

Living the life I want

A guide to help with planning

Acknowledgements

The Intellectual Disability Behaviour Support Program, UNSW Sydney project team comprised: Dr Angela Dew, Dr Susan Collings, Ms Isabella Dillon Savage, and Associate Professor Leanne Dowse.

The planning guide was developed through body mapping sessions with 30 people with cognitive disability and complex support needs and focus groups with 10 family members. A number of participants engaged further by providing expert advice on the development and refinement of the content and layout of the guide. Feedback was provided on three occasions, and recommended changes incorporated into the final version.

We extend thanks to:

- All the people with disability who took part in the body mapping workshops and their support workers. These people lived in metropolitan, regional and rural areas of New South Wales (NSW), Australia. This guide would not have been possible without their willingness to share their experiences of planning via their body maps.
- The family members in metropolitan, regional and rural areas of NSW who took part in focus groups.
- The organisations which helped us recruit participants and organise body mapping and focus group sessions.
- Ms Emma Gentle, Arts Therapist who co-led all body mapping sessions.
- The project Steering Committee, Individualised Options, FACS.
- The talented graphic designers, David Thomas and Sandra Coates, at Bug Communication.
- Dr Ariella Meltzer who provided expert advice on Easy Read.

Suggested citation: Dew, A., Collings, S., Dillon Savage, I., & Dowse, L. (2017). *Living the Life I Want: A guide to help with planning*. UNSW: Sydney.



The development of this planning guide was funded by the NSW Department of Family and Community Services.

About this book

What is this book about?



This book is about knowing how to live the life you want.

It will help you think about how to make **goals** and **plans** for what you want to do in your life.

How do I use this book?



This book has information to **read**.



It also has information to **fill in about you**.



You can **draw or write** about yourself.



You can do it **by yourself or with help**.

Your supporter can find out how to help you use the book by looking at the Supporters' Guide section on page 25.

Goals

What is a goal?



A goal is an idea about something you want to do in the future.

It is something that you think will be good to do and that will give you the life you want.



Some goals are small.

A small goal is buying your favourite food at the supermarket.



Some goals are big.

A big goal is moving into your own home.

Plans

What is a plan?



A plan is thinking about all the things you need to reach your goal.

It means thinking about things like:

- The steps **you** will do
- The steps **other people** will do
- How long it will take
- What help you need



Some plans are small.

Writing a shopping list is a small plan for what to buy at the supermarket.



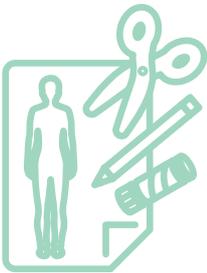
Some plans are big.

Moving into your own home means planning lots of things, like who you will live with, where you will live, when you will move and how you will pay.

Making goals and plans using a body shape



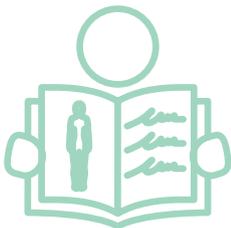
This book helps you think about how to make goals and plans for what you want to do in your life.



The book shows you how to make goals and plans using a **body shape** to:

- Draw, write and stick on things that show what you want to do in your life
- You might like to use: crayons, textas, magazine pictures, glitter, coloured paper, glue-sticks, scissors.

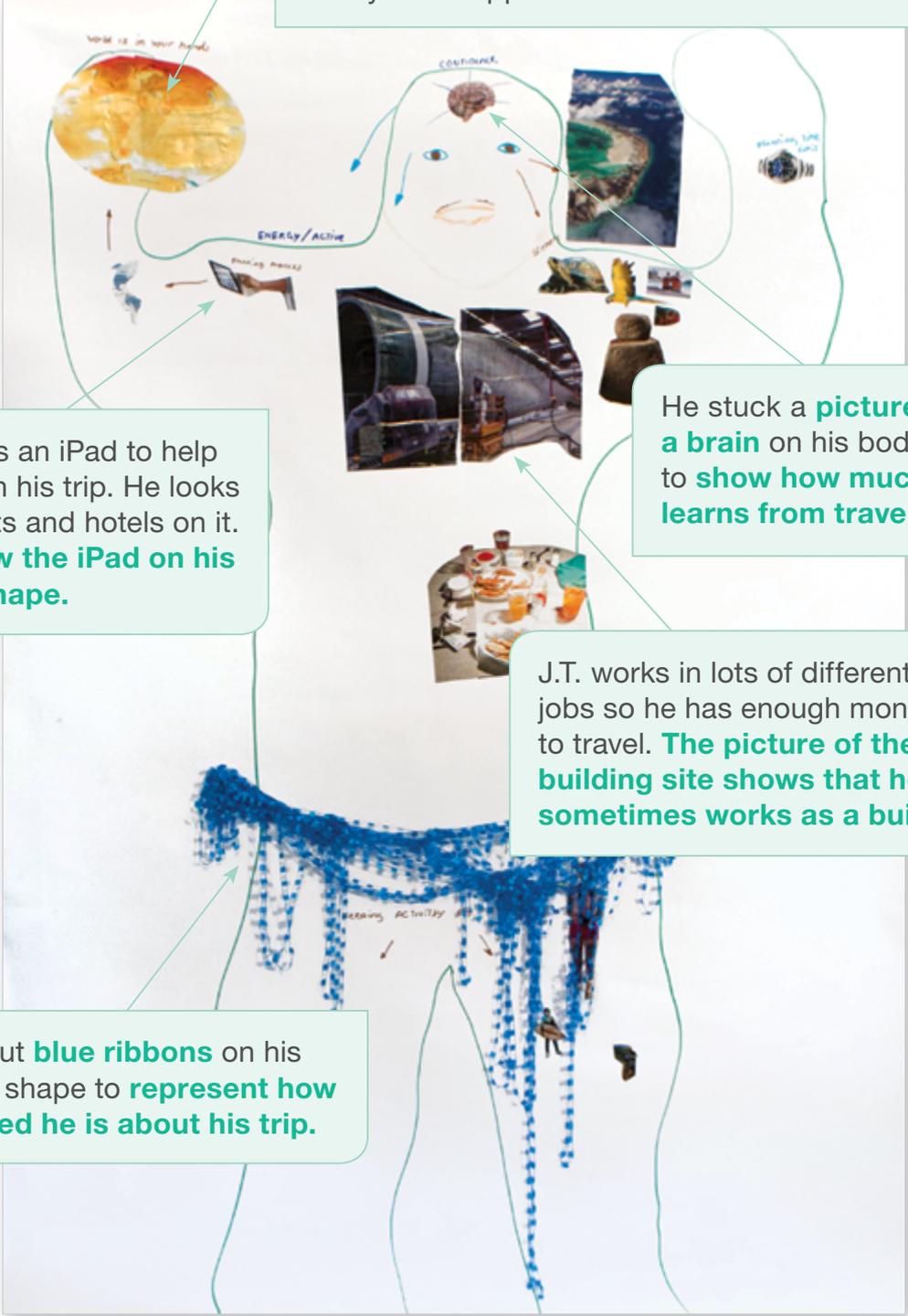
It is a fun way to make goals and plans.



