Government of **Western Australia**
Department of **Health**

Hospital Stay Guidelines: Part 2

A guide for disability service organisations & support workers

Contents

Introduction

The Guideline outlines opportunities for all areas of the health system and the disability sector to enable better engagement and planning when an individual with complex needs relating to their disability is:

- Attending the emergency department
- Attending an outpatient clinic at a hospital or health campus
- Being admitted to hospital
- Preparing for discharge

Support workers and Disability Service Organisations (DSO's) should assist people with disability to use the following tools:

- Individual Health Profile
- Hospital Passports
- Scripts and techniques on how to support an individual in hospital

An individual with complex disability needs may have:

- High medical/physical support needs
- Health needs which require a high and persistent level of supervision and individualised health care support
- Intellectual disability
- Developmental delay
- Autism Spectrum Disorder or a neurodivergent diagnosis
- Acquired Brain Injury
- Degenerative neurological conditions such as Huntington's disease, Motor Neuron disease
- Behaviours which can be seen as challenging
- Complex communication needs

The Role of Support Workers in Hospital

The United Nations Convention on the rights of Persons with Disabilities, Article 21 states that: *"persons with disabilities can exercise the right to the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice including by augmentative and alternative communication".*

This means people with disability who have complex communication needs, must have somebody with them during a hospital stay who knows them well, or have access to a device to assist with communication.

Your unique knowledge of the person you support can help to make the hospitalisation processes much easier for everyone.

If you are concerned that the health of the person you support is deteriorating, it is important to make their needs known.

If the person you are supporting is an inpatient at **Perth Children's Hospital** and you are concerned that their condition is deteriorating and you feel the critical care they need is not being provided, you can make the CARE Call. See **Appendix 1.**

"Aishwarya's Care" has been implemented in all WA public hospitals with paediatric services. This builds on the existing CARE Call system which allows people to escalate care for them or their loved ones whose condition is deteriorating in hospital. People can make the CARE Call from their mobile – look for the signs in the Emergency Department.

In the hospital, you can speak to the Nurse Coordinator on the ward. If you wish to make a complaint, liaise with the 'Patient and Family Liaison Officer'.

The following are some common concerns reported during a hospital experience:

- Unmanaged pain
- Needs not met due to communication limitations
- Distress or sensory overload
- Difficulty coping with procedures
- Supported shared decision making and informed consent not being adequately supported
- Medication
- Lack of parent/carer training

For a range of scripts and techniques on how to support an individual in a hospital in relation to these concerns, see **Appendix 2**. It may be helpful to 'rehearse' responses to prepare to advocate in a hospital setting.

The Role and Responsibilities of Disability Service Organisations in Hospital

In the Emergency Department:

- Prepare the person during the journey to emergency about what to expect, if possible
- Support the individual with information and assistance to reduce fear and anxiety and to make them as comfortable as possible in the emergency department.
- Ensure the individual's relevant documentation is passed to hospital staff (See Appendices 4 and 5)
- Advise the hospital staff of the current GP's name, practice and contact details.
- Assist the hospital staff with any other required information, such as medication chart.
- Report to hospital staff any observations of behaviour that may be difficult to interpret or any other responses by the individual
- Familiarise the hospital staff with, and demonstrate if necessary, the individual's method of communication
- **Remain with the individual during admission** until decisions are made about the individual's care coordination and treatment plans.
- Participate in any other care coordination discussions as required.
- Communicate care coordination and transfer of care discussions to the individual and/or their representative.

Triage is a system of assessment which identifies who needs to be treated first in the emergency department. At triage:

- Be prepared for a possible lengthy wait
- Keep the individual comfortable and ensure they do not become distressed
- Support the individual to participate in the triage process
- Be available to answer any questions from hospital staff
- Be prepared to advocate for the individual if required (speak up if you think the individual is deteriorating and you have concerns).

The DSO support staff accompanying the individual to emergency department needs to be prepared for either a hospital admission or being discharged from emergency department.

If the individual is to be admitted, communicate to hospital staff any risks or needs. These may be:

- Can the individual be left alone?
- What support needs are required in relation to feeding, self-care, mobility, continence, communication, behaviour management?

The DSO staff or carer should be aware that they may be included in a case conference around the health care management plan for the individual.

Transport back from Emergency Department

Attendance at the emergency department does not automatically result in a hospital admission.

The support organisation should plan transport home from the emergency department in the event that the individual is not admitted to hospital, noting that discharge from the emergency department can occur at any time of day or night.

Planning and preparation for admission to hospital

See **Appendix 3** for what to pack.

