

**Supporting Aspirations** 

# Independent living

Tutor guidance and resources







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## **Independent living pathway**

The aim of the **Independent living** pathway is to enable young people to build skills that enable self-determination and control over their lives.

The Independent living pathway comprises three modules:

- **Looking after myself** this module will enable the young person to develop self-care skills that promote being in control and having the support they prefer when needed
- **Engaging with my environment** this module will enable the young person to actively participate in their environment, promoting engagement and intentional communication
- **Using my technology** this module will enable the young person to use technology to engage with others and their environment, developing understanding of cause and effect

Completion of these modules will include the completion of an **Independent living profile** for each learner. This pathway profile includes all the relevant information a young person will need to take with them to a new setting and in preparation for adulthood. More information about the pathway profile can be found on page 5.

#### **Working with learners with PMLD**

The modules within the Independent living pathway are all concerned with building skills that enable self-determination and control over one's life.

Many people with profound and multiple learning difficulties (PMLD) will have physical and multi-sensory impairments that reduce their ability to engage with their environment. This can result in a state of learned helplessness, which is described in the **Looking after myself** module. Most people will rely on care and support for all aspects of everyday living and may have learned to wait for things to happen to them, rather than with them.

For young people with PMLD, having communication skills with which to express their own feelings and choices is perhaps the most important independent living skill. People with PMLD will have communication outcomes within their EHCP and can work on their **Communication passport** within the **My relationships** module (see Friends, relationships and community pathway).

Alternative and augmented communication (AAC) is a broad term to describe the many approaches that can be implemented to improve communication for people who do not use verbal communication. The use of AAC is recognised as a means to encouraging engagement throughout all of the modules within the Independent living pathway. Ensuring young people have access to equipment and resources for this is detailed in the **Using my technology** module.

### Independent living pathway

#### Links between modules

The three modules within the **Independent living** pathway are interlinked and provide a holistic approach to all aspects of a young person's health and wellbeing. They can be completed as standalone modules, but will be most effective if all three are undertaken to develop an **Independent living profile**. This can be used in preparation for moving onto a new setting or working with new staff and peers.

#### Links to EHCP

The activities chosen within the **Independent living** modules should relate to one or more outcomes in the individual's Education Health and Care Plan (EHCP) or Individual Development Profile (IDP). The modules can be used to inform the development of the EHCP, particularly around independent living.

The **Module completion log** provides a place for staff to make an explicit link to outcomes in the EHCP or make suggestions for future outcomes. More information about this resource can be found on page 13 of the **Introduction to the tutor guidance and resources**.

#### Independent living profile

This profile includes all the relevant information a young person will need to take with them to a new setting and in preparation for adulthood. This profile is completed as part of the three modules within the Independent living pathway.

The profile includes information around:

- How I can look after myself
- How I can engage with my environment
- How I can use technology
- Other ways I can be independent

A copy of this resource can be found on pages 6–10; it is also available in Word document format for centres that wish to complete it electronically.



# Independent living profile

1 This profile is all about my independent living skills.

My name:	My photo:
	J
Date developed:	

This profile provides information about my independent living skills. This will support me to plan for good life outcomes as I move into adulthood.

#### It contains:

- How I can look after myself
- How I can engage with my environment
- How I can use technology
- Other ways I can be independent



# How I look after myself

Strategies to motivate me to do things for myself:
How I prefer to be assisted:



# How I engage with my environment

Ways I engage with my environment:		
Strategies to motivate me to do things for myself:		
How I prefer to be assisted:		



# **How I use technology**

Ways I use technology:
Strategies to motivate me to do things for myself:
How I prefer to be assisted:



# Other ways I can be independent

Ways I can be independent:	
Strategies to motivate me to do things for I	myself:
How I prefer to be assisted:	
	Data
Completed with support from:	Date:



**Supporting Aspirations** 

# Looking after myself

Tutor guidance and resources



#### Aim of module

This module provides a learning opportunity to explore how a young person with PMLD can develop skills to look after themselves, appropriate to their level of ability.

In this module, young people will have opportunities to explore what they can do for themselves and how they can be actively involved in getting the type of support that works best for them.

Many people with PMLD will require daily support for basic everyday tasks (eg eating, drinking, personal care). For some people this will include using equipment such as hoists, standing frames and wheelchairs.

This reliance on others to provide care and support in nearly all everyday situations can result in a state of learned helplessness. This is when a person learns, through repetition, that they are powerless so they make no effort to change or escape from their situation. This is not about people being lazy; it is a result of complex interrelated factors, such as:

- assumptions that a person can't do something because they have a learning disability
- staff wanting to be as helpful as possible, because that is what doing their job well is about
- parents and carers showing their love and care by attending to a person's needs
- time pressure to make certain things happen at a certain time during the day
- a belief that because someone hasn't done it yet, they won't ever be able to do it

These factors, together and individually, result in people with PMLD being denied the experience of learning to do something for themselves. This reinforces the idea that disabled people cannot look after themselves and need to rely on others for all aspects of their self-care. This is a stereotype that will perpetuate when people leave school and enter college or adult services. It will form the reputation that the person takes with them into adult life and can determine what kinds of activities and opportunities are available.

Having control over your own body and how others are caring for you is seen as a major contribution to positive mental health and wellbeing. It is unlikely that people with PMLD understand the concept of being supported, but we know that people do respond to the type of care they receive, and that they have preferences for the type of person that provides this and the approach used.

This module focuses on what people can do rather than what they cannot. Traditionally independent living skills have been viewed as learning to manage money, cook a meal, go shopping, travel on your own or look after your own home. For a person with PMLD, it must be seen as levels of engagement with activities that happen as part of daily life. These will be highly personalised to the individual, their abilities and the contexts they are living in. What people with PMLD can and cannot do for themselves may change depending on their environment and who they are with – this is perfectly acceptable. We all behave differently depending on where we are and who we are with. This module provides an explicit opportunity to explore where independence can be developed and how this can be built upon.