On the next page is a body shape made by someone called J.T. You can use it to think about how to fill in your own body shape.

J.T. body shape

J.T. loves to travel. He is planning a trip overseas. **The picture of the world in his hand shows that J.T. knows he can make his dreams happen.** Some people in J.T.'s life did not think he should travel. He now makes sure he has friends and family who support him to live the life he wants.



J.T. uses an iPad to help him plan his trip. He looks up flights and hotels on it. **He drew the iPad on his body shape.**

He stuck a **picture of a brain** on his body shape to **show how much he learns from travelling.**

J.T. works in lots of different jobs so he has enough money to travel. **The picture of the building site shows that he sometimes works as a builder.**

J.T. put **blue ribbons** on his body shape to **represent how excited he is about his trip.**

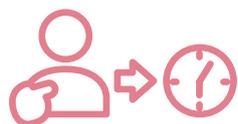
J.T. found drawing the different things he needs to do on his body shape really helpful. It helped him think about everything that he has to plan before he goes away. It also helped him think about who could help him with his plan and how he was feeling.

What is in this book?



Stage 1: Getting to know me

- Part 1: This is me..
- Part 2: This is how I...



Stage 2: Thinking about my goals



Stage 3: Making it happen

- Part 1: Head (thinking)
- Part 2: Hands (doing)
- Part 2: Heart (feeling)



Stage 4: Doing it, thinking about it, changing it

On this page you can explain who *you* are. You can...



Draw pictures
on the body shape.



Write on the lines.

Stage 1: Getting to know me

Part 1: This is me...

- I know what I like to do
 - I have people who are important to me
 - I try new things
-

Layla example:

I am Layla and...

I like...

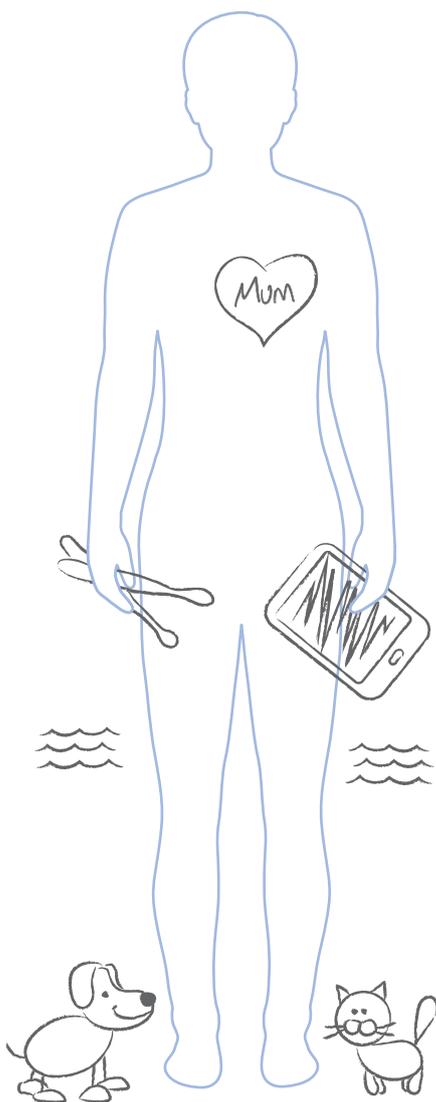
I like pets, being near the water and
being independent.

These people are important to me...

My mum is very important. I also like
my support worker.

New things I have tried...

I have learnt how to play the drums
and to use an iPad.





What about you?

