



Down Syndrome Victoria
Participant
Handbook

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Down Syndrome Victoria

Participant Handbook

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About Down Syndrome Victoria

Down Syndrome Victoria (DSV) is Victoria's statewide peak organisation representing people with Down syndrome and their families. It is a not-for-profit organisation established in 1978 to provide support, information and resources to people with Down syndrome, their families and the broader community.

DSV works alongside people with Down syndrome and their families, so that they may reach their full potential and live the lives they choose. DSV provide parents, families, professionals and friends of people with Down syndrome with support, information, and resources.

Please note that Down Syndrome Victoria does not provide a crisis service. For urgent assistance please call:

Parentline  **13 22 89**

Lifeline  **13 11 14**

Kids Helpline  **1800 551 800**

(for callers aged 5–25 years)

Down Syndrome Victoria is a member of Down Syndrome Australia. DSV operates in accordance with a Constitution and is led by a Chief Executive Officer, who reports to a Board of Management.

All our operations are based on the following values:

- **Rights** - People with Down syndrome are individuals whose abilities, rights and dignity should be recognised, respected and promoted.
- **Self-determination** - People with Down syndrome should be the authors of their own lives and should be provided with appropriate support to make meaningful choices.
- **Inclusion** - People with Down syndrome should have the same rights, responsibilities and opportunities as all individuals in the community.
- **Resilience** - Resilient families will raise resilient individuals with Down syndrome who are more able to reach their full potential.
- **Support** - Peer support for people with Down syndrome and their families is critical to building individual and collective resilience.
- **Empowerment** – DSV will work together with people with Down syndrome – we will not do to, or do for, but do with.

Contact Details

 **1300 658 873**  **info@dsav.asn.au**

 **552 Victoria Street, North Melbourne VIC 3051**

Our opening hours are 10:00am to 4:30pm, Monday to Thursday.

DSV also operates outside of standard times to best meet participant needs.

Our Services

We provide whole of life support services to people with Down syndrome and their families, at all stages of life, but particularly at times of diagnosis and at life's transition points. This includes:

- Prenatal support, including personal support for expectant parents
- New parent support, including workshops, resources and connecting with other parents
- Adult support and ongoing support with post school transition, employment and accommodation options
- A statewide network of Support Groups, including MyTime and Club21, a peer support group for adults with Down syndrome
- Education support – including the Education Support Service (ESS), education conferences, workshops, information and support for teachers and parents
- Professional support
- Training and information workshops covering a wide range of Down syndrome and NDIS related topics
- Library facilities and resources for members including books, DVD's, kits and journals
- Systemic advocacy; working towards the full economic and social participation of people with Down syndrome in the community
- National Disability Insurance Scheme (NDIS) registered services including, but not limited to increased social and community participation supports.

For more information about these services please call us on **1300 658 873**, visit our website (downsyndrome.org.au/vic) or speak to a member of our staff.

Service Quality

To deliver services as a NDIS Registered Provider, Down Syndrome Victoria complies with the NDIS Quality and Safeguards Framework.

This means we:

- **comply with the NDIS Act 2013 (Cwth);**
- **comply with the NDIS Terms of Business for Registered Providers and any Conditions of NDIS Registration; and**
- **obtain and maintain accreditation against the NDIS Practice Standards.**

The NDIS Practice Standards are quality standards that govern how Registered NDIS providers must deliver services.

The Standards that relate to Down Syndrome Victoria are:

Schedule 1 – Core Module

1. Rights of participants and responsibilities of providers
2. Provider governance and operational management
3. Provision of supports
4. Support provision environment

As set out in this handbook, Down Syndrome Victoria is committed to delivering services in compliance with these standards and to continuously improving our service delivery. We operate in accordance with comprehensive policies and procedures, which are reviewed regularly and incorporate participant and other stakeholder feedback.

NDIS Code of Conduct

Down Syndrome Victoria and its staff comply with the NDIS Code of Conduct.

In providing supports or services to people with disability, Down Syndrome Victoria and its staff will:

- **act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions;**
- **respect the privacy of people with disability;**
- **provide supports and services in a safe and competent manner, with care and skill;**
- **act with integrity, honesty and transparency;**
- **promptly take steps to raise and act on concerns about matters that may impact the quality and safety of supports and services provided to people with disability;**
- **take all reasonable steps to prevent and respond to all forms of violence against, and exploitation, neglect and abuse of, people with disability; and**
- **take all reasonable steps to prevent and respond to sexual misconduct.**

Anyone can raise a complaint about potential breaches of the NDIS Code of Conduct. See the Feedback, Compliments and Complaints section of this booklet for more information.