This will involve staff in observing how a person engages when an activity of daily living is taking place and trying out different strategies to test what is the most effective way to encourage engagement and independence. This can be recorded on the **Looking after myself assessment** and **Looking after myself record** templates (see page 20–24). This will collate staff observations and suggestions for ways to encourage the person to have control over meeting their basic needs and letting others know how they want to be supported. These documents can be used to develop the Independent living profile, which can be used to inform new settings about the independence skills a person has and can continue to develop.

#### Aspects of self-care

The aspects of self-care activities that should be recorded using the **Looking after myself** assessment and **Looking after myself record** templates are:

- eating
- drinking
- personal care (eg using toilet, pad changes, cleaning hands and face, wiping nose)
- clothes
- positioning
- · moving around
- my own belongings

Where a person can already complete an aspect independently, it is important to say how they usually do this. This will be vital for any new services they use in the future who may make assumptions about what someone can or can't do, which can lead to people losing their skills very quickly.

People with PMLD need repetition and consistency to learn, so any strategies to support independence must be given time to develop. This could be over months or years; this module can only be effective if it is worked on regularly (eg on a daily basis) and all staff are aware of the support strategies being tried. It is not helpful if, after a few weeks, staff say something isn't working when it has not been tried consistently or using the communication strategies that staff know will motivate the person.

Enabling communication and being a good communication partner is essential to the intensive interaction approach (see Useful links on page 19). It is advised staff receive training in this as an approach to connect and share time with a young person on their terms; this approach will support the person to understand they can have control and can affect change, building intentional communication.

It will be useful to involve multi-disciplinary team members (eg occupational therapist, physiotherapist, speech and language therapist) to develop strategies that can support self-help. These professionals will be able to advise on specialised equipment and resources that support independence. This may also include use of alternative and augmented communication (AAC) technology (see **Using my technology** module). Any assessments or activities within this module must not contravene advice and guidance provided by these





multi-disciplinary professionals. Staff should use a multi-disciplinary and person-centred approach to delivering care and support, promoting independence wherever possible.

Involving parents and carers in finding out how people behave in different environments will also be helpful. There is nothing like finding out someone has been doing something at home for years but never in your centre – or vice versa. Sharing strategies about what works is useful, but keep in mind parents and carers can, and often do, have different approaches that are well established and work for them but may not work for you.

#### Format of delivery

This module is best delivered flexibly throughout the time a young person is in a centre. This is because the self-care aspects involved will occur regularly during the day, at different times for different young people. These activities are a natural part of any day and will happen during lesson time and often outside of a scheduled timetable. It is important that opportunities for learning happen according to when the young person needs these to happen and they are in context (eg do not practise putting on a coat or jumper unless you need to put it on) as it may indicate to a person something is about to happen (eg going outside or the end of the day).

The amount of time needed to complete the module will depend on the individual. Enough time must be given to observe, record and develop tested strategies on how the individual can engage and build skills in this area. This could be over months, a term or a year.

Filming evidence of what works or what doesn't work for the young person and reviewing this with people who know the person well will enable staff to assess if their intuition about a person's communication preferences is correct and based on sound evidence.

Providing good quality support and care and enabling young people with PMLD to learn these skills for themselves will necessitate the use of positive touch. This refers to touch that is used to communicate feelings, choices, intentions and requests. Young people with PMLD are often receivers of touch used in care tasks (eg personal care), whereas positive touch is used solely for the purposes of communicating and building a relationship. Positive touch is a powerful tool, whether you are the giver or receiver.

Details of the kind of touch a person likes to give and receive can be recorded using the **Looking after myself assessment** and **Looking after myself record** templates. Centres may have their own templates for positive touch profiles that they build up over time; this would be an example of good practice to add as evidence to this module.

Centres should ensure staff are aware of how to use touch positively to communicate, understanding the purpose of touch and how to know when permission is given; this will safeguard young people from intentional and non-intentional abuse.



#### For example:

A young person has drinks in a cup with a spout that regulates how much liquid can be drunk. They have an eating and drinking plan from their speech and language therapist that states the approach to use to prevent choking and to ensure that daily hydration needs are met.

Staff use body signing – taps to the lips and a sensory cue of holding the fruit squash bottle near to the person's nose – before attempting to assist with the drink. This is followed by holding the cup to the person's lips and waiting for approximately twenty seconds before the person moves their mouth to sip from the cup. When this person is drinking, they lift their head up and maintain eye contact with the staff member. At times they lift their hands to the cup as if to hold it. In between taking sips of drink, the person smiles and moves their head from side to side. Staff interpret this as the person is enjoying their drink. Having a drink encourages the person to look around, see their environment and share attention with their staff.

The staff member speaks to the speech and language therapist and asks them to observe to see if the person could be encouraged to hold their own cup. The occupational therapist also assesses if a different type of cup would provide a better gripping opportunity. The new cup is tried and after two weeks of the staff member following this routine, the person holds their new cup by the handles for up to five sips. This is monitored by the speech and language therapist to ensure there is no risk of choking.

The staff member continues to observe and support when required. Other staff notice that the person is more motivated by a particular member of staff who sings a made-up song about having a drink using the person's name. Other staff then try this to see if it works for them. This person is making progress in being able to control what happens to them; this could, in the longer term, build their cognitive understanding of cause and effect and intentionality.

In relation to eating and drinking, for people who receive their food through an enteral feeding system (eg PEG, bolus set, pump set), it is still appropriate to encourage them to take an interest and be involved in what is happening to them. The young person can be involved in gaining access to the PEG site, body movements to accommodate the PEG tubing and watching the PEG tube being filled or the pump being changed.

The approach to all personal care and support activities should be one of doing something with the person, not to them. All responses from a person should be understood as having meaning and all ways to involve people in being active in their care and support routines should be encouraged.



#### Suggested activities

The learning activities used to complete this module will be present throughout the young person's day. These are naturally occurring and will be highly personalised for the individual.