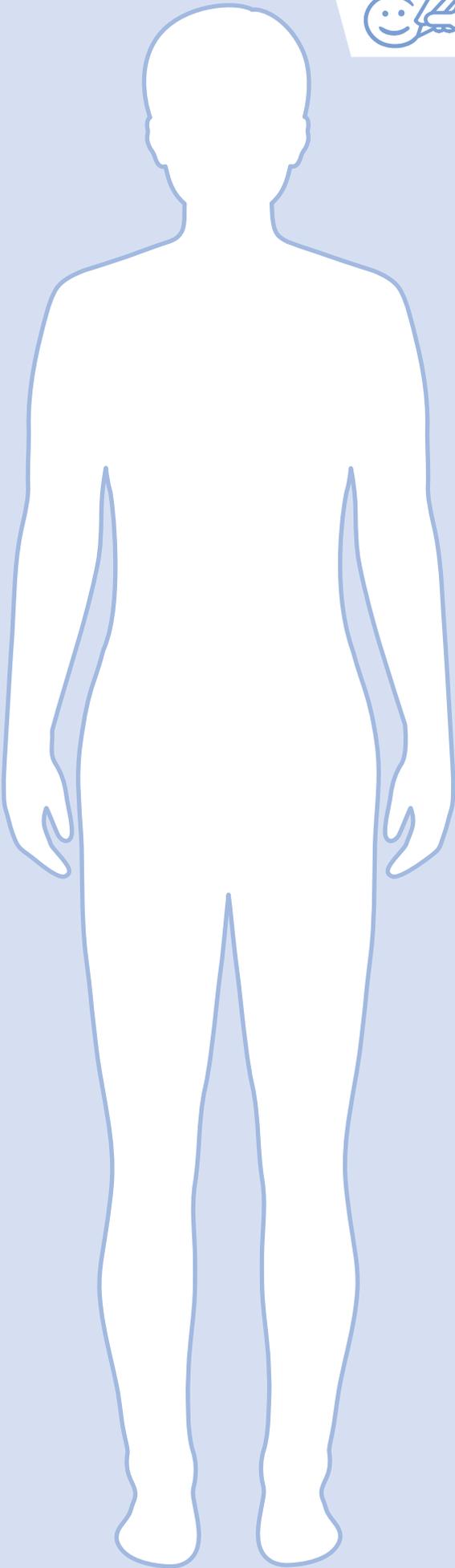


I am _____ and...

I like...

These people are important to me...

New things I have tried...



On this page you can explain how you do things. You can...



Draw pictures
on the body shape.

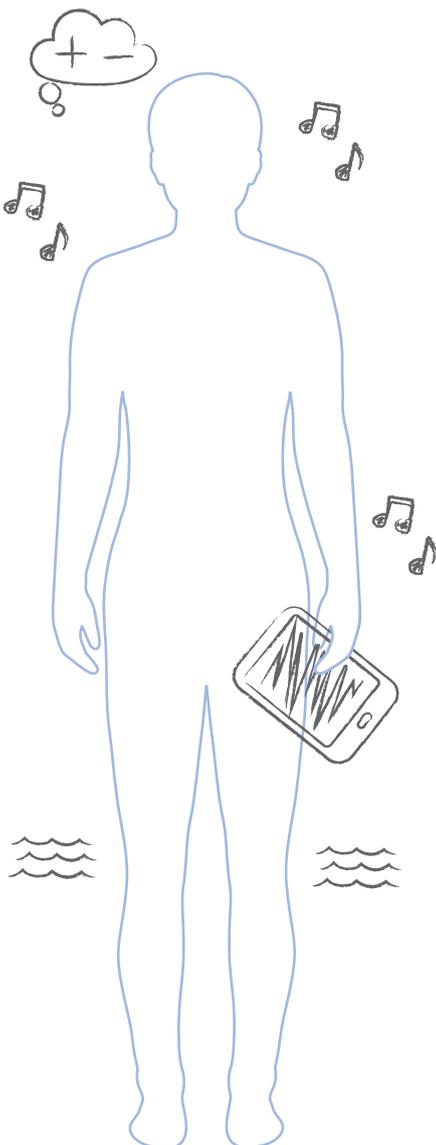


Write on the lines.

Stage 1: Getting to know me

Part 2: This is how I...

- Make decisions
- Communicate
- Get information
- Cope with problems



Layla example:

I am Layla and...

I make decisions by...

I think of the options, the positives
and negatives, and talk to my mum
and support worker.

I communicate by...

I make up my mind and then tell
people my decision.

I get information by...

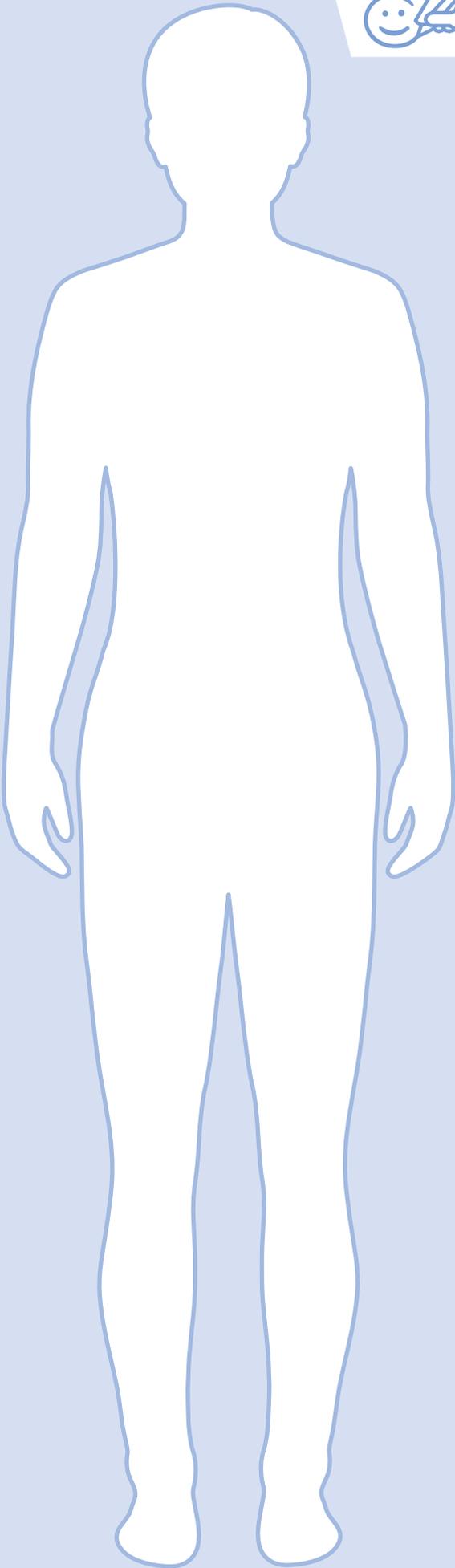
I find things out using my iPad and
by asking people I trust.

I cope with problems by...

I go for a walk by the water and
listen to music to feel calm.



What about you?



I am _____ and...

I make decisions by...

.....
.....
.....
.....
.....

I communicate by...

.....
.....
.....
.....
.....

I get information by...

.....
.....
.....
.....
.....

I cope with problems by...

.....
.....
.....
.....
.....

