



Down Syndrome
Victoria

Supporting Victorian families since 1978

Planning For Life Beyond School



Resource funded by

downsyndromevictoria.org.au

nib foundation

Introduction

This booklet is designed to help you work through the decisions you need to make about leaving school.

While it can seem too hard sometimes, with too many options, it helps if you can focus on one bit at a time.

The key is to look at what you want for your child and usually it is to live an 'ordinary' life - for them to have the same opportunities as any other person.

Most 15-18 year olds work through this with a little support or some ideas from family and friends. However, for the family of a person with Down syndrome it can feel like the family is making all of the suggestions and decisions and this puts a lot of stress into the process. You can feel like you are always questioning your decisions.

'Am I making the right decisions for my child?'

'Have I included them enough?'



Having a Life

1. Sharing ordinary places
2. Making choices
3. Developing abilities
4. Being treated with respect and having a valued social role
5. Growing in relationships

(John O'Brien's Framework for Service Accomplishment)

Words of Wisdom - these hold true for all of your children

1. Have a vision: what do you want for the future?
2. Remember that you know your child best
3. Be prepared to work as part of a team to get the best possible outcomes for your child.
4. Aim to live an ordinary life.
5. Be confident that any decision you make will be the right one at that particular time given what you know.
6. Realise that no decision is set in stone - you can always change if circumstances change.

Decision Flowchart

Family situation

- Amount of informal support provided
- Work situation of others in family
- Travel support required

Work

- Supported
 - Open
- Disability Enterprise
- Disability Support Pension

Personal Skills

- Skills and strengths
- Likes and dislikes
- Vision and dreams

Developing a Plan

- Supports needed
- Funding required

Training

- TAFE course
- Work skills
 - Life skills
- Short courses

Recreation

- Leisure options

Life Skills

- Transport training
 - Cooking
 - Cleaning
 - Banking

Volunteering

- Formal
- Informal

Personal skills

The best place to start is by looking at the personal qualities and skills of the young person with Down syndrome.

What are their strengths?

What are they good at?

What do they like doing?

It is equally important to know what they will never want or be able to do. (You are unlikely to want a job mowing lawns if you can't stand noise.)

Knowing these things will help you narrow down the possibilities.

Some people use a one page profile as a way to summarise the skills, strengths and areas where support is needed. (See 'Jackson Glenn - One Page Profile' at the back of this book).

It is important to give everyone a chance to consider what they would like to be or do and to set their sights high.

Check our website at downsyndromevictoria.org.au for further information

Family situation

When you start to think about your child leaving school, it can be daunting for them and you.

It is a transition point for them but it is also a crossroads for the whole family. It is a time when you go from having your child at school for 6 hours a day to ??

It is a time when families look for support in a number of areas. Sometimes the hardest part is trying to work out the logistics of work or study requirements for everyone in the family, travel arrangements and formal or informal support. You may have an ISP or FFYA funding.

As we transition to the NDIS there are two systems operating depending on whether you are in an NDIS area or not.

If you are not in an NDIS site then you can claim the Mobility Allowance for travel support and the Carer Allowance for informal support. If you are in one of the NDIS trial sites then you can have travel support and informal carer support as part of your plan.



Work

Employment offers many advantages other than simply a source of income. Work gives structure, a sense of purpose, feelings of competency and pride while offering an opportunity to learn new things and meet new people.

Work allows us to be productive, promotes independence, and enhances self-esteem.

Often the young person will have trialled some work placements during the last couple of years at school. Hopefully these will help to narrow down the field of work that the person wants to move into.

Sometimes the best trials are those that parents, family or friends find through their network of personal contacts.

There are a number of employment options available to people with Down syndrome entering the workforce.

Open employment

This involves working independently in a job in the community with no support services.

Disability Employment Service

This involves working in an open setting and receiving support to learn the skills necessary to enter and maintain a job in the workplace. DES' assist job seekers to gain and maintain employment in the open employment market. They provide training, job placement and on-the-job support.