This module encourages staff to see everyday care and support routines as opportunities for learning and promoting independence. This may challenge settings where these tasks are viewed as functional and something to be done with speed so people can return to the real learning. The opportunities provided within care and support tasks need to be viewed as integral to learning and valued as opportunities for progression.

As these activities can take place across different times and locations, staff will need to ensure they are recording what happens during activities on a regular basis.

#### Ideas for activities

It is not suggested that all the self-care activities should take place at once. It is better to choose an activity where staff think there is potential to work with the young person on a particular area, or where staff have noticed the person is particularly motivated to participate, is engaged with what is happening, leads the activity, lets staff know what they want to happen and responds positively to any care and support provided.

The aspects of self-care activities that should be explored in this module are:

- eating
- drinking
- personal care (eg using toilet, pad changes, cleaning hands and face, wiping nose)
- clothes
- positioning
- moving around
- my own belongings

Centres should add to this list if there is another aspect of self-care relevant to the individual.

For all aspects of self-care identified within this module, staff should be collecting evidence from observations of how the following happens:

- how a young person lets staff know they need or want this to happen
- how a young person can make a choice around this
- how a young person can assist themselves
- what motivates a young person to assist themselves
- how a young person lets staff know what they want (eg more, less, stop, start)
- how a young person prefers to be assisted
- what good support looks like for the young person in this activity



Personal care is a sensitive aspect of self-care. Staff need to be mindful to record this within the framework of building independence skills using their knowledge of the individual to prevent any distress or discomfort (ie balancing promoting independence with keeping a person safe and well). The person's best interests should always remain paramount.

Staff will need to ensure that working on this module does not mean that a young person's care and support needs are not met as required when there is an expectation that the person does the activity themselves (eg if a person is working on holding their own spoon to eat but one day they do not, staff would be expected to assess this situation and provide assistance in the most appropriate way so as to not leave the person without food).



Centres may wish to use activities from ASDAN's **Lifeskills Challenge** to structure the suggested activities. More guidance on using Lifeskills Challenge to support Supporting Aspirations modules can be found in the members area of the ASDAN website.

#### Support strategies and module templates

Young people working towards Entry level will have a wide range of learning support needs. Many young people with PMLD will require physical support and a skilled communication partner to access the world around them.

The type of support required and the frequency with which this is provided may fluctuate during the module activities. Support will be highly personalised to the individual and staff may need to explore a variety of strategies and adapt these in order to ascertain what works best.

These high levels of dependency may be unlikely to change throughout a lifespan or may increase. Some young people may have days when they need more or less support because of their health needs. It is more useful to provide information on support strategies that work in specific contexts to maximise independence and avoid reinforcing dependency wherever possible, with a recognition this can change depending on individual need.

The **Module completion log** should be completed by the teacher/tutor at the end of each module and should include information on what good support looks like.

#### Sensory cues and prompts

Staff should use sensory cues and prompts before any self-care activity to provide the maximum opportunity for a person to process what is about to happen. These cues can involve smells, positive touch and body signing, images, sounds and objects of reference. It is important that these are used consistently throughout the day and are meaningful to the person.





The module templates listed below should be completed in order to demonstrate achievement of the module outcomes. It is expected that these templates will be completed by staff on behalf of the learner. If a young person does not use any formal verbal language, staff will need to develop strategies to ensure what is completed on the templates reflects the young person's experience and choices.

#### Looking after myself assessment and Looking after myself record

The **Looking after myself assessment** template should be used at the start of the module to record observations around self-care activities. A separate template should be completed for each of the aspects of self-care listed above; these should not be undertaken all at the same time.

Staff should identify which activities are motivating for the person and where there are already signs the person is engaged, can use their independence skills or wants to do more. These should be shared with the multi-disciplinary team around the person. This assessment should be made more than once and by more than one staff member to look for changes in how the person interacts, engages and responds to encouragement.

The information gathered in the **Looking after myself assessment** can be used to document progress within the **Looking after myself record**. This template can be used to regularly check against progress or targets in each aspect of self-care. A separate template should be completed for each of the aspects of self-care listed above; these should not be undertaken all at the same time.

This record builds on the assessment by setting achievable and meaningful targets. It should be agreed and reviewed by a multi-disciplinary team at least once a term.

#### Independent living profile

This module will support the completion of the **How I look after myself** section of the **Independent living profile** for the Independent living pathway. This profile includes all the relevant information a young person will need to take with them to a new setting and in preparation for adulthood.

#### **Individual objectives**

Each young person will have an individual learning plan or similar in their setting. Where possible these objectives should be used within the module to support the young person's educational development.

Staff may choose to set specific objectives for the module, especially as certain skill development will lend itself to specific tasks (eg I will alert staff when I want my drink by eye-pointing towards my cup) and this will appear within the young person's individual learning plan. This can be added to the **Module completion log**.



#### Module outcomes

The outcomes for this module are:

- I have completed **Looking after myself assessments** (or an equivalent from my centre) that show the self-care activities I have participated in
- I have completed **Looking after myself records** (or an equivalent from my centre) that record how I am making progress towards my self-care targets
- I have participated in learning opportunities that promote independence skills in self-care
- I have completed the **How I look after myself** section of the **Independent living profile**, which informs people what I can do now and how I prefer to be assisted

#### Person-centred planning tools

The following person-centred tools can be used to support the module:

- Like and admire at the start of the module
- **Relationship circle** to be shared with parents, carers and families
- Matching support to identify which staff can support and motivate a young person in their self-care activities
- Important to, important for in self-care, ongoing throughout the module
- Good day, bad day to see what days a young person might be more (or less) able to assist themselves
- **Decision making profile** to understand how and when a young person can make choices about their self-care

#### **Useful links**

https://www.intensiveinteraction.org/

# Looking after myself assessment



① Complete a separate assessment for each aspect of self-care.