On this page think about your goals. You can...



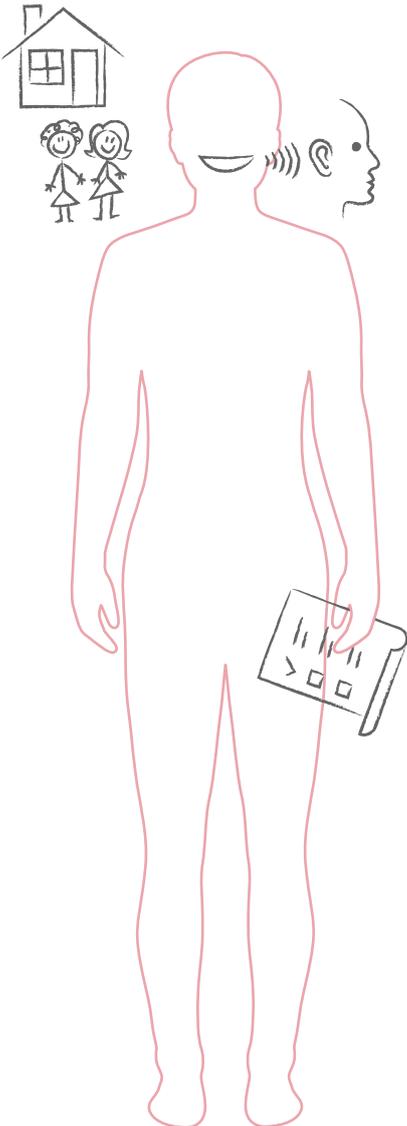
Draw pictures
on the body shape.



Write on the lines.

Stage 2: Thinking about my goals

- My goals
- My most important goal
- These people could help me



Layla example:

I am Layla and I'd like to...

My goals are...

I would like to move out of home
and become more independent.

My most important goal is...

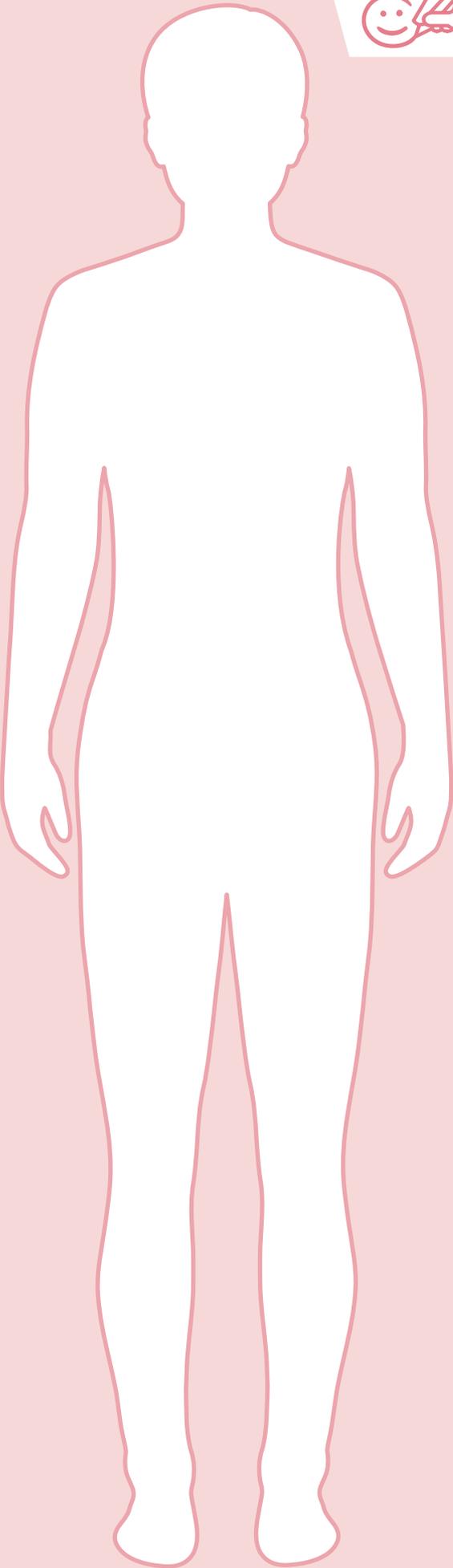
I would like to choose where I live
and who to live with.

These people could help...

I would like my mum to listen to me
and understand why.



What about you?



Goals...

My goals are...

My most important goal is...

These people could help...

On this page you will start making a plan to reach your goal.

You will...



Write about the things that might **get in the way** of your goal.



Write about the things that **you will need** to help make your goal happen.

In **Stage 3**, you will plan how to make your **most important goal** happen. Stage 3 is divided into three parts: **Head** (thinking); **Hands** (doing) and **Heart** (feeling).

Stage 3: Making it happen



Part 1: Head (thinking)

Layla example:

Things that get in the way...

Layla does not know what housing is available in her area. When she looks online it is very confusing.



Things I can do...

Layla goes to a neighbourhood centre where the people help her understand the important information.

Layla has never lived out of home before so she lacks confidence and doesn't know where to start.



The local self-advocacy organisation introduces Layla to Julia who has already moved out of home. Julia gives Layla some good tips.

Layla is worried she won't know what to do in an emergency when she is living on her own.



Layla and her mum find the emergency contact numbers and save them into Layla's mobile phone.



Part 1: Head (thinking)

Things that get in the way...

Things I can do...

Handwriting practice area with 10 horizontal dotted lines.



Getting information

Handwriting practice area with 10 horizontal dotted lines.

Handwriting practice area with 10 horizontal dotted lines.



Trying new things

Handwriting practice area with 10 horizontal dotted lines.

Handwriting practice area with 10 horizontal dotted lines.



Being safe

Handwriting practice area with 10 horizontal dotted lines.

On this page you will continue making a plan to reach your goal. You will...



Write about the things that might **get in the way** of your goal.



Write about the things that **you will need** to help make your goal happen.

