



ACT
Down Syndrome
Association

Building Independence

For Employment



In order to be happy and confident in not only the workplace, but in life in general, people need to have a sense of independence. This level of independence will vary from person to person, but it is an important skill that will benefit your person through their life.

Often parents and carers struggle with the idea of “letting go” of any child, let alone a child with a disability. However, it is important to begin working on independence at the same age (if not earlier) as all other children in order to maintain the same life “pattern”.

Independence is NOT necessarily living without support, but it is about having choice and control over your life – “agency”. Agency is defined as the capacity of individuals to act independently and make their own free choices.

People with disabilities can be supported to learn skills to become more independent and to make decisions about their own life. It is important to remember that just because a carer does not agree with a decision does not mean that the person should not get a chance to make those decisions.

So what is independence?

The UN Convention of the Rights of People with disability outline what the key elements of independence for persons with disabilities are:

- Individual autonomy
- The opportunity to be actively involved in decision making processes, and
- The opportunity to access the physical, social, economic and cultural environment.

So, what can you do to begin working towards a more independent lifestyle with your person?



Seek to support, not to control

Parents and carers all do their best to protect their loved ones, often under challenging circumstances. Sometimes when people care about another's well-being, they can tend to want to control the situation to protect and nurture. However, it is likely that the more you control the situation, the less responsibility others will take on, which includes the person you are trying to protect. This can lead to your person becoming dependant on you for more aspects of life than you anticipated.

Instead of seeking to manage every interaction, situation, and decision that your person may be in, try to begin to find ways that you can gradually switch to offering support. This can often be as simple as a change in language that you use. For example, instead of telling your person what they will be doing, ask them what they would like to do. Explaining why you would like them to do a particular task is also useful in giving the context and then follow up with a request that they might like to do the action gives context and choice.

It is important to discuss with your person why they would like to do something and to discuss risks associated with that decision. Making a gradual transition will give your person a sense of security and confidence in the process of moving to greater self-determination and independence.

Establish a circle of support

A large part of promoting and developing independence is to have others involved in supporting and assisting your person when needed. Families are often deeply dedicated to their person and can find it difficult to take a “step back” and involve other family members, family friends or even paid supports. Many carers find that they may struggle with a sense of failure or guilt that they are not undertaking enough of a caring role. It is important to remember that this is not the case! It is important to remind yourself that by creating a larger network of support you are ensuring your loved one has the security and stability of additional carers in their life, which will be vital if a situation arises where you are no longer able to provide the care they require. Remember that this can give your loved one the benefit of new and interesting experiences.

Establishing a trusted support network is something that will take time as you look for the people that you trust, your person trusts, and who are ready willing and able to being part of this journey. These types of people aren't necessarily going to be easy to find, but the best place to start is close to home. Think about your family, your friends, your neighbours, or even a select few “outsiders” from your local community. Building your support network can take time but it is worth being patient and finding the right people for your loved one.

Start slow with daily life decisions

Promoting independence requires patience and is about making a series of small steps and changes that add up to a more empowered lifestyle. The challenge is that many adults and children with disabilities have experienced strongly nurturing and protective environments. Independence and decision-making may be foreign concepts, which means that if things happen too quickly, fear and anxiety of the unknown can take over. By starting slowly with daily life decisions, these skills can be transferred to more challenging aspects or decisions. Simple everyday tasks to start with could be:

- How they will wash the dishes
- What to cook for dinner
- What they would like to take to lunch at school
- What hair style they would like
- What clothing they will wear

Once they are comfortable with making these daily lifestyle decisions, you can start to develop other skills with low risk daily activities such as the cooking and the washing and ironing. When you are both ready, move onto social decisions and life skills – communication, navigating relationships, and independently shopping and participating in community groups.

By having positive experiences with these “life skills” the built confidence will be beneficial in preparing and developing employment skills.

It is important to note that there is no set amount of time that it should take for your person to develop these skills and feel confident in making daily life decisions. Each person will have their own pace of learning, and realistically there will be a few bumps along the road. Take it slow and see what happens.

Dignity of Risk

“Dignity of risk is the principle of allowing an individual the dignity afforded by risk-taking, with subsequent enhancement of personal growth and quality of life.”