Aspect of self-care:

#### Initial feedback from staff observations:

How I let you know I need or want this to happen

How I can make a choice around this

How I can assist myself

What motivates me to assist myself

How I let you know what I want (eg more, less, stop, start)

How I prefer to be assisted

What good support looks like for me in this activity



# Looking after myself assessment

Initial feedback from staff observations:		
Does this require referral or assessment? (eg occupational health, speech and language therapist, physiotherapist).		
Sign and date when a referral has been made:		
Signature:	Date:	



# Looking after myself assessment

Suggestions for independent skills to be worked toward	ls:
What strategies to try:	
What strategies to try:	<b>✓</b>
What strategies to try: Sensory cues	✓
Sensory cues	✓
Sensory cues Prompts	
Sensory cues	
Sensory cues Prompts	
Sensory cues  Prompts  Body signs	



# Looking after myself record

1 Complete a sepa	rate record fo	or each aspect of self-care.
Aspect of self-care:		
What I can do now		Strategies to motivate and support me:
Observations of who		e this: - what worked or didn't work well



# Looking after myself record

what I am working towards:		support me:		
Observations of who	en I have don	e this:		
Date	What I did -	what worked or didn't work well		



# Looking after myself Module outcomes checklist

Learner name:			
			<b>~</b>
I have completed <b>Looking after myself ass</b> that show the self-care activities I have par			
I have completed <b>Looking after myself records</b> that record how I am making progress towards my self-care targets.			
I have participated in learning opportunities that promote independence skills in self-care.			
I have completed the <b>How I look after myself</b> section of the <b>Independent living profile</b> , which informs people what I can do now and how I prefer to be assisted.			
I have a completed <b>Module completion log</b> for this module.			
Completed by:			



**Supporting Aspirations** 

# Engaging with my environment

Tutor guidance and resources



#### Aim of module

This module provides a learning opportunity to explore how a young person with PMLD can engage with and control the environment around them.

The daily and regular reliance on care and support that a person with PMLD may require can lead to a schedule of activities that are done to people, rather than with them. This module is focused on how people can be supported to engage with people, places and activities that provide opportunities to practise being in control – through exploring what stimulates and motivates. For many people with PMLD, the environment can refer to what is happening in their proximity and this may be very limited. For some people the environment can be much wider in scope (eg a room, a building, a large outside space). Staff should consider what the term environment means for the individual.

The concept of learned helplessness is discussed in the **Looking after myself** module (see page 11) and understanding this concept will support staff to understand why a person may appear passive and disengaged, often waiting for a staff member to make something happen for them. For people who require support with all aspects of daily living and have limited physical mobility, this may mean spending a large amount of the day in a wheelchair observing the world as it happens around them. This module is about identifying opportunities to change that, now and in the future, so that when the young person moves on to new settings they can continue good practice in keeping people's minds and bodies active.

Being able to control what happens in your life, when other people make decisions about what is in your best interests on a daily basis, is challenging. Staff working with people with PMLD will need to work with a multi-disciplinary approach to consider what is important for people (ie to have a good life) and what is important to them (ie the things that make their life enjoyable and meaningful). An important aspect of this is finding out what does work for the person and how this can be developed to promote their sense of self within their world; this is central to a person-centred approach.

Developing an understanding of cause and effect is a key developmental milestone and the basis of building intentional communication. The relationship between an action and its consequence is fundamental to having control over one's life. For a person with PMLD, this cognitive process may take a long time to develop and requires repeated, frequent opportunities to practise before it can be generalised. The use of AAC can support this (eg switch-based activities) where a person has access to the tools to make this happen. In this case staff should be clear that the aim is not for a person to learn how to use a switch; the aim is to understand what happens as a result of something you have done yourself. Sensory exploration can also stimulate and motivate (see Useful links on page 35 to Sensory Beings by Joanna Grace and Sensology by Flo Longhorn). Sports, games, drama and music activities can all promote turn taking and choice making – as well as cause and effect and opportunities for social interaction. The activity, alongside the people and place, are the vehicles to develop engagement and control.



People with PMLD need repetition and consistency to learn, so the activities undertaken to promote engagement should not be one off events – although sometimes a one-off or unplanned event can reveal a person's interests in unexpected ways. This is sometimes called unintended outcomes; staff should record when this happens and consider how they could be repeated or extended to test out if they are an accurate reflection of the young person. It is expected that centres will use indicators of engagement as regular practice with people with PMLD; this continuum can be used within the **My engagement profile** template (see page 33) to keep a record of what activities promote the highest levels of engagement. Centres may have their own recording tools for levels of engagement, which are acceptable if they include information on the context (eg people, places, activity) and are not simply a numerical scale.

Trying out new activities or being in new environments with a person with PMLD will require staff to make a risk assessment and decide what is an acceptable level of risk. It is important to remember that people change over time; a risk assessment that was followed when someone was younger may no longer be fit for purpose. The type of risks staff need to consider will depend on the individual; these risks should be considered by the centre before an activity is planned and delivered. This is not to say that staff should be risk averse, but that they should approach each activity and individual with a positive view, using all the information they have about a person and reviewing this on a regular basis.

Enabling communication and being a good communication partner is essential to the intensive interaction approach (see Useful links on page 35). It is advised staff receive training in this as an approach to connect and share time with a young person on their terms; this approach will support the person to understand they can have control and can affect change-building intentional communication.

It will be useful to involve multi-disciplinary team members (eg occupational therapist, physiotherapist, speech and language therapist) to develop strategies that can promote levels of engagement and control. These professionals will be able to advise on specialised equipment and resources that support independence. This may also include use of AAC technology (see **Using my technology** module). Any assessments or activities within this module must not contravene advice and guidance provided by these multi-disciplinary professionals. Staff should use a multi-disciplinary and person-centred approach to delivering care and support, promoting independence wherever possible.