Stage 3: Making it happen



Part 2: Hands (doing)

Layla example:

Things that get in the way...

Layla sometimes feels anxious when she thinks about moving out of home.



Being healthy

Things I can do...

When Layla starts to feel anxious she goes for a walk by the water and makes sure she eats healthy food. This makes her feel good.

Layla's mum isn't always helpful. She doesn't think Layla is ready to move out of home by herself. She suggests Layla moves into a group home with other people with disability. Layla doesn't want to do that.



Having support

Layla introduces her mum to Julia (her friend from self-advocacy). Julia has a disability and lives by herself. Julia tells Layla's mum how great it is living independently.

Layla doesn't earn much money and is unsure if she can afford to pay rent and bills.



Having money

Layla needs to make a budget so she can save to move out. She might have to work more.



Part 2: Hands (doing)

Things that get in the way...

Things I can do...

Handwriting practice area with 10 horizontal dotted lines.



Being healthy

Handwriting practice area with 10 horizontal dotted lines.

Handwriting practice area with 10 horizontal dotted lines.



Having support

Handwriting practice area with 10 horizontal dotted lines.

Handwriting practice area with 10 horizontal dotted lines.



Having money

Handwriting practice area with 10 horizontal dotted lines.

On this page you will continue making a plan to reach your goal. You will...



Write about the things that might **get in the way** of your goal.



Write about the things that **you will need** to help make your goal happen.

Stage 3: Making it happen



Part 3: Heart (feeling)

Layla example:

Things that get in the way...

Layla decides to go to a cooking class at TAFE. When she goes to sign up, she is told that the class might be too hard for her.

Layla feels anxious and a bit scared about going back to the office to sign up for the cooking class.

When Layla joins the class, some people make her feel different and left out.

Attitudes

Courage to speak up

Belonging

Things I can do...

Layla talks to the cooking teacher who tells her the class is for everyone.

Layla talks about her anxiety to her self-advocacy group. They help her to feel brave and decide on the best way to deal with this.

Layla's cooking buddy is very nice and makes her feel like she belongs. Sometimes they go for coffee together after class.



Part 3: Heart (feeling)

Things that get in the way...

Things I can do...



Attitudes



Courage to speak up



Belonging

On this page you will get to review your goals and plans. You will...



Write about what you **learnt** from doing your goal and plan.



Write about what you think **went well** or what you would **change**.



Write about what you might **change** on your plan.

Stage 4:

Doing it, thinking about it, changing it

Doing it



We all learn by giving things a go.

It can take time to work out what you **really want** and how to **make it happen**.

Often you learn about yourself by making mistakes.

Layla example:

Layla achieved her goal to find a place to live.

Layla has been in her new home for a year now.

Living out of home gave her the chance to try lots of new things.

Some things worked and some did not. Layla is not allowed to have a pet where she lives and she wants a dog.

What did you learn from doing your goal and plan?

.....

.....

.....

Thinking about it



It is important to take the time to think about what **worked well** and what you would **do differently** next time.

Sometimes you might realise that there are **other things** you now want.

Layla example:

Living out of home has taught Layla a lot about herself.

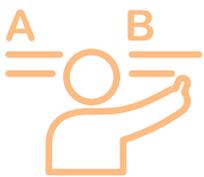
She really likes being more in charge of her life.

But there aren't a lot of social activities in her local area.

Layla realises she sometimes gets lonely.

What do you think went well and what would you do differently next time?

Changing it



You might **add things** to your plan to make it work better for you.

Sometimes other people can help you do this.

Layla example:

Layla decides to move. She wants to live where there is more to do and she can make friends. She will find a place where she can have a dog. Layla's friend Julia says she can have pets at her house.

Layla decides to move in with Julia. This move means Layla will have a dog and will be living with a friend.

What do you think you might change on your plan?

What's next?

Your next goal



Now you have used the resource for your **most important goal**, you can think about your **next most important goal** using Stages 3 and 4 to think how to make **it** happen.

Supporters' guide

This section of the resource is for supporters: family members, advocates or support workers who assist a person with intellectual disability and complex support needs to plan.

Introduction

This resource is designed to be used by a person with intellectual disability and complex support needs. Some people may need support to use the resource.

If you are the person helping, the following tips will be useful:

- Take time to go through the resource with the person.
- It might take several sessions to work through the resource.
- The Easy Read layout is designed to help the person understand the material as much as possible but based on your knowledge of the person, you will find it helpful to explain using examples from the person's own life and experiences.
- Encourage the person to draw on the body shapes provided – drawing is a very helpful way of communicating ideas especially for people who may find it hard to write or verbalise their responses. In developing this resource, we used a technique known as body mapping to get people to visually depict their ideas about planning.

If you want to know more about body mapping we explain it later in this section. Here are some ideas to help the person draw:

- » The person may need a few ideas about how to visually represent these on their body map. It's OK to provide some suggestions, but the person needs to be in charge of what they put on the map and where they put it. You can make your own body map if you like: this body map is for the person you are supporting!
- » The idea is not to create a work of art (although many body maps are beautiful to look at) but rather for the person to show, using images and words, their plan.
- » **Body mapping is not for everyone, so if the person is uncomfortable with having their body mapped or finds it difficult to use a pre-drawn outline, reassure them that it is perfectly fine to write their answers.**
- There are no right or wrong ways to use the body shapes; each person's will be unique.

The 'Living the Life I Want' resource

The 'Living the Life I Want' resource is laid out in four stages. For each stage, you will find:

- General statements about what is in the stage (left-hand side of the page);
- An example (right-hand side) of 'Layla' (a made-up name). The Layla example is to provide the person using the resource with some ideas about how to draw and write about each section;
- A fold out worksheet where the person can draw and write about their own goals and plans.



Stage 1 is called 'Getting to know me'
and has two parts:

- Part 1: This is me...
- Part 2: This is how I...



