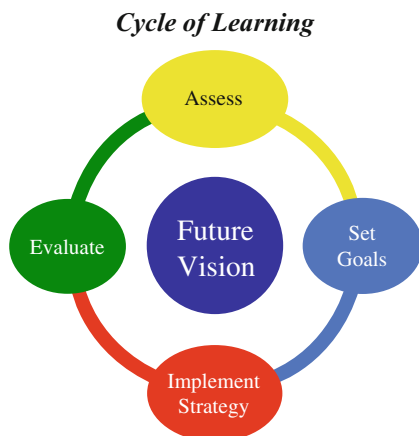


Chapter 8

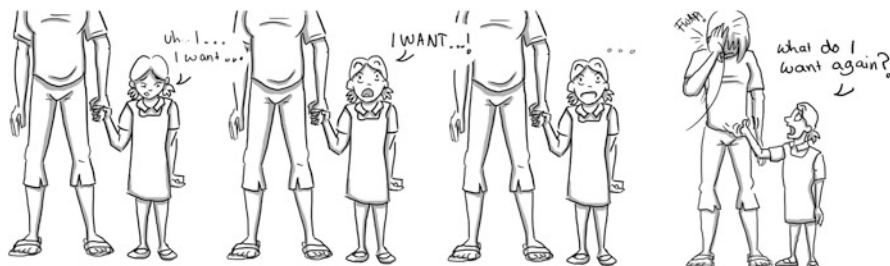
Facilitating Self-Determination Through Education Planning

Abstract This chapter demonstrates how one parent utilised the Cycle of Learning to facilitate her son's self-determination and self-advocacy skills. Self-determination is critically important in enabling individuals with autism spectrum disorder (ASD) to achieve long-term outcomes as they travel through school and into adult life. Supporting self-determination does not start when an individual is an adolescent, but must begin when they are very young. Parents and professionals can use strategies throughout their child's life to support them to develop self-determination and to take charge of their own planning and problem-solving. Mitchell's story exemplifies one adolescent's journey towards developing self-determination. This chapter examines current research related to self-determination for individuals with ASD, and explores the benefits of self-determination and the implications for parents as they strive to develop their child's self-determination, including helping them to become more self-aware, and to self-regulate and advocate for their own support. The final section presents research on the use of the Cycle of Learning to help parents identify evidence-based strategies that will help them to facilitate their child's self-determination skills and provide them with opportunities to practise these skills to address problems in their child's life. Finally, potential barriers that may impede parents and children with ASD from achieving their goals will be outlined, and possible strategies for overcoming these barriers discussed.

Illustration 8.1

8.1 Introduction

As demonstrated in the previous chapters, the *Cycle of Learning* (CoL) provides a useful framework for parents, enabling them to create learning plans that will help their child to achieve their hopes and dreams. As children grow and mature, however, it is important that parents help them to create and implement their own plans, providing them with a foundation of skills that will enable them to take charge of their own lives, and become independent and successful adults. By engaging with their children around the CoL, parents can facilitate their children's skills in self-determination and enable them to identify their future visions, set priorities and goals, identify their strengths and weaknesses, formulate a plan of action and evaluate their own progress.

Illustration 8.2

8.2 What Does the Research Tell Us?

The past 20 years have seen an increased awareness of the importance of allowing individuals with autism spectrum disorder (ASD) to self-advocate and create their own pathways (Wehmeyer, Bersani, & Gagne, 2000). As children with ASD move into adolescence and adulthood, developing their self-awareness, ability to self-advocate and overall self-determination becomes particularly important (Field & Hoffman, 1999; Shogren & Turnbull, 2006; Wehmeyer, 1999). People with ASD and other disabilities often experience diminished quality of life, restricted living options, greater social isolation and disproportionate levels of unemployment (Wehmeyer, 2014). Promoting self-determination for individuals with disabilities provides a critical step in addressing such inequalities, and building a foundation of knowledge and skills linked to increased learning and improved post-school outcomes (Field & Hoffman, 1999; Shogren & Turnbull, 2006; Wehmeyer, 1999, 2014).

Wehmeyer (2005, p. 117) defines self-determination as “acting as the primary causal agent in one’s life and making choices and decisions to improve one’s quality of life”. An individual demonstrates self-determination if they engage in actions that reflect four essential characteristics: (1) the individual acts autonomously; (2) the behaviour is self-regulated; (3) the individual initiates and responds to the event in a psychologically empowered manner; and (4) the individual acts in a self-realising manner (Wehmeyer, 2014; Wehmeyer & Smith, 2012). In other words, self-determination involves the merging of an individual’s knowledge, beliefs and skills to enable them to engage in goal-directed, self-regulated and autonomous behaviour (Field, Sarver, & Shaw, 2003). Individuals who demonstrate self-determination are able to make informed choices and decisions, set and attain goals, self-advocate and act in an empowered way, operate with self-knowledge and awareness, problem-solve, self-regulate behaviour and demonstrate independence (Karvonen, Test, Wood, Browder, & Algozzine, 2004; Wehmeyer, 2014; Wehmeyer & Abery, 2013). Self-determined people make things happen in their lives. They have skills that allow them to make choices, decisions and plans as they control and shape their futures and work towards achieving personally meaningful goals and dreams (Algozzine, Browder, Karvonen, & Test, 2001; Field & Hoffman, 1999; Ludlow, 2010; Wehmeyer, 1999).