#### Format of delivery

This module can be delivered flexibly across a person's weekly timetable. Centres can decide if it is best for an individual to work on this module within specific sessions or within all learning opportunities provided. Set activities (eg drama, sport) may take place at the same time each week; this repetition and frequency will support the learning process and staff can record levels of engagement throughout. Opportunities for intensive interaction can and should be happening at any time; these will also provide valuable evidence of how a person can engage and control what happens to them and with other people.

The amount of time needed to complete the module will depend on the individual. Enough



time must be given to observe, record and develop tested strategies on how the individual can engage and build skills in this area. This could be over months, a term or a year.

Filming evidence of what works or what doesn't work for the young person and reviewing this with people who know the person well will enable staff to assess if their intuition about a person's communication preferences is correct and based on sound evidence.

Providing good quality support and care and enabling young people with PMLD to learn these skills for themselves will necessitate the use of positive touch. This refers to touch that is used to communicate feelings, choices, intentions and requests. Young people with PMLD are often receivers of touch used in care tasks (eg personal care), whereas positive touch is used solely for the purposes of communicating and building a relationship. Positive touch is a powerful tool, whether you are the giver or receiver.

Details of the kind of touch a person likes to give and receive can be recorded as part of the **Looking after myself** module.

Centres should ensure staff are aware of how to use touch positively to communicate, understanding the purpose of touch and how to know when permission is given; this will safeguard young people from intentional and non-intentional abuse.

To promote engagement in an activity, staff may use a hand under hand strategy. This can support a person who needs extra encouragement to touch or hold an item, with which they can practice their understanding of cause and effect. People may be tactile defensive and require this form of support to build confidence in themselves to touch and hold an item. People should never be coerced into exploring a resource or activity that they have shown little or no interest in; staff should consider alternative resources or activities that do interest the person based on their preferences. All touch strategies should be recorded to enable an assessment of what works best for the individual.



#### For example:

A young person has shown an interest in taps and running water. When they hear staff turn on taps in a personal care room or a classroom, they will turn their head towards the sound and vocalise.

During a weekly cooking session, staff provide a shallow bowl of water and guide the person's hands towards the bowl. At first the person draws their hands back and appears not interested. Staff try pouring the water from one container to another and this regains the person's interest, but not to reach or feel the water. After several more sessions, staff move the person's wheelchair to the sink unit and turn the taps on. The person is immediately re-engaged and tries to reach towards the taps. Staff introduce a game of anticipation by turning the taps on and off, waiting to see if the person can anticipate them being turned back on. Staff say "here we go" and make a slow reach for the tap before it is turned on, to see if this supports anticipation.

After this has been repeated for several weeks, staff observe the person will show excitement just before the tap is reached; the next stage will be to encourage the person to reach for the tap themselves. Staff think this activity will highly motivate the person because they are interested in the sound of water. Now the staff say "here [name of person] goes" and wait to see the response. Waiting is important because it is during that time the person is making a connection between what they want and how they can make it happen. It may be necessary to return to an earlier stage if there is a long break between sessions, holidays or illness.

The waiting pays off and the person does reach for and turns on the tap. This causes them great excitement along with lots of positive reinforcement from others, which is also highly motivating. This person has exerted control over their environment.

This example demonstrates how centres can practise cause and effect with everyday resources. It is not that the person needs to know how to turn a tap on or off, although this is a useful self-help skill; it is the understanding that they can make something happen themselves. In time this could be generalised to other situations; it is important this is an activity the person enjoys and is motivated by.

It is important for staff to know what sensory activities can under or over stimulate and adjust activities for the individual. Some people can be motivated by strong sensory feedback in one area but be overwhelmed in another; this may be particularly relevant for people with autistic spectrum disorder. A sensory profile developed with an occupational therapist who has expertise in sensory regulation will support this.

The approach to all activities should be one of doing something with the person, not to them. All responses from a person should be understood as having meaning and all ways to involve people in being active in their care and support routines should be encouraged.



#### Suggested activities

The learning activities used to complete this module will be highly dependent on the individual's preferences. It is unlikely a person will be motivated to engage if the activity holds no interest for them. There will be a much higher chance of success if the activity is fun, the person enabling the activity knows the person well and has a good relationship with them, and the environment is accessible and inclusive.

#### Ideas for activities

Centres should use a range of activities to promote the understanding of cause and effect. Activities should be chosen based on the needs and preferences of the individual, for example:

- Intensive interaction turn-taking games (eg burst-pause sequence)
- Hide and seek games
- Mirroring
- Using gross or fine body movements to make an item move or make a sound (eg mobiles, large balls, parachute games, rolling items down a tube, knocking items down, stacking them up, using containers to load and unload)
- Arts and craft messy activities (eg using paint, clay, foam, materials)
- Arts and craft activities using a touch screen or switch (eg art and design apps)
- Choosing between two motivating activities by using a switch to make a choice
- Making a simple toy turn on and off
- Using the natural environment (eg opening and closing doors, pressing buttons on a lift)
- Using an everyday item for a self-care task (eg cutlery, cup, clothing, washcloth)
- Making sounds or visual changes through turning electrical items on and off using a switch (eg screen, blender, hoover, bubble tube, spotlights, fans with ribbons or bells attached)
- Using apps on an iPad for cause and effect (Switch Road Map by Ian Beam, see Useful links on page 35)
- Call and response activities using instruments and vocalisations
- Sensory exploration of items (eg colour, sound, texture, smell, shape). Items can be low-cost items sourced from discount shops or similar; centres should always check the size, shape and materials that are given to learners who like to explore with their mouths
- Use items to make sensory boxes see Pinterest for inspiration for themed boxes
- Sensory stories using items that stimulate the senses to tell a story
- Turn-taking games with staff and peers (eg when I do this, you do this back to me)
- Drama games using dressing up, music, props and people



Centres may wish to use activities from ASDAN's **Lifeskills Challenge** to structure the suggested activities. More guidance on using Lifeskills Challenge to support Supporting Aspirations modules can be found in the members area of the ASDAN website.