Your Rights

Down Syndrome Victoria respects and fully commits to upholding the rights of all people. We are also committed to ensuring you, our Participants, are aware of your rights and responsibilities and can be confident in exercising them.

In supporting you to exercise your rights, we comply with the United Nations Universal Declaration of Human Rights, United Nations Convention on the Rights of Persons with Disabilities, National Disability Insurance Scheme Act 2013 and NDIS Practice Standards (2018) - Rights and Responsibilities.

In supporting you to exercise your rights, we comply with the United Nations Universal Declaration of Human Rights, United Nations Convention on the Rights of Persons with Disabilities, the United Nations Declaration on the Rights of the Child, NDIS Act 2013 (Cth), and the Victorian Charter of Human Rights and Responsibilities Act 2006, Equal Opportunity Act 2010, Racial and Religious Tolerance Act 2001;

You have the right to access supports that:

- promote, uphold and respect your legal and human rights; respect
- your culture, diversity, values and beliefs;
- respect and protect your dignity and right to privacy;
- are free from violence, abuse, neglect, exploitation or discrimination; and allow you to exercise informed choice and control.



It is our responsibility to:

- tell you about and uphold your rights;
- provide supports in a way that promotes, upholds and respects your rights to freedom of expression, self-determination and decision-making;
- support you to make informed choices, exercise control and maximise your independence in relation to the supports we provide;
- respect your autonomy, including your right to intimacy and sexual expression;
- provide you sufficient time to consider and review your support options and seek advice if required, at any stage of our service delivery;
- support you to access an advocate (including an independent advocate) of your choosing;
- support you to engage with your family, friends and community in the ways you want;
- treat you fairly, with courtesy, dignity and respect and without discrimination;
- give you information about our services and associated costs, as well as other support options, within and outside Down Syndrome Victoria;
- involve you in decisions about your supports, as well as our programs and policies; provide services that consider and respect your lifestyle, cultural, linguistic and religious background and preferences;
- protect your personal information and only use it for the right reasons;
- support you to provide us with feedback on our service, including complaints;
- promptly address enquiries and complaints about the supports you are receiving;
- support you to connect with other services, including advocates, interpreters and translators, if needed;
- support you to have a person to speak on your behalf for any purpose; and
- provide safe and appropriate services that are culturally relevant and support your needs and goals.

As our participant we ask that you:

- provide us with information that will help us to best support you;
- tell us if things change or you cannot keep an appointment or commitment;
- act respectfully and safely towards other people using the service, and towards our staff;
- provide us with feedback about our service and how we can improve;
- promptly pay the agreed fees associated with your services; and
- tell us as early as possible if our services are not required.

You can request Down Syndrome Victoria's full Participant Charter from any of our staff members.

Diversity & Participation

All aspects of Down Syndrome Victoria's service delivery promote participants' active participation and inclusion in the community. We support participants to develop and maintain their independence, problem solving, social, and self-care skills; as appropriate to their age, developmental stage, cultural background or other needs and goals.

Ways we do this include:

- delivering services in a way that respects individuals' personal, gender, sexual, cultural, religious, or spiritual identity;
- employing and developing a diverse and culturally competent workforce;
- working collaboratively with disability-specific, mainstream, Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) services to support holistic service delivery; and
- using a strengths-based approach to identifying individual Participant needs and life goals, particularly in relation to recognising the importance of family, extended family, kinship, cultural, spiritual, language and community ties.

Interpreting and Translation

The delivery of safe, high-quality services relies on effective communication. Where required to support your interactions with us, interpreters and translators will be made available at no cost.



Advocacy

Down Syndrome Victoria continually strives to be a leading authoritative voice for the Down syndrome community. We are committed to the full participation of people with Down syndrome in the economic and social life of the community.

Down Syndrome Victoria also fully supports your right to have an independent advocate support you in your interactions with us. If you'd like help finding an independent advocate, please speak to one of our staff.

Alternatively, the following organisations can assist you:

Office of the Public Advocate

Phone: (03) 9603 9500

TTY: (03) 9603 9259

National Disability Advocacy Program (NDAP)

Use the Disability Advocacy Finder at:

<https://disabilityadvocacyfinder.dss.gov.au/disability/ndap>

Victorian Advocacy League for Individuals with Disability (VALiD)

Phone: (03) 9416 4003, Freecall (rural callers): 1800 655 570

Email: office@valid.org.au



Privacy and Confidentiality

Down Syndrome Victoria values and respects the privacy, confidentiality and dignity of our participants and their families, as well as our staff. We collect, use, protect and release personal information in full compliance with all relevant State and Federal privacy legislation.