A list of DES providers can be found at disabilityemployment.org.au/provider-search/vic

Australian Disability Enterprise

This involves working in self-contained settings with others who have disabilities. There are a range of work tasks provided in each setting. A list of ADE providers can be found at ade.org.au/ades-directory/ade-interactive-map

Disability Support Pension

People with Down syndrome are eligible to apply for a Disability Support Pension when they turn 16 years of age, as well as other payments such as Mobility Allowance and Pensioner Education Supplement.

More information and details about each of these options and the process undertaken to obtain a Job Capacity Assessment can be found at humanservices.gov.au/customer/themes/people-with-disability



Training

Many young adults are looking for extra training when they leave school as they may not be ready for a job. Even those that do have a job will often combine it with some ongoing skill development.

Further education options may include Apprenticeships and traineeships, Vocational Education and Training (VET) or learn local courses. education.vic.gov.au/training/learners/Pages/default.aspx

VET courses

There are also short courses in local community areas for a term at a time.

education.vic.gov.au/training/pages/default.aspx
employment.gov.au/transition-work



Volunteering

This is an option to try out different settings to find out what the person wants to do or simply to give back to the community and make social connections.

Volunteering can be done on a regular, formal basis or it can be casual and informal.

Some people will volunteer at the local school, library or hospital. Others will prefer to give some time to an op shop or soup kitchen.

Your local council may have a list of organisations looking for volunteers and you can always approach Volunteering Victoria volunteeringvictoria.org.au to see what they have available.

Quick Links

volunteeringvictoria.com.au
education.vic.gov.au/training/pages/default.aspx
employment.gov.au/transition-work

Life skills

There are organisations that provide activities for people with disabilities.

These activities can include:

- Transport training
- Shopping
- Cooking
- Cleaning
- Banking

A list of the current service providers can be found on the DSV website: downsyndromevictoria.org.au

Often these services are funded as part of an individual plan for life after school. The activities may take place on a 1-1 basis or as part of a small group.

Alternatively the individual may use their funds to have a support worker available to support them personally in a home or community setting.

Recreation

It is important that young adults with Down syndrome are able to take part in recreation activities of their choice.

This may mean being involved in:

- Sport
- Fitness - gym, swimming
- Music or dance
- Hobbies or clubs

Sometimes these activities are family based and sometimes the young person will be supported by a friend, or a support worker.

These services may be funded as part of an individual plan for life after school.

A list of the current service providers can be found on the DSV website: downsyndromevictoria.org.au



People who can help you

How do you find the right combination of options?

There are many people who you can ask for help during this process.

It is good to get ideas from different people but don't ask so many that you get yourself completely confused.

Sometimes it is useful to think about what a 'good week' might look like. A weekly timetable can help to get your ideas onto paper.

Remember to focus on your young person and what you all think will be best for them. Include your young person in the decision making process as much as possible.



People who can help you and other places to look:

- Local Area Coordinator
- School staff • Therapy provider
- Other parents
- Down Syndrome Victoria
- Websites • Resources
- Visits to services:
[dhs.vic.gov.au/
for-individuals/disability](http://dhs.vic.gov.au/for-individuals/disability)

Developing a plan

We all have rough plans about where we would like to be in a couple of years time, what we would like to be doing, where our next holiday will be, but we don't often write them down.

They are not rules to be strictly followed but more like 'guidelines' for where we might like to get to.

Young adults with disability need the same chance to think about what they would like to do and where they might like to be.

Often this requires a more detailed process because there are more people involved and if the young adult wants to reach the point they are aiming for then it requires everyone involved in their life to know what that point is and how they can work with the person to help them get there.

It is useful to have a vision for where you are aiming and then develop plans for a year or two at a time.

Often young adults want more choices, increased decision making, greater independence, and with this comes more responsibility.