The period of admission can range from a few hours (for day surgery) to several weeks. Planning should start as soon as the admission is scheduled in order to prepare the individual for the admission and ensure their safety and wellbeing during the hospital stay.

- Inform and involve the individual's representative in planning for the admission, where appropriate
- Where possible have relevant supporting documentation completed and available - See Appendices 4 & 5
- Ensure all equipment that is provided by the DSO is labelled (property bag and list)

Admission via specialist

- Accompany the individual to their appointment
- Support the individual to participate in the consultation
- Ensure that communication between the specialist and the individual's representative occurs if the representative is unable to accompany the individual to the appointment

Preadmission Clinic

- The individual who has legal responsibility for consent should accompany the individual to this appointment – if this is not possible, the DSO staff or carer should attend.

Admission planning

- Provide contact details of the individuals' representative to hospital admissions staff once the decision is made to admit the individual to hospital (if the individual is unable to provide consent)
- Attend a pre admission process meeting (arranged by the hospital) to include relevant hospital staff, DSO staff, the individual and their representative, if possible
- Arrange a hospital stay planning meeting with the DSO staff, individual and individual's representative – this is scheduled by the DSO
- Ensure that information about the hospital admission, hospital routines and procedures are communicated to the individual in the individual's own communication style
- Prepare the individual's documentation, as per the **Appendices 4 and 5**, to be up to date and ready to go with the individual on the day of admission
- Identify the support needs of the individual whilst in hospital and clarify the availability of DSO staff to meet needs during the admission
- Ensure that equipment needs are identified, these may include mobility aids, communication aids and medical and therapeutic devices

During Admission

Consider the support the individual will require during his/her hospital stay, including:

- re-clarifying medical consent and decision making protocol
- liaising with the hospital staff around possible behaviour support issues and assistance required with individual care e.g. meals, bathing, equipment
- considering support to be provided by the DSO, if feasible
- clarifying support roles between the hospital staff and the DSO staff, e.g. the need for special nurses
- considering information required from the hospital to the DSO provider at the time of discharge
- adequate planning around discharge timing to ensure the necessary supports are in place at the disability facility
- jointly agreeing and document supports to meet the individual's needs - this should be done as soon as practicable either prior to transfer to the ward, or once the individual is settled in the ward.

Discharge

An effective discharge from hospital is reliant on good discharge planning; this requires partnership between the individual, their key supports, the DSO and hospital system.

- Planning for discharge should commence at the time of admission and should include all stakeholders.
- Individuals presenting with acute health issues may incur changes to their disability support needs due to that health incident. These changes should be considered in accordance with their original accommodation circumstances and its ongoing ability to support those changes.

The hospital system and the DSO or key support person have a shared accountability for the individual's ultimate discharge outcome.

Discharge planning needs to consider the long-term sustainability and suitability of the discharge option with a view to preventing readmission and/or discharge to inappropriate accommodation options.

- Ensure the hospital has all documentation regarding confidentiality and release of information back to the DSO so that all relevant discharge information can be provided
- obtain regular updates, preferably daily, on the individual's progress and treatment to understand their current and future support needs
- communicate information regarding changes to health and care needs and the impact on long term support requirements to the individual and their representative
- if a NDIS participant and a significant change of support is needed as a result of the hospital admission, request sufficient reports and evidence from the hospital staff to submit a Change of Circumstance or Plan Review to support funding review.

- communicate information to the relevant funding agency regarding possible changes to long term care and support
- support the individual during any transfer across health services to ensure continuity of support and carry-over of essential discharge information
- participate in planning for the individual's care coordination in hospital and transfer of care out of hospital
- determine if the individual's mobility has changed as an inpatient and if they require any mobility aids and/or additional rehabilitation, or referral to a community physiotherapist
- facilitate participation in discharge planning of the individual and significant others
- reassess the individual prior to the proposed discharge date to ensure that the individual is now able to be supported within their current accommodation option
- ensure that the individual has appropriate transport on the day of discharge
- where possible, ensure time of discharge allows for someone at the accommodation to receive the individual and has a full understanding of any changes to care requirements
- ensure the hospital has provided a discharge summary and any new prescriptions PRIOR to discharge.

Considerations for a successful discharge (responsibilities of DSO's)

Advise:

- the hospital of the individual's NDIS Specialist/Support Coordinator, if they have one
- the individual's current level of functioning and whether it is the same as their usual ability preadmission or if their care needs have changed since their hospital admission
- if the discharge care plan provides a guide/criteria of what support can be accessed in the community to support changes in care needs
- who makes the decision that the individual can return to their original accommodation option and/or who is responsible for planning and decision making if the individual will require alternative accommodation
- who the hospital liaises with to explore alternative accommodation options
- what services the individual is eligible for, whether they are able to access services in their area to support changed care needs and if they connected into those services.
- If the individual requires new services or if pre-existing services on hold and need to be reinstated

After Discharge

Monitor the individual and if you are concerned seek further medical attention and, in an emergency, return to the emergency department. If it is not an emergency call the GP, Practice Nurse or After-Hours GP Locum Service.