Down Syndrome Victoria will only collect information necessary for safe and effective service delivery. We will only use private and sensitive information for the purpose it was collected and will secure it safely. When we collect your information, we will explain why we are collecting the information and how we plan to use it. We will only take photos or videos of you with your consent. Additionally, any photos or videos of you will only be used externally with your permission.

Information about you will only be released to other people or services with your informed consent, in an emergency, or where such disclosure is required or authorised by law.

You may access the information we hold about you, including to update or correct it, subject to certain exceptions. If you wish to access your information, please speak to a staff member.

When your information is no longer needed for the purpose for which it was obtained, we will destroy or permanently de-identify it.

You can request Down Syndrome Victoria's full Privacy Statement from any of our staff members.



Feedback, Compliments and Complaints

Compliments, complaints and other forms of feedback provide Down Syndrome Victoria with valuable information about participant satisfaction and an opportunity to improve upon all aspects of our service.

We encourage feedback and comments on the services we provide, both positive and negative. Your complaint will be treated with confidentiality and sensitivity.

Feedback, compliments and complaints can be lodged:

- **directly with a staff member, either verbally or by submitting a completed Feedback and Complaints Form;**
- **by email to: info@dsav.asn.au; by**
- **phone on 1300 658 873;**
- **in writing to: Down Syndrome Victoria, 552 Victoria Street, North Melbourne VIC 3051; or anonymously,**
- **through any of the above means.**

Feedback and Continuous Improvement

In addition to the above, Down Syndrome Victoria is continually seeking feedback on how we can improve the services we provide. This includes through satisfaction surveys, requests for feedback by staff after you interact with us and involving participants and other stakeholders in our service delivery planning and review processes. Please feel free to provide any suggestions or ideas to a staff member.

Complaints

We encourage anyone with a complaint to speak directly to a Down Syndrome Victoria staff member in the first instance, who will attempt to resolve the issue immediately.

If the matter cannot be resolved promptly or within 1-2 working days, it will be escalated to Down Syndrome Victoria's Chief Executive Officer as a grievance.

You can use Down Syndrome Victoria's Feedback and Complaints Form to formally lodge your grievance and a staff member can assist you to do this if you wish.

Your complaint will be formally acknowledged within two working days and a staff member will keep you updated regarding its resolution. Down Syndrome Victoria aims to respond to all complaints and grievances as quickly as possible, and within 28 days from acknowledgement.

If a complaint or grievance cannot be responded to in full within 28 days of acknowledgement, you will be provided with an update, which will include when a full response can be expected.

If you feel a complaint has not been sufficiently or appropriately addressed, you can seek further support from Down Syndrome Victoria's Chief Executive Officer or the President of DSV's Board, or alternatively through any of the following agencies:

NDIS Quality and Safeguards Commission

Online: www.ndiscommission.gov.au

Phone: 1800 035 544

Australian Human Rights Commission

Phone: 1300 656 419

Online: www.humanrights.gov.au



The Victorian Equal Opportunity and Human Rights Commission
(for complaints relating to human rights and discrimination):

Online: www.humanrightscommission.vic.gov.au

Phone: 1300 292 153;

Email: complaints@veohrc.vic.gov.au; and

Post: Level 3, 204 Lygon Street, Carlton, VIC, 3053.

Participants also have rights and protections under the Australian Consumer Law (ACL), including provisions on customer guarantees and unfair contract terms.

[Consumer Affairs Victoria](#) provides information and advice about customer disputes under the ACL.

All feedback and complaints will be used by Down Syndrome Victoria to continuously improve our service delivery.

Accessing Down Syndrome Victoria's Services

We aim to provide accessible services to you that are safe, engaging and responsive to your support and communication needs.

Down Syndrome Victoria provides whole of life support services to people with Down syndrome and their families. Access to services is based on relative need, service capacity, the best interests of the person wishing to use our service and any potential impact on existing participants.

Anyone wishing to access our services must participate in an Intake Interview. Where required, we will provide you with information and support to access a person of your choice, such as an advocate, to assist you in this process. The purpose of this interview is to assess your needs and whether Down Syndrome Victoria is able to support you. You will be contacted within one working day of the Intake Interview and advised of the outcome.

If you are offered services and accept, we will work with you and your supporters to assess your needs and develop and agree upon a Service Agreement. This will be completed during an Assessment and Planning Interview, which will take place within 5-10 working days of your acceptance.