#### Support strategies and module templates

Young people working towards Entry level will have a wide range of learning support needs. Many young people with PMLD will require physical support and a skilled communication partner to access the world around them.

The type of support required and the frequency with which this is provided may fluctuate during the module activities. Support will be highly personalised to the individual and staff may need to explore a variety of strategies and adapt these in order to ascertain what works best.

These high levels of dependency may be unlikely to change throughout a lifespan or may increase. Some young people may have days when they need more or less support because of their health needs. It is more useful to provide information on support strategies that work in specific contexts to maximise independence and avoid reinforcing dependency wherever possible, with a recognition this can change depending on individual need.

The **Module completion log** should be completed by the teacher/tutor at the end of each module and should include information on what good support looks like.

#### Sensory cues and prompts

Staff should use sensory cues and prompts before any self-care activity to provide the maximum opportunity for a person to process what is about to happen. These cues can involve smells, positive touch and body signing, images, sounds and objects of reference. It is important that these are used consistently throughout the day and are meaningful to the person.

#### Behaviour and communication

This module is concerned with people being engaged and having control over their environment. It is important to state that some people with PMLD may have learned to do this through behaviours of concern; these are behaviours that may challenge other people and the environment. This can include self-harm or harming others. Through negative reinforcement of behaviours, which are expressions of communication, some people have learned to affect what happens to other people and themselves by engaging in activities that others find dangerous, inappropriate or harmful. It is likely people with PMLD will not have the cognitive function to understand the consequences of these behaviours; punishment or withdrawal of support must never be an option.

It is widely accepted that a model of positive behaviour support (PBS) is a preferred strategy to pro-actively prevent behaviours of concern. This module does not cover PBS strategies. It is advisable that settings seek specialist advice from people trained in PBS when there are behaviours of concern to ensure these are not reinforced when planning and delivering activities to promote engagement and control. It is a key PBS strategy to use a personcentred approach to ensuring people have lives that are meaningful and promote their wellbeing.



The modules within the Independent living pathway aim to enable people to move into adulthood with information that supports them to have positive life outcomes. The **Understanding my behaviour** module (in the Good health pathway) provides an opportunity to explore and record how behaviour strategies can support a person to move into adulthood.

The module templates listed below should be completed in order to demonstrate achievement of the module outcomes. It is expected that these templates will be completed by staff on behalf of the learner. If a young person does not use any formal verbal language, staff will need to develop strategies to ensure what is completed on the templates reflects the young person's experience and choices.

#### My engagement profile

This template provides a record of the activities and strategies that motivate a person to engage and have control over their environment. This template states the level of engagement that has been observed in an activity, and provides suggestions for continuing and developing this. A separate template should be completed for each engagement activity.

It is expected that centres will use indicators of engagement to record the young person's level of engagement in the **My engagement profile** template. Centres may have their own recording scale for levels of engagement, which are acceptable if they include information on the context (eg people, places, activity) and are not simply a numerical scale.

The information in the **My engagement profile** will enable any new centres to continue this work and prevent people losing their skills during transition. When people move to a new setting it can take time to get to know new routines, people and environments; skills that have been hard worked for can be lost quickly. If staff in new centres can continue familiar activities, albeit in a new environment, there is a greater chance of the person maintaining their skills.

The **My engagement profile** should be reviewed by a multi-disciplinary team and checked for consistency. Some people may engage in activities more readily with certain staff. It is important that successful strategies are passed on to new centres and the approach that is most preferred is continued.

#### Independent living profile

This module will support the completion of the **How I engage with my environment** section of the **Independent living profile** for the Independent living pathway. This profile includes all the relevant information a young person will need to take with them to a new setting and in preparation for adulthood.



#### **Individual objectives**

Each young person will have an individual learning plan or similar in their setting. Where possible these objectives should be used within the module to support the young person's educational development.

Staff may choose to set specific objectives for the module, especially as certain skill development will lend itself to specific tasks (eg I will select the music I want to listen to by choosing between three images, where one is a non-preferred selection) and this will appear within the young person's individual learning plan. This can be added to the **Module completion log**.

#### Module outcomes

The outcomes for this module are:

- I have a **My engagement profile** (or an equivalent from my centre) that shows the activities and strategies that enable me to engage with and control my environment
- I have participated in learning opportunities that promote engagement and control in my environment
- I have completed the **How I engage with my environment** section of the **Independent living profile**, which informs people what I can do now and how I prefer to be assisted

#### Person-centred planning tools

The following person-centred tools can be used to support the module:

- Like and admire at the start of the module
- Working, not working ongoing throughout the module
- Important to, important for to identify what will motivate a young person
- Matching support to identify which staff can motivate a young person
- **Decision making profile** to understand how and when a young person can make choices and decisions
- From presence to contribution to identify what it would look like if a young person was fully engaged in an activity



#### **Useful links**

- https://www.intensiveinteraction.org/
- http://www.thesensoryprojects.co.uk/
- http://flopublications.com/index.php/9-training-workshops/9-planning-a-sensory-curriculum-for-special-learners
- http://www.inclusive.co.uk/Lib/Doc/pubs/switch-progression-road-map.pdf

# My engagement profile



① Complete a separate profile for each engagement activity.

Engagement activity:	
Strategies used to promote my engagement	
What I can do	
My level of engagement in this activity	
What I need to continue with this activity	
Ways to develop this in the future	



# **Engaging with my environment Module outcomes checklist**

Learner name:			
			<b>~</b>
I have a <b>My engagement profile</b> that shows activities and strategies that enable me to ewith and control my environment.			
I have participated in learning opportunities promote engagement and control in my en			
I have completed the <b>How I engage with my environment</b> section of the <b>Independent living profile</b> , which informs people what I can do now and how I prefer to be assisted.			
I have a completed <b>Module completion log</b> module.	for	this	
Completed by:		Date:	



**Supporting Aspirations** 

# Using my technology

Tutor guidance and resources



#### Aim of module

This module provides a learning opportunity for a young person with PMLD to use technology to develop their understanding of cause and effect, a foundation of independent living skills for people who are at the earliest stages of learning.