Acknowledgements

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- Tricia Dewar, Brightwater
- Sharleen Chilvers, Nulsen Disability Services.

Appendix 1 – CARE Call

CARE call

Are you worried about the condition of your child in hospital?

We will listen to you.

There are different ways to let us know that you are worried. The CARE Call steps will help you progress your concerns.

CARE call steps

Step 1

Talk to your child's nurse or doctor

Use the bedside call bell or go to the nurses' station to talk to your child's nurse or doctor about your concerns and ask for an assessment.

Step 2

Talk to the Nurse Coordinator

Ask to speak to the Nurse Coordinator in charge of the ward. They will be wearing a yellow sash around their neck.

Step 3

Make the CARE call

If you think the condition of your child is urgent, or your concerns still have not been heard, you can make a **CARE call on 6456 0337.**

What will happen when you make the call?

Making a CARE Call will reach the Medical Emergency Team (MET), who will ask for:

- your name
- your child's name
- the ward and bed number.

Someone from the MET team will come and provide an **urgent review**.

When shouldn't I make a CARE Call?

CARE call is **only for patients who are at Perth Children's Hospital.**

Appendix 2 – Communication Scripts

Scripts to help communicate needs in a hospital setting

Pain	**Possible staff observation -** "They are not in any pain/they don't seem to be in pain" **Response -** "He doesn't show pain in the usual way, but we know he's in pain by …. [the paleness of his face/clenching of his hands. See FLACC Pain Scale
Communication	**Possible staff observation -** "So she is non-verbal/can't talk/doesn't understand what I am saying?" **Response -** "She is able to understand, she just communicates in other ways, with …… [Auslan/ braille/ natural gestures/using her iPad/ visual symbols]. If you speak directly to her, I can help explain to her what you mean, or we can use this picture communication symbols board. See Medical Signing Board.
Communicating with People with Down Syndrome	See Down Syndrome Factsheet
Distress	**Possible staff observation -** "You'll have to calm him down/stop this behaviour or take him home/come back another time" **Response -** "His fear of unfamiliar surroundings is increasing his distress. If we can help him regulate his emotions by doing… [giving him his favourite thing to hold/ by distracting him/ turning the lights down] he'll be better able to co-operate" or "We have a Positive Behaviour Support Plan that documents strategies to help, I have a copy to share with your team."
Coping with procedures	**Possible staff observation -** "Don't move/stop them moving, I have to insert this canula". **Response -** "Can I just let her know what is about to happen, and check she is ok with you holding her arm first please?"

Supported shared decision making and informed consent	**Possible staff observation -** "I'll need you to just sign this form for him.' **Response –** "If you can outline the possible risks, I'll explain in a way he can understand, to tell him what we are signing and give him a choice." "If you can simplify the language and take a little more time he can decide." See Individualised Supported Decision-Making Booklet.
Medication	**Possible staff observation -** "I'll just need you to take your tablets now." **Response -** "We have had a concern in a past admission with a wrong dose/ wrong medication/ wrong timing. Could I ask if we can cross check before he takes these medications, please."
Lack of parent/carer training	**Possible staff observation -** "If you watch me insert the naso-gastric tube/ Peg tube a couple of times then you'll be able to do it yourself if it comes out again." **Response –** "I really feel under prepared to take on a task like this, which needs almost nurse-level training. Can I take a video of how you do it to refer back to later please, and is there someone I can call after discharge to guide me?" Using carefully considered, respectful alternatives can change the entire experience of a hospital journey, all the way from admission to discharge.

Appendix 3 – Packing Checklist

Checklist of what to take to hospital for the person you support:

- Medical information forms **e.g. Health Passport, Individual Health Profile**
- Cards - Medicare card / private health care card / Health Care Card / Pension Concession
- Current GP contact details (&/or Paediatrician / Specialist)
- Current medications and a list with dosage amounts: Do not assume that all medication will be available at the Hospital, and their dosages/strengths
- Lists of recent symptoms/doctors'/appointments etc.
- Clothes for day wear and discharge
- Equipment such as orthotics, hearing aids, splints, tube feeding equipment, wheelchair, ventilator, Continence aids etc
- Communication devices with charger/s
- Items of comfort, such as sensory items, books, or any activities the individual enjoys
- A familiar pillow, quilt, blanket, favourite drinking cup/water bottle
- Pyjamas (top with buttons, if possible) and slippers/socks
- Toiletries – toothbrush, toothpaste, brush/comb, shampoo, moisturising creams.