Person-centred planning

There are a number of approaches to person centred planning and Helen Sanderson has identified five key features:

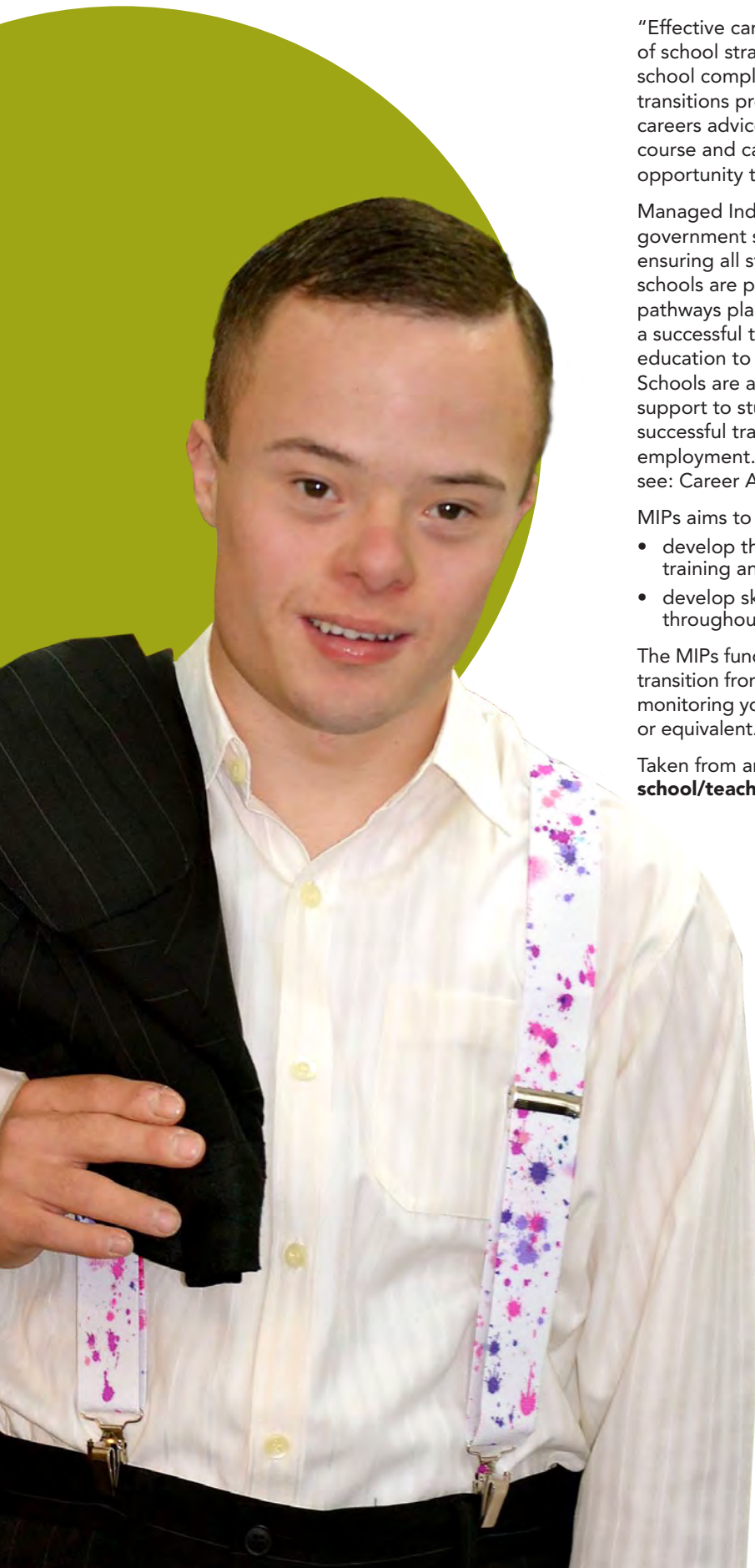
- The person is at the centre of all planning
- Family members and friends are partners in planning
- The plan reflects what is important to the person, their capacities and what support they require
- The plan results in actions that are about life, not just services, and reflect what is possible, not just what is available
- The plan results in ongoing listening, learning and further action and helps the person to get what they want out of life.