(Ibrahim J., and Davis M. (2013). Impediments to applying the ‘dignity of Risk’ principle in residential aged care services. Australian Journal of Aging, 1-6.)

The dignity of risk can be considered as a fundamental principle or practice in your duty of care. By empowering our people to take risks in exercising choice and control, we are allowing them to practice making good decisions which ultimately makes them more capable.

Balancing safety and the right to make own decisions

We know for a lot of families it is difficult to feel confident that the person will make the right decisions.

Positive risk-taking can have a number of benefits including:

- Increased independence and social interactions
- Increased skills around decision making
- Achieving goals such as living independently and living a life aligned with personal values
- Improved self-esteem

Being overprotective doesn't allow for having and realising hopes and dreams. It doesn't build self-esteem or self-efficacy (or agency) and may impede basic human rights. If we acknowledge a person's right to make decisions and take risks, we must also be comfortable if they make a decision we do not agree with.

Dignity of Risk is a:

- Process, not a one-off event or outcome
- Is person-centred – ensures the person's voice is at the centre of all decision-making
- Upholds the person's rights
- Respects the person's values and beliefs

Sometimes there is a tricky bridge to span between the principles of Dignity of Risk, and achieving this in reality. It often involves weighing up 'rights' vs 'risks' and may feel like a lapse in "duty of care". In some cases, families may need to be more involved if they feel that the person is putting themselves in a situation that is threatening their safety and the risk of harm is too great. The need for more or less intervention will inevitably be on a case-by-case basis. Hopefully, as your person gains experience and confidence, the need for intervention will diminish.

Tips in regard to Dignity of risk

- **Consider** what safeguards will ensure maximum independence whilst guarding against abuse.
- **Promote** open and ongoing education and communication from a young age about the person rights in regard to being safe and making their own decisions.
- **Build** circles of support / supportive networks early in life and invest in these over time.

Emotions are catching

Emotions are contagious. Feelings like fear, anxiety and negativity can be felt by the people around you, even when you do not mean them to be. However, emotions such as hope, happiness and positivity are just as catching as negative emotions and an optimistic outlook can make it easier for everyone to embrace change. The journey towards independence can be challenging, so remember to celebrate the small wins. Others will feed off your energy and build confidence as a result.

Learn from each other

The more you, your person, and your support network can work together to adapt and understand each other, the quicker and smoother the progress will be. Talk openly about the things you are struggling with, ask for guidance from others, and do whatever you can to build a high level of trust and open communication with your person. This will allow any challenges to be brought to the surface more quickly, a solution to be found, and for any problems to be rectified before they become unwieldy.



Practical strategies to support independence

- **Plan ahead** and start the discussions early – the when/who/how/why of gaining more independence can be a gradual process and the conversations should start early in the person life.
- **Sharing your vision** with those around you helps others to be part of the pathway to independence, and enables them to be more intentional about seeking opportunities to support you all on this journey (e.g. can a friend offer the opportunity for a short house-sitting stint, which could also be supported by friends / family? Do you know someone willing to offer a work experience opportunity in their place of business?).
- **Having high expectations** and ensuring the whole 'team' subscribe to these.
- **Build confidence** through a focus on strengths and interests, rather than just focussing on all the challenges / barriers. Consider working through 'positives and negatives' lists whenever a hope or dream is raised that seems at first to be unattainable.

- **Encourage skill development** – practice, and intentionally allowing time for this; avoid ‘doing for’; use visual cues / supports / alarms to build predictable routines (but also teach some problem solving strategies for when a routine is disrupted); plan for successful steps to independence – avoid over-scheduling or committing your loved one to too many activities, especially during transition times – try and implement no more than one new change at once; think about personal care and any particular considerations here (e.g. managing periods; supporting bathing as an adolescent / adult – are there any cultural aspects to be mindful of)
- **Consider developing a ‘checklist’** of smaller goals to achieve, with timeframes, in the lead up to larger transitions such as moving out of home; or starting work.
- **Consider documenting / journaling progress** along the way; celebrate all the little steps in between
- **Circles of support** – think about setting up a circle of support and talk to the person with disability about this.
- **Give your loved one time to consider**, internalise and then own each step along their journey to independence.