Technology provides access to learning opportunities that builds from the milestones of contingency, responding to contingency awareness and beyond. Learning that an action you take influences the world around you is a key stage in cognitive development.

Alternative and augmented communication (AAC) is a broad term to describe the many approaches that can be implemented to improve communication for people who do not use verbal communication; technology is one of these approaches. For people with PMLD who may not have the prerequisite skills to learn verbal communication, technology does not replace regular and consistent human interaction that supports engagement.

Many people with PMLD will have physical and multi-sensory impairments that reduce their ability to engage with their environment. This can result in the state of learned helplessness, which is explained in the **Looking after myself** module (see page 11). Most people with PMLD will rely on care and support for all aspects of everyday living and may have learned to wait for things to happen to them, rather than with them.

Learning to control an event that is rewarding, enjoyable and meaningful encourages young people to become active participants in their own lives. Using technology (eg switch-based activities) may be the only time in a day when a person can act completely independently of others; as such, it is a powerful tool for developing independence.

Staff who know the person well will be able to identify what motivators the person best responds to (eg audio, visual, texture, smell, movement) as part of a multi-sensory environment. Many centres will have access to sensory rooms or sensory equipment that can stimulate a person's senses in one or a combination of ways. Technology can be used to enable the person to access what motivates them the most. The reward for a young person in creating an event that they find enjoyment in, is that they will want to repeat it. The skills learned in this process can be explored further in choice-making and turn-taking. Being able to make a choice independently, and make that choice happen yourself, starts with understanding that you have the power to do this. Technology enables people with PMLD to lead and influence what happens in their environment.

Technology also provides opportunities for social interaction that build intentional communication. For people who are non-verbal, being able to attract other people's attention and hold a conversation using a communication tool (eg a BIGmack) will increase their opportunities to develop intentionality. All communication should be responded to as if it were intentional on the part of the person; this is how people learn that when they express themselves, they will get a response. The purpose of this module is not to teach language, but to increase opportunities for engagement and interaction.





Centres will have staff who are trained to assess and observe people using technology. It is strongly advised that occupational therapists are involved in assessing good seating positions for people to access technology; there is no point to providing technology that the person cannot reach or operate independently. There are a wide range of switch-based resources (see Useful links on page 45) that will ensure, through careful assessment, that a person can access technology that they can activate easily.

Centres will have dedicated staff who understand what level of activity is most appropriate for an individual. This should be carefully observed and given time to assess if it works for the person. This module includes a **My technology profile** template that provides information about the technology that works best for the person. When young people move between settings this information can be lost, equipment may not be available and staff may not have the same level of training and skill to ensure there is access in the same way. Equipment that belongs in one setting will usually not travel with the person. Centres need to consider what they can do in advance of a new person's arrival to provide useful technology; it may be possible for families and carers to purchase technology (eg using the person's personal budget) or for centres to apply for funding (eg from charities).

#### Format of delivery

This module can be delivered flexibly across a person's weekly timetable. Centres can decide if it is best for an individual to work on this within all learning opportunities provided, or in a specific session dedicated to the use of technology. People may use technology for a specific purpose (eg when in a sensory room to operate equipment, such as bubble tube or lights) or people may have specific sessions where they use technology (eg using eye gaze or apps on an iPad during break times).

The amount of time needed to complete the module will depend on the individual. . Enough time must be given to the assessment of motivators, ensuring the positioning of the technology and that the resource is easily accessed, and that the person has time to process what effects they are causing. This could be over months, a term or a year.

Filming evidence of what works or what doesn't work for the young person and reviewing this with people who know the person well will enable staff to assess if their intuition about a person's communication preferences is correct and based on sound evidence.



#### For example:

A young person is motivated by the music of High School Musical. Staff have observed this as when YouTube clips are played during break times, the person immediately moves their head towards the sound, they smile and vocalise. This stops when the clip stops playing.

Staff assess that the person would need a head switch to operate technology as they have very little fine or gross motor control and would not be able to easily press or squeeze a switch; they can make controlled head movements.

A switch is connected to the large TV screen. The person can use their head switch to make the YouTube clip start; it will stop after thirty seconds. The person needs repeated opportunities to develop an understanding that their action of moving the switch with their head will make the music begin again. The occupational therapist observes and assesses the switch should be moved to the left side of the person's head and their wheelchair placed alongside the TV screen. This is because they also have a visual impairment and will be able to most easily see the screen from the left-hand side.

The person is provided with the switch every break time, for at least 15 minutes each day. They use the head switch to activate the clip on many occasions but staff are not sure this is intentional.

After several weeks, staff change the YouTube clip for one of a non-preferred type of music to assess if the person will still use the switch as consistently. The person does not. They return to the preferred clip and return to regular daily practise. Staff use the word 'more' to encourage the person to make the clip start. Staff do not say 'use the switch' as this would focus the attention on the switch rather than the effect it is creating, which is the purpose of the activity.

Staff continue this activity and try out different motivational activities using the head switch to assess if the person understands they are controlling the clip.

### Suggested activities

The activities will be determined by what motivates a person and what type of technology is most accessible for them to operate independently.

An assessment by staff who are trained in using accessible technology along with input from multi-disciplinary team members (eg occupational therapist, physiotherapist, speech and language therapist) on how to maximise access to the technology and advise on appropriate levels is essential.

The following examples can be used to provide inspiration.



#### Operating equipment

- Bubble tubes
- Fans
- Lights
- Moving toys
- Projectors
- Blenders
- Hoovers
- Screens (eg TV, computer monitors) and visual stimuli

#### Apps on an iPad

• Cause and effect apps (eg Big Bang, see Useful links on page 45)

#### Eye gaze

Accessing a computer to track individual items by looking or blinking

#### Other activities

- BIGmack communicators
- Sequencers
- Randomisers



Centres may wish to use activities from ASDAN's **Lifeskills Challenge** to structure the suggested activities. More guidance on using Lifeskills Challenge to support Supporting Aspirations modules can be found in the members area of the ASDAN website.