Once you are a participant, we will review the provision of your supports every 12 months with you and your supporters. Flexibility will be provided regarding the timing of review assessments, based on your needs and wishes, and you can request a review at any time.



Service Refusal

We will accept your choice if we offer you a service and you choose not to accept.

Down Syndrome Victoria may refuse to offer a person service where:

- they do not meet our eligibility requirements;
- other potential participants are assessed as a higher priority based on our Priority of Access considerations;
- we do not have the capacity to cater to additional participants; or
- we do not have the resources to cater to the specific needs of the person.

Where services cannot be provided, we will assist you with referrals and support to access alternative services.

Any person refused services has the right to appeal. Appeals should be directed in writing to Down Syndrome Victoria's Chief Executive Officer.

Waiting List Processes

A person who meets Down Syndrome Victoria's eligibility requirements and cannot be offered a service due to lack of service capacity can elect to be placed on our Waiting List.

Potential participants on our waiting list will be contacted at least every three months to:

- advise them of their current status;
- check whether they want to remain on the list; provide
- referrals to other service providers if required; and advise
- the estimated wait time remaining.



Leaving Down Syndrome Victoria's Services

All participants have the right to leave Down Syndrome Victoria's services at anytime and a decision to do so will not prejudice future access to the service. You must give us at least 2 weeks notice if you wish to leave our services before the end date in your Service Agreement.

All participants exiting the service will be offered an Exit Interview, where we can discuss the reason for them leaving and obtain feedback about how we can improve our processes. We also provide assistance and resources to support people exiting or changing services. This includes an agreed Exit Plan, as well as the identification of, referral to and support accessing alternative services.

Participants who have chosen to exit our services have the right to re-access services within a 1-month period of exiting, without having to follow formal access processes, provided the necessary resources are available.

If you wish to end your service provision, please speak to a Down Syndrome Victoria staff member.

Service Termination

Down Syndrome Victoria may terminate a participant's services when:

- they are unwilling over a period of time to work towards agreed goals;
- other people using the service, staff or the person themselves are at risk of harm;
- financial requirements are not being met;
- severe incompatibility with other participants using the service is displayed; or
- dramatic health changes require significantly increased levels of care or a service model not provided by Down Syndrome Victoria.

Any person whose services are terminated has the right to appeal. Appeals should be directed in writing to Down Syndrome Victoria's Chief Executive Officer.

Fees and Charges

Fees and charges for our services vary depending on the service and the source of funding for that service (e.g. government funded, or participant funded). We will discuss prices with you before providing services and include all fees in a Service Agreement. The Service Agreement contains detailed information about the services we will provide you and when fees must be paid. This must be agreed to by you before services can commence.

Down Syndrome Victoria will provide you with regular invoices and statements to assist you to manage payment for our services. If you have difficulty paying your fees for any reason, we encourage you to discuss this with a staff member so that mutually acceptable payment arrangements can be put in place.

Freedom from Harm, Abuse and Neglect

When visiting our office or taking part in our services, you have the right to be free from harm and any form of abuse or neglect. Down Syndrome Victoria treats any allegation of abuse, assault or neglect very seriously. Allegations may be subject to both mandatory reporting and police involvement. If you have any concerns or are aware of a situation where abuse or neglect may be occurring, please notify a Down Syndrome Victoria staff member.

Down Syndrome Victoria employs skilled staff who respect the rights of people with disability, are aware of current policies and legislation pertaining to abuse, neglect and unexplained absences and will support people and their families, guardians and advocates to access complaint mechanisms and raise any concerns they have about our services. All staff undergo comprehensive criminal history screening and other mandatory checks prior to employment.

Occupational Health and Safety

Down Syndrome Victoria is committed to providing services in a safe and healthy environment. Occupational Health and Safety (OH&S) is the responsibility of all DSV stakeholders – including staff, volunteers, participants, families, carers and visitors. We ask that you report any hazards or risks you become aware of and act in a way that protects yours and others' health and safety when visiting our office or participating in our services.

Community Participation and Inclusion

Down Syndrome Victoria is committed to working with you to dismantle barriers, change attitudes and promote positive attitudes to create opportunities for your full inclusion and participation in your community. We work closely with a range of organisations to support you and encourage you to speak to a staff member if you have any specific needs or goals that could be met by another organisation.

Thank you

Thank you for considering Down Syndrome Victoria. Down Syndrome Victoria works alongside people with Down syndrome and their families so they may reach their full potential and live the lives they choose. We hope your experience of our service aligns with this approach and we look forward to welcoming you.



Down Syndrome
Victoria