Some person centred approaches, or 'tools' that use person centred planning include:

- Personal Futures Planning
- Making Action Plans (MAPS)
- Planning Alternative Tomorrows with Hope (PATH)
- Essential Lifestyles Planning

www.helensandersonassociates.co.uk

Managed Individual Pathways (MIPS)



“Effective careers and transition programs are a vital component of school strategies to improve student engagement and increase school completion. Schools should have in place careers and transitions programs that provide every young person with careers advice to support them to make informed and effective course and career decisions, so that students can have every opportunity to succeed, and lead fulfilling and productive lives.

Managed Individual Pathways (MIPs) funding supports Victorian government schools’ careers and transition programs, including ensuring all students aged 15 years and over in government schools are provided with an individual Career Action Plan (MIPs/ pathways plan) and associated support as a means to making a successful transition through the senior secondary years of education to further education, training or full-time employment. Schools are also funded through MIPs to provide additional support to students at risk of disengaging or not making a successful transition to further education, training or secure employment. For sample Career Action Plan templates, please see: Career Action Plans

MIPs aims to help young people to:

- develop their knowledge and understanding of education, training and employment options, and
- develop skills to effectively manage their careers and pathways throughout their lives.

The MIPs funding supports a key strategy to improve the transition from school by strengthening school responsibility for monitoring young people’s pathways until they complete Year 12 or equivalent.”

Taken from and for more information: education.vic.gov.au/school/teachers/support/pages/mips.aspx

School Systems

*The information below is taken from education.wa.edu.au
All school systems follow a similar process.*

At the beginning of the transition planning process the young person and their parents develop a vision statement of their hopes, dreams and aspirations for the future - what the young person would like to be doing years after leaving school.

The vision statement (or desired post-school outcomes) considers a range of future life environments and roles, including:

- employment/work
- volunteering
- living arrangements
- sport, recreation and leisure
- social/personal
- education and training
- worker
- housemate
- team member
- friend
- student

A young person may revise or refine their vision of the future over time as they engage in a range of learning experiences and develop new skills and understandings about themselves and the world. The closer a young person gets to leaving school, the more detailed and realistic their vision should be.

Planning needs to be flexible and responsive to changing needs and circumstances. It should begin early. In selecting priority planning areas the transition team considers:

- desired post-school outcomes
- the young person's current skills, understandings, needs and capabilities
- the young person's needs in relation to the different environments within which they live and learn now and in the future e.g. what skills, understandings, services and supports are needed
- number of priority areas - 1 to 2 at any given time may be realistic
- planning that leads to the greatest level of independence now and in the future and those areas needed to be worked on the longest
- the fact that not all young people will require planning in all areas

Long-term goals and short-term objectives and actions/strategies are established for achievement in identified priority planning areas.

In selecting priority planning areas and identifying long-term goals and short-term objectives, the team considers the skills, understandings, information, services, supports and accommodations that the young person will need in their future environments and desired roles. This includes:

- independent living
- community participation
- career planning and employability skills
- vocational learning and training



- leisure and recreation activities
- personal wellbeing
- self-determination skills
- transport and mobility
- communication and social skills
- timely, up-to-date, easy-to-understand information about options, services, supports and accommodations

The team works out together:

- how they will contribute to achieving identified goals and objectives
- timelines for goals and objectives
- who takes responsibility for various actions/activities
- where learning and experiences will happen - at school, at home, in the community

Regular meetings and informal interim contact will allow the team the opportunity to monitor and review progress and achievement and to re-plan.

dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/transition-support-for-young-people-with-a-disability-leaving-school-incorporating-futures-for-young-adults-and-transition-to-employment-guidelines

Individual transition plan

An Individual Transition Plan (ITP) is an action plan, a statement of responsibility, and an accountability document.

A transition plan should be a flexible document that shows:

- the young person's developing skills and understandings
- changing goals, aspirations, interests and needs
- changes in the young person's environments
- new information about future options
- the effectiveness of identified actions and strategies.

An ITP should set clear, measurable and achievable goals so that everyone in the group has a sense of direction and focus, to make sure that everyone is working towards the same purpose.