#### Support strategies and module templates

Young people working towards Entry level will have a wide range of learning support needs. Many young people with PMLD will require physical support and a skilled communication partner to access the world around them.

The type of support required and the frequency with which this is provided may fluctuate during the module activities. Support will be highly personalised to the individual and staff may need to explore a variety of strategies and adapt these in order to ascertain what works best.

These high levels of dependency may be unlikely to change throughout a lifespan or may increase. Some young people may have days when they need more or less support because of their health needs. It is more useful to provide information on support strategies that work in specific contexts to maximise independence and avoid reinforcing dependency wherever possible, with a recognition this can change depending on individual need.



The **Module completion log** should be completed by the teacher/tutor at the end of each module and should include information on what good support looks like.

#### **Technology**

Using technology can provide an opportunity for a person to act completely independently; this may be unusual for the person if they require one-to-one support in order to engage in everyday activities. Staff should not be observant during activities using technology and can provide the same one-to-one support, even from a distance. Staff may need to prompt people and use verbal encouragement through keywords (eg more, stop) or countdowns, if appropriate.

How close staff need to be and how much verbal interaction they use will depend on the person. Initially staff may need to model using the technology being used. Staff will need to know to wait for the person to operate the technology by themselves, however tempting it can be to help by stepping in. Careful monitoring and assessment of how the person is or isn't using the technology should take place with staff who understand contingency awareness and can map their individual progress.

The module templates listed below should be completed in order to demonstrate achievement of the module outcomes. It is expected that these templates will be completed by staff on behalf of the learner. If a young person does not use any formal verbal language staff will need to develop strategies to ensure what is completed on the templates reflects the young person's experience and choices.

#### My technology profile

This template provides information about how a person accesses and uses technology and for what purpose. It includes space to record:

- how the person is positioned and has access to the technology
- what the person does now and ideas for the future this is important as it will show new settings what should continue
- information on where to access technology so it can be replaced easily

The profile should be reviewed regularly by people who know the person well and who understand how technology supports their independence.

#### Independent living profile

This module will support the completion of the **How I use technology** section of the **Independent living profile** for the Independent living pathway. This profile includes all the relevant information a young person will need to take with them to a new setting and in preparation for adulthood.



#### **Individual objectives**

Each young person will have an individual learning plan or similar in their setting. Where possible these objectives should be used within the module to support the young person's educational development.

Staff may choose to set specific objectives for the module, especially as certain skill development will lend itself to specific tasks (eg I will use a switch to turn the blender on and off in my cookery session) and this will appear within the young person's individual learning plan. This can be added to the **Module completion log**.

#### Module outcomes

The outcomes for this module are:

- I have a My technology profile that provides information on the technology I can use, how and why I use the technology, support strategies, positioning and where to access the technology
- I am working with my technology to increase my understanding of how I can control my environment.
- I have completed the **How I use technology** section of the **Independent living profile**, which informs people what I can do now and how I prefer to be assisted

#### Person-centred planning tools

The following person-centred tools can be used to support the module:

- Like and admire at the start of the module
- Important to, important for to identify what will motivate a young person
- **Working, not working** to identify if the technology a young person is using is right for them, ongoing throughout the module
- Matching support to identify which staff can support a young person
- Communication chart to identify what a young person is trying to communicate





#### **Useful links**

- http://www.inclusive.co.uk/apps
- http://www.inclusive.co.uk/articles/switch-progression-road-map
- https://www.hirstwood.com/
- https://senclassroom.wordpress.com/apps-used-in-the-classroom/sensory-apps/
- http://teachinglearnerswithmultipleneeds.blogspot.com/2011/09/free-online-switch-activities.html
- https://tarheelgameplay.org/



# My technology profile

1 This profile is about how I use technology.

What motivates me to engage with the world around me:	My photo:
with the world dround file.	
How I use technology in my learnir	ng <b>now</b> :
How I might continue this learning	in the future:



# My technology profile

How this supports my independent living skills:		
Activities I might like to try in the future using my technology:		
People who need to technology:	e involved in supporting me to access	
-	e involved in supporting me to access  Role:	
technology:		
technology: Name:		
Name: Contact:	Role:	
Name: Name: Name:	Role:	
Name: Name: Name:	Role:	



# This is me using technology

① Complete a separate sheet for each type of technology.

Photo of me using my technology:	This is called:
Photo showing positioning and what the device or equipment looks like	Why it motivates me:
My positioning:	How I operate it:
I am learning to:	In the future, I might be able to:
How to support me:	Where you can get this device:



# This is me using technology

① Complete a separate sheet for each type of technology.

Photo of me using my technology:	This is called:
Photo showing positioning and what the device or equipment looks like	Why it motivates me:
My positioning:	How I operate it:
I am learning to:	In the future, I might be able to:
How to support me:	Where you can get this device:



# This is me using technology

1 Complete a separate sheet for each type of technology.

Photo of me using my technology:	This is called:
Photo showing positioning and what the device or equipment looks like	Why it motivates me:
My positioning:	How I operate it:
I am learning to:	In the future, I might be able to:
How to support me:	Where you can get this device:



## Using my technology Module outcomes checklist

Learner name:		
		<b>~</b>
I have a <b>My technology profile</b> that provide information on the technology I can use, had I use the technology, support strategies, post and where to access the technology.	w and wh	ny
I am working with my technology to increase my understanding of how I can control my environment.		
I have completed the <b>How I use technology</b> section of the <b>Independent living profile</b> , which informs people what I can do now and how I prefer to be assisted.		
I have a completed <b>Module completion log</b> for this module.		
Completed by:	Date:	