Stage 2 is called
'Thinking about my goals'



Stage 3 is called 'Making it happen'
and has three parts:

- Part 1: Head (thinking)
- Part 2: Hands (doing)
- Part 3: Heart (feelings)



Stage 4 is called
'Doing it, thinking about it, changing it'

Working through each section of the resource with the person

Stage 1: Getting to know me

We found that all the people we worked with to create the resource had a very strong sense of who they are – their strengths and what they would like to change. Stage 1: Getting to Know Me captures this sense of self.

For practitioners:

This stage matches 'Stage 1: Pre-planning' in 'Being a Planner with a Person with Complex Support Needs: Planning Resource Kit' (Practitioner Kit).

Part 1: This is me...

As a first step in planning, the person should spend some time identifying the things about themselves they think are important. As a supporter who knows the person well you can help them do this by talking with them about what they like to do, who is important to them, and new things they have tried. The example of Layla will help both the person and you to think about each of these areas.

Part 2: This is how I...

The second part of 'Getting to know me' provides details about how the person does a range of activities which are important to consider in planning: how they make decisions, communicate, get information, and cope with problems. Again, use Layla's example as a prompt and, on the fold out worksheet, encourage the person to represent both visually and in words how they do things.

Some people might find it helpful to use a daily calendar to identify the activities, times, places and people that are important to include. At the back of this section you will find an example of a daily planner that you and the person can fill in.

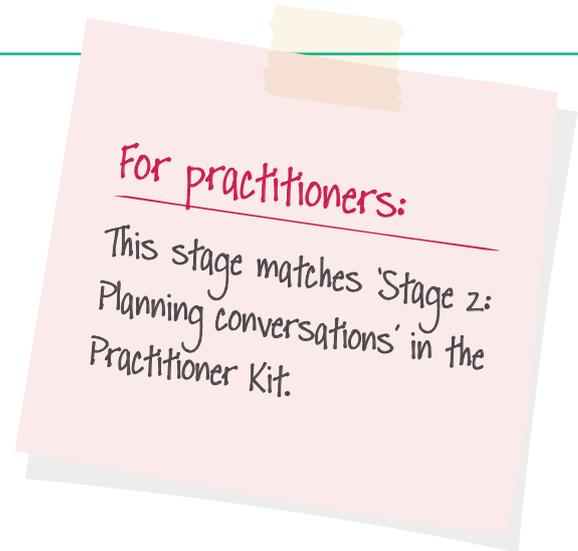
Stage 2: Thinking about my goals

Stage 2 is designed to get the person to identify the goals that will be part of their plan. The person may identify more than one goal and you should then work with them to decide which is their most important goal and who might help them to achieve this.

Again, the example of Layla will help both the person and you to think about each of these areas.

To help the person engage with this section, you could ask the person to think about examples of previous goals they have set and how they achieved these.

Stages 3 and 4 involve working on the goal the person has identified as their most important goal. These stages can then be repeated for additional goals.



Stage 3: Making it happen

Stage 3 is a very important component of planning with a person with intellectual disability and complex support needs. It is however quite a complex process and it will be best to take your time in working through this with the person.

Setting goals is a very important part of planning; however, for many people with intellectual disability who also have complex support needs, a range of factors arise when setting goals. These may include: getting information, trying new things, being safe, being healthy, having support, having money, people's attitudes, having the courage to speak up for themselves, and belonging.

An important aspect of planning is recognising potential barriers and pre-empting solutions. Stage 3 is divided into 'Head', 'Hands', 'Heart' and is designed so that you can discuss potential barriers with the person and talk about what they will need to make their plan work.

Layla's story is an example of challenges that can arise when planning, and how they are overcome.





Part 1: Head (thinking)

This section includes:



Getting information

Talk with the person about:

- » what information they might need to meet their goal;
- » where they could get that information from;
- » how they will get the information;
- » whether the format of the information is accessible (e.g., Easy Read, pictorial, video).



Trying new things

Not everyone has had opportunities to try new things. Encourage the person to 'step outside their comfort zone' when making plans to achieve her/his goal.

Help the person to think about:

- » what new things they have tried in the past;
- » what has stopped them trying new things;
- » how they overcame barriers to trying new things in the past;
- » how they will overcome barriers to achieving their new goal.



Being safe

Talk with the person about:

- » whether they or someone close to them might have any safety concerns about them achieving their new goal;
- » whether this is an actual or imagined safety concern;
- » what they will need to think about and do to make sure they are safe.



Part 2: Hands (doing)

This section includes:



Being healthy

Talk with the person about:

- » whether they have any physical or mental health problems that might impact on their goal;
- » what things they can do to feel good and stay healthy so they reach their goal.



Having support

Discuss with the person:

- » whether they have the support they need to reach their goal;
- » what support they think they will need to reach their goal;
- » whether the support they have is helpful or unhelpful to them reaching their goal;
- » how they can maximise the helpful support and change the unhelpful support.



Having money

Talk with the person about:

- » how much money they might need to reach their goal;
- » whether they have enough money now for the goal;
- » where extra money might come from;
- » if they would like to find work, work more, work less;
- » what skills they have (or may need to get) for budgeting their money.



Part 3: Heart (feeling)

This section includes:



Attitudes

Discuss with the person:

- » whether they have encountered people's positive or negative attitudes that might impact on them achieving their goal;
- » whether someone's attitude has ever stopped them doing something;
- » what support they might need/want to help them overcome the impact of people's attitudes on their goal.



Courage to speak up

Talk with the person about:

- » whether they feel they are listened to when they speak up for themselves;
- » whether they feel confident telling people about their goal;
- » what strategies they could use to build their courage to speak up and advocate for themselves.



Belonging

Talk with the person about:

- » whether they feel part of a community;
- » what activities or groups they would like to join to meet new people or try new things.

By the end of working through Stage 3, the person should have a realistic plan to achieve their goal. The plan will address both what might get in the way and how they will work around and resolve any barriers. The person may now want to re-do the daily planner adding in new activities to match the new plan. The person may also want to repeat Stages 3 and 4 for additional goals.