What to take as a support person:

- Basic toiletries (electrical items such as hairdryers are not usually permitted for safety reasons)
- Medication and/or dietary supplements
- Comfortable clothes
- Pen and notebook to write down questions for hospital staff, to record information that you learn, and to write reminders for yourself
- Water bottle
- Mobile phone and charger
- A list of contact numbers you may need
- Access to money for meals /snacks /car park
- Books and magazines to keep yourself busy
- You won't have much storage space and it's unlikely to be secure, so leave your valuables at home

Appendix 4 - Health Passport Options

Julian's Key Health Passport (Preferred)

This is a booklet that can contain all of the information that you need Hospital staff to know.

https://www.health.qld.gov.au/__data/assets/pdf_file/0032/858362/3.-Julians-Key-Health-Passport-100gsm-LHC-staple.pdf

My Health Matters Folder – Council for Intellectual Disability

A simple resource can be printed out to help medical staff know:

- How the individual communicates
- What emotions they are expressing
- Health and personal history information

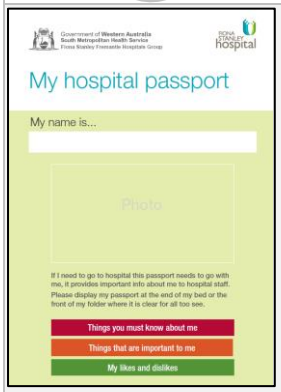
It was co-designed by GP's and people with an intellectual disability.

https://cid.org.au/resource/my-health-matters-folder/

WA Emergency Care Plan – Kalparrin

This document is tailored towards children and could also be used to inform new support providers.

https://www.kalparrin.org.au/wp-content/uploads/2021/04/Kalparrin-Emergency-Care-Plan-WEB.pdf



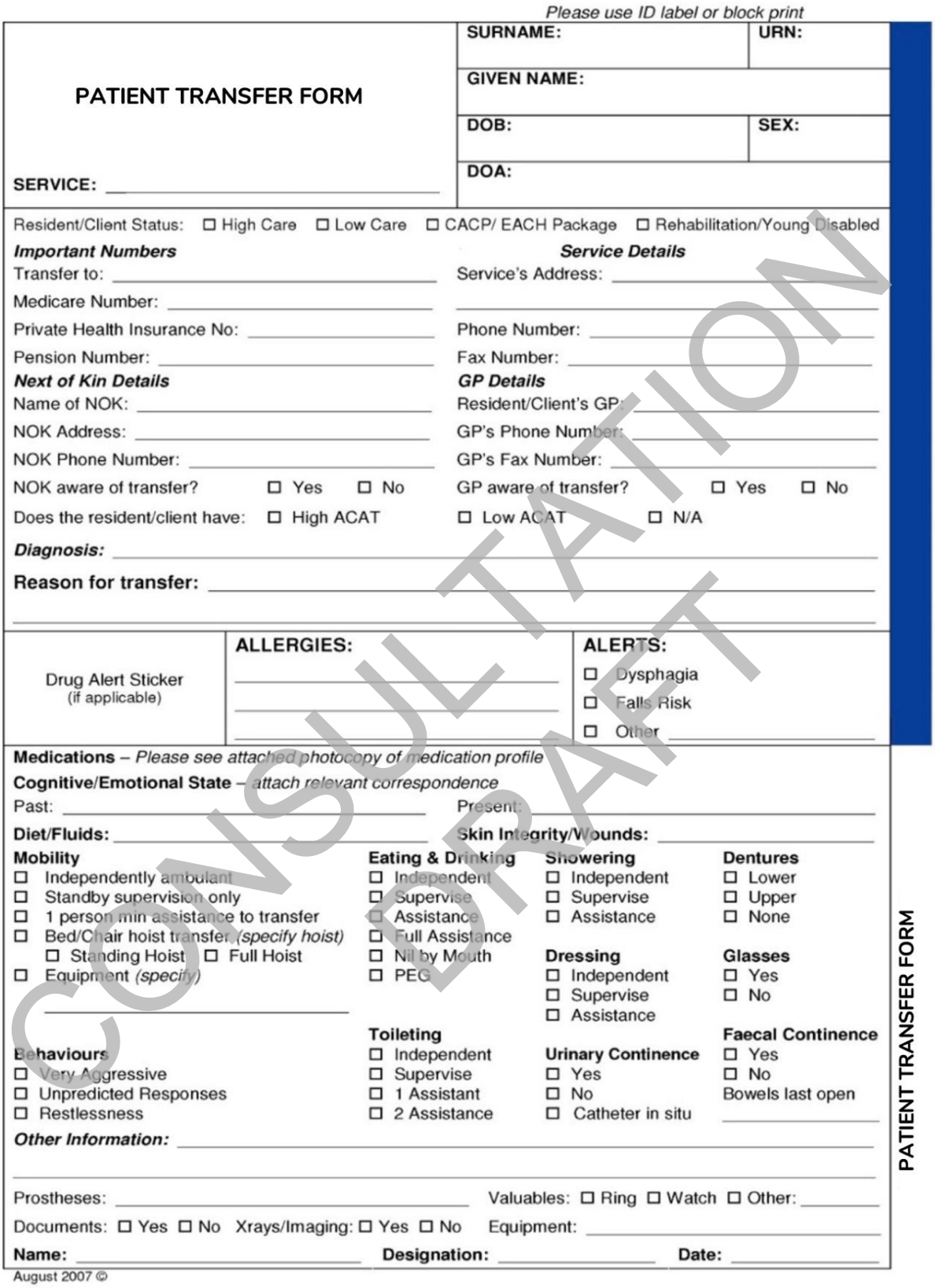
My Hospital Passport – Developmental Disability WA

