of Neurology and Psychiatry and Yuhei Yamada of Porque, the organisation of persons with psychosocial disabilities, on the topic of disaster preparedness that is inclusive of people with psychosocial disabilities

Video Material “Everyday Disaster Preparedness—Learning from the Experiences of Persons with Psychosocial Disabilities”

- Produced by Porque, the Organisation of Persons with Psychosocial Disabilities
- Concept: Yuhei Yamada, Mao Sagara
- Photography and Editing: Yoshikazu Hara
- Narration: Mai Aizawa
- Cooperation: National Center of Neurology and Psychiatry, Little Bit, a support group for people with developmental disabilities in Kumamoto Prefecture
- Deko-boko Life Design, a specified nonprofit organisation
- Supported by: Kirin Welfare Foundation, a public interest incorporated foundation, FY2023 “Kirin Welfare Power Development Project”



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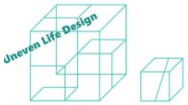
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