Stage 4: Doing it, thinking about it, changing it

Planning is an ongoing process, not a one-off event. This final stage encourages the person to realise that plans don't always work out perfectly and that 'giving it a go' is an important part of knowing what we want (and don't want) to do. After doing something new, taking time to think about what worked and didn't work is vitally important. This time for reflection means the person can change the things that didn't work by building on the things that did.



Doing it

As the person's supporter, you should encourage the person to take some chances and try new things. We all learn by giving things a go. It can take time to work out what you really want and how to make it happen. Sometimes it doesn't work out exactly the way you hoped or things get in the way. People learn about themselves by making mistakes.



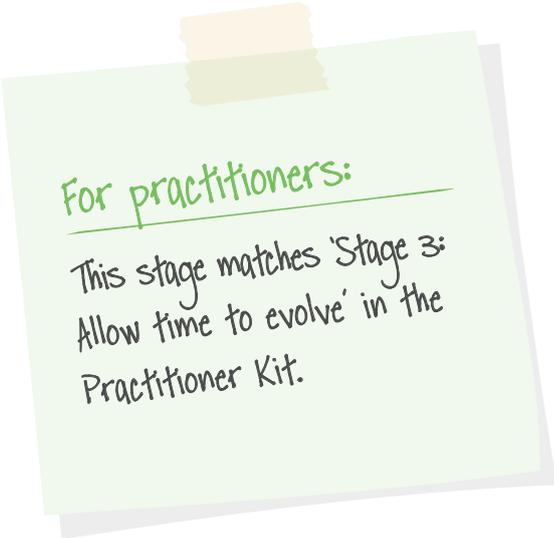
Thinking about it

It is important for you and the person to take the time to think about what worked well and what they would do differently next time. By doing something new the person may think differently about their goals. Sometimes the person might realise that there are other things they now want to do.



Changing it

The person can build on what went well and change the things that didn't. The person might add things to the plan to make it work better. As a supporter, you can help the person to do this.



For practitioners:

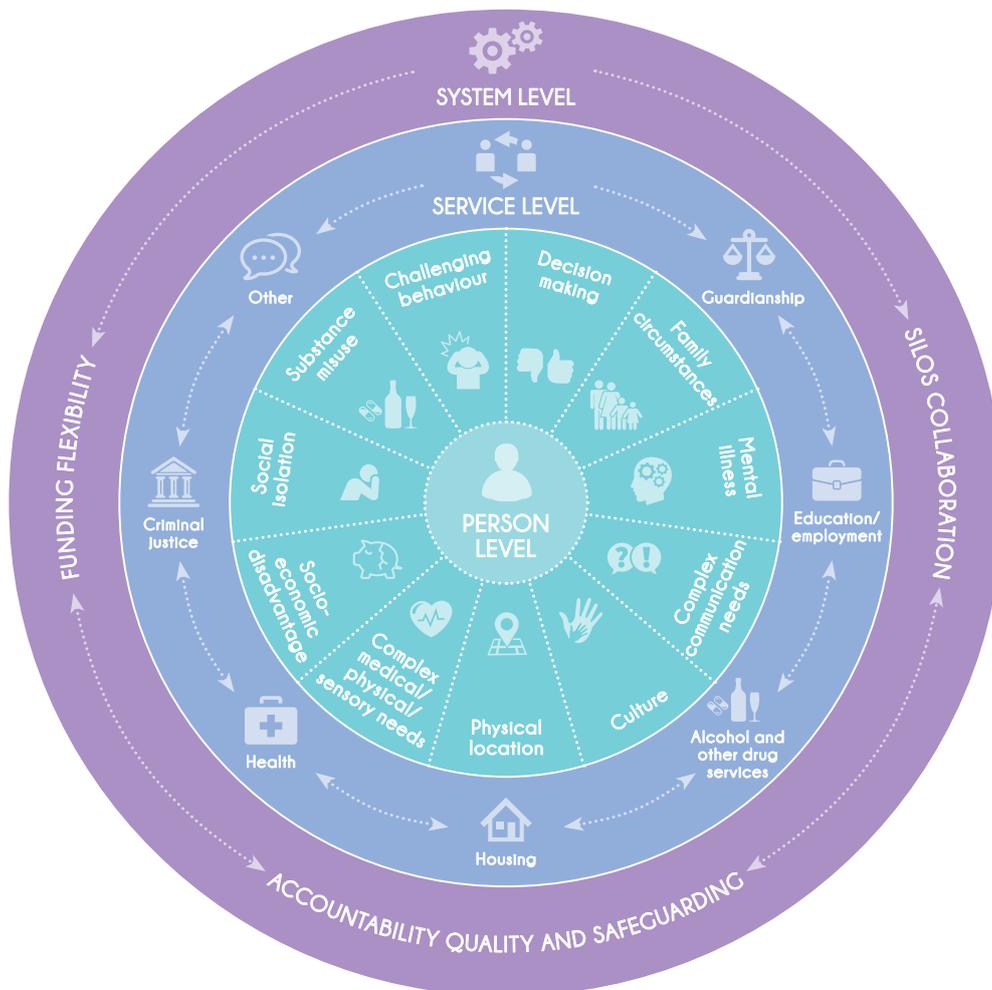
This stage matches 'Stage 3: Allow time to evolve' in the Practitioner Kit.

Complex support needs

You might not be familiar with the term 'complex support needs'. A person may be considered to have complex support needs due to a depth and breadth of needs across person, service and system levels. The diagram below highlights some of the complexity domains identified in the 'Being a Planner with a Person with Complex

Support Needs: Planning Resource Kit' which we developed in 2015/16 for use by practitioners. This resource can be downloaded for free from the Intellectual Disability Behaviour Support (IDBS) website:

www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/projects/completed-projects/



Thinking about complexity in this way can help you consider different challenges that the person you support may face. This is important when helping them to decide on goals and develop a plan.