This passport is in Easy Read format and is also child-relevant, developed by Fiona Stanley Hospital.

https://ddwa.org.au/wp-content/uploads/2021/08/FSH-Paediatric-Passport.pdf

	**Valued Lives My Health Passport – Health and Disability Commissioner of New Zealand.** https://valuedlives.org.au/wp-content/uploads/2020/06/Valued-Lives-Participant-Health-Passport.pdf

Appendix 5 – Individual Health Profile



Please use ID label or block print

PATIENT TRANSFER FORM

SURNAME: | **URN:**

GIVEN NAME:

DOB: | **SEX:**

DOA:

SERVICE: _____

Resident/Client Status: ☐ High Care ☐ Low Care ☐ CACP/ EACH Package ☐ Rehabilitation/Young Disabled

Important Numbers

Transfer to: _____

Medicare Number: _____

Private Health Insurance No: _____

Pension Number: _____

Service Details

Service's Address: _____

Phone Number: _____

Fax Number: _____

Next of Kin Details

Name of NOK: _____

NOK Address: _____

NOK Phone Number: _____

NOK aware of transfer? ☐ Yes ☐ No

GP Details

Resident/Client's GP: _____

GP's Phone Number: _____

GP's Fax Number: _____

GP aware of transfer? ☐ Yes ☐ No

Does the resident/client have: ☐ High ACAT ☐ Low ACAT ☐ N/A

Diagnosis: _____

Reason for transfer: _____

Drug Alert Sticker (if applicable)

ALLERGIES:

ALERTS:

☐ Dysphagia

☐ Falls Risk

☐ Other _____

Medications – *Please see attached photocopy of medication profile*

Cognitive/Emotional State – *attach relevant correspondence*

Past: _____ Present: _____

Diet/Fluids: _____ **Skin Integrity/Wounds:** _____

Mobility

☐ Independently ambulant
☐ Standby supervision only
☐ 1 person min assistance to transfer
☐ Bed/Chair hoist transfer *(specify hoist)*
☐ Standing Hoist ☐ Full Hoist
☐ Equipment *(specify)*

Eating & Drinking

☐ Independent
☐ Supervise
☐ Assistance
☐ Full Assistance
☐ Nil by Mouth
☐ PEG

Showering

☐ Independent
☐ Supervise
☐ Assistance

Dressing

☐ Independent
☐ Supervise
☐ Assistance

Toileting

☐ Independent
☐ Supervise
☐ 1 Assistant
☐ 2 Assistance

Dentures

☐ Lower
☐ Upper
☐ None

Glasses

☐ Yes
☐ No

Faecal Continence

☐ Yes
☐ No

Bowels last open _____

Behaviours

☐ Very Aggressive
☐ Unpredicted Responses
☐ Restlessness

Urinary Continence

☐ Yes
☐ No
☐ Catheter in situ

Other Information: _____

Prostheses: _____ Valuables: ☐ Ring ☐ Watch ☐ Other: _____

Documents: ☐ Yes ☐ No Xrays/Imaging: ☐ Yes ☐ No Equipment: _____

Name: _____ **Designation:** _____ **Date:** _____

August 2007 ©

PATIENT TRANSFER FORM

(Note: Sticker and Form are in development)

This document can be made available in alternative formats on request for a person with disability.