Parents have a significant contribution to make and should have ongoing opportunities to participate and provide input to the development of the ITP.

ITP meetings are a chance to discuss and resolve issues, collaborate and share information, and develop action plans.

education.vic.gov.au/school/teachers/teachingresources/careers/Pages/disabilitypathways.aspx

How do I work with the school?

An effective partnership

An effective partnership starts with good communication, sharing of knowledge, and being able to work from different sides towards a common goal.

Communication

It is really important to have open communication between school and home.

At the end/beginning of the school year it is useful for parents and staff to sit down and review the ITP and set goals for the year.

In Victorian schools young people are supported through the Program for Students with Disabilities. Strengthened Pathways Planning is available as a career planning tool: education.vic.gov.au/school/teachers/teachingresources/career/pages/disabilitypathways.aspx

Some parents prepare a one page profile (See 'Jackson Glenn - One Page Profile' at the back of this book) and others prefer to provide an update in a booklet or verbally at the meeting.

Whatever you choose make sure that it indicates what the person is good at, what they can already do, where they might need support and what the current aims are.

Sharing knowledge

- Have any new information available.
- Be prepared to answer any questions that people may have
- Share any strategies that you think will work well
- Provide information/resources about Down syndrome as needed
- Let the school know about any training or work opportunities

Working together

- Set common goals/tasks for school and home
- Establish a method of regular communication
- Plan strategies together
- Be aware of the individual plan goals



What happens when things aren't going as planned?

Advocacy

There may be times when things are not going as well as you had hoped.

This is when it is important to have open communication with the school and advocate for your child.

It is best to deal with an issue as soon as possible and start by going to the person who is closest to the issue. Often this will be the classroom teacher.

You need to be prepared with any written information, know your rights, and your options.

You may take someone to support you if needed.

Calmly state the issue, and then be prepared to listen, negotiate and compromise if needed.

Remember that you are in this for the long haul so decide what your goals are, which battles to fight and which ones to let go.

Further information

You may find the websites below useful for further resources and ideas.

Helen Sanderson Associates

www.helensandersonassociates.co.uk

Helen Sanderson Associates is an international development, training and consultancy team, working with people to change their lives, organisations and communities through person centred thinking and planning. Some useful planning tools and other resources including communication/behaviour chart and one page profiles

Ticket To Work Program

tickettowork.org.au

Life beyond school: Exploring the possibilities

valid.org.au/resources/books/explorepossibilities.pdf

Department of Human Services: Exploring the possibilities

dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/exploring-the-possibilities-post-school-for-disabled-young-people



Jackson Glenn - One page profile

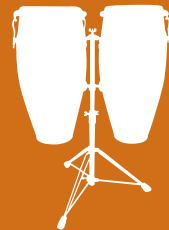
What people like and admire about Jackson:

- His rhythm and drumming ability
 - Energetic personality
 - Passion for music
 - His creativity
- Tries his best playing music
- He knows how to party!



What is important to him:

- Loves having fun and going out with his family
- To play gigs with his band 'The Glenn Family Band'
- To spend time with his girlfriend
- To continue to work at the supermarket
 - To go out with his friends
 - Dancing to music
 - To watch his favourite television shows



How to help Jackson have a good day:

- Give Jackson time to wake up and have his shower
- Explain to Jackson what is happening today
 - Allow ample time for Jackson to have lunch
- For people to speak to Jackson nicely and not to be rude
 - Chat to Jackson about his day

How to best support him:

- Speak to Jackson in a slow and clear voice to allow him time to process what you have asked of him
- Use small words as Jackson will find them easier to understand
- Give Jackson only one or two instructions at a time.
- Tell Jackson when plans are changing so he will have time to think about what is happening in his day
 - If Jackson appears anxious please ask him what is wrong as he might misunderstand what is happening or what has been said
 - Suggest listening to music if Jackson appears anxious and needs to feel calm





Down Syndrome Victoria

Supporting Victorian families since 1978

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