How the resource was developed

Body mapping

Body mapping is a technique used in research, therapy, and community development. Body mapping is a visual way to get a person to think about their ideas and feelings (typically represented inside the body outline) as well as services, supports and those who help them (typically represented outside the body outline).

To develop this planning resource we used body mapping with 30 people with intellectual disability and complex support needs to help them to tell us about their planning experiences and decide what needed to be in the resource. Each person created two body maps: one about a past experience and one about the future goal they would like to plan for.

Many of the people who participated and their supporters, told us they thought body mapping was a useful and fun tool for planning.

What we did:

- We asked people if we could trace a life-sized outline of their body on a large piece of paper. **Most people were happy to do this but a few felt uncomfortable and for those people, we provided a pre-drawn outline.**
- We found having the full-sized body outline helped people put themselves at the centre of their plan.
- We provided crayons, textas, magazine pictures, glitter, fabric, beads, coloured paper, post-it notes. You will also need glue-sticks and scissors. All the materials we used were readily available and inexpensive. The picture below shows the materials we used set up on a table so participants could choose the items they wanted to use.



-
- We guided participants through making their body map

- » We started with an example of a plan we had made (going to hospital for an operation) and drew examples on a body map outline to show both the internal (anxiety, pain, relief, etc.) and external (paperwork, X-rays, hospital staff, bandages, family support, etc.) aspects of the plan.

- » After giving the example, we asked people to think about what they wanted to plan for.

Once the person had an idea for their plan, we guided them through making their body map by asking them ‘who, what, where and how’ questions such as: What is your plan? Who might help you? What things (money, resources) would you need to make your plan happen? Where would you find those things? How would achieving your plan make you feel?

From these research sessions, we learnt about the different goals, capacities, challenges and experiences of planning of people with intellectual disability. This data informed the content of the resource guide and allowed us to develop an evidenced based guide that reflects the needs of people with intellectual disability.

Below is a photo of a researcher and participant making a body map.



Example of a daily planner

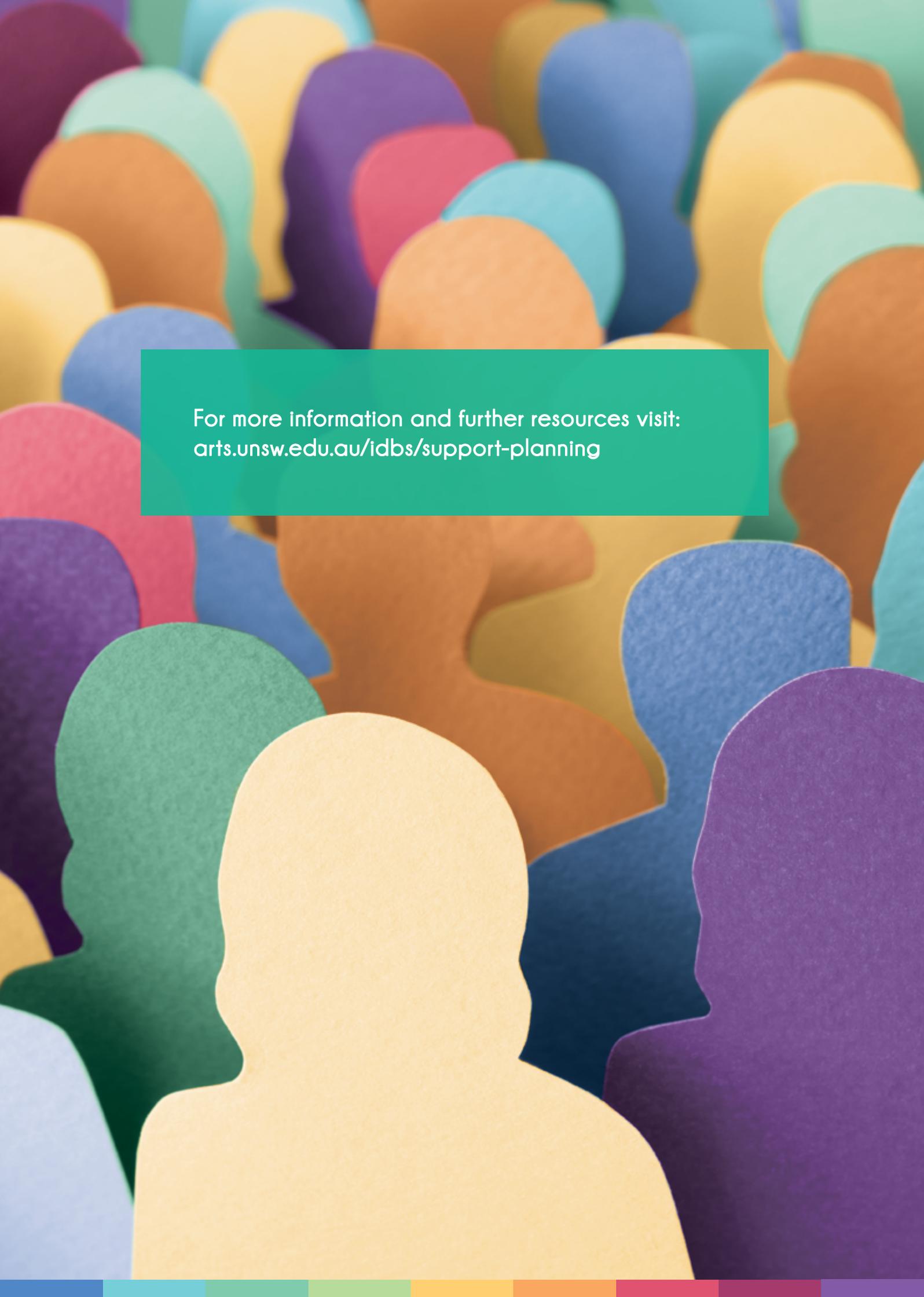
Day/time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning							
Afternoon							
Evening							

Notes

A series of horizontal dotted lines for writing notes.

Notes

A series of horizontal dotted lines for taking notes.



For more information and further resources visit:
arts.unsw.edu.au/idbs/support-planning