There is overwhelming research linking self-determination to a number of benefits for individuals with disabilities. Individuals who demonstrate self-determination are more likely to experience success both in school and as they move into post-school employment and social contexts. Research indicates that individuals who leave high school with a greater level of skills associated with self-determination achieve more positive outcomes as adults than individuals who lack these skills (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer & Schwartz, 1997). In addition, self-determination has been linked to increased academic achievement (Lee, Wehmeyer, Soukup, & Palmer, 2010), as well as positive outcomes in employment, independent living (Wehmeyer & Palmer, 2003), recre-



Fig. 8.1 The benefits associated with self-determination

ation and leisure (McGuire & McDonnell, 2008), and increased life satisfaction (Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006). The multiple benefits associated with self-determination are presented in Fig. 8.1. Many of these benefits have been found to generalise to other contexts, and to extend past the specific intervention period.

Seven skills are commonly associated with self-determination. These are choice-making, decision-making, goal-setting and attainment, problem-solving, self-management and self-regulation, self-advocacy, and self-awareness (Carter et al., 2013a, b). Wehmeyer, Shogren, Zager, Smith and Simpson (2010) add that self-efficacy and perceived control are also components of self-determination. Instruction in self-management and self-regulation has been highlighted as particularly important for children with ASD (National Autism Center, 2011; Wong et al., 2014). Additionally, individuals with ASD have emphasised the importance of developing self-awareness and self-advocacy in individuals with ASD (Barnard-Brak & Fearon, 2012; Shore, 2008).

Studies reveal that parents recognise the value of self-determination skills for their children with ASD, but feel that their children often do not possess these skills to any level of competence (Carter et al., 2013a). Similarly, a majority of teachers indicate that promoting self-determination skills is important, but only a small percentage (22%) report that they specifically target self-determination skills in either general instruction or in individualised education plans (Wehmeyer, Agran, & Hughes, 2000). As a result, researchers increasingly have advocated for parents and professionals to work collaboratively to facilitate the development of self-determination skills for children with ASD, beginning in early childhood (Chambers et al., 2007; Lee, Palmer, Turnbull, & Wehmeyer, 2006). In this way, children are more likely to enjoy success through their schooling, and ultimately experience greater quality of life outcomes.

As children with ASD grow into adolescence, it is even more important that they are supported to move towards greater autonomy, becoming dependent on themselves rather than others to develop and implement realistic life plans. This will optimise their opportunities to live as successful adults in society and enjoy quality of life outcomes (Field et al., 2003; Fullerton & Coyne, 1999; McDougall, Evans, & Baldwin, 2010; Wehmeyer & Abery, 2013; Wehmeyer & Schwartz, 1997). Currently, studies overwhelmingly focus on teaching self-determination to students with disabilities when they reach high school. Yet research suggests self-determination is something that develops over time and in different contexts, and cannot be taught in specific blocks of time (Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013). Moreover, Wehmeyer et al. (2010) stress that children with ASD are particularly vulnerable to learning the skills of self-determination as separate components without connecting them to address real-life problems. Thus children with ASD must not only be taught the component skills associated with self-determination, but must also be provided with opportunities to engage in these skills in meaningful ways in a variety of contexts.

To address this gap, parents can play a significant role in creating expectations, environments and a continuum of opportunities, allowing their child to build capacity and competence in self-determination from early childhood (Jackson, 2012; Palmer, 2010; Palmer & Reynolds, 2012; Weir, Cooney, Walter, Moss, & Carter, 2014). Parents can assist their child to take control of decisions and choices that impact their lives, develop a vision for their future, create and implement realistic plans and actions, and evaluate their own progress as they move towards greater independence, thereby optimising future opportunities and quality of life outcomes (Field & Hoffman, 1999; Fullerton & Coyne, 1999; Lee et al., 2006; Wehmeyer, 2014). The home is also the first place where children have the opportunity to make choices and solve their own problems. In order to promote generalisation of skills, however, children with ASD must be provided with skills and opportunities to develop their self-determination in both the home and school contexts.

The Self-Determined Learning Model of Instruction (SDLMI) has been developed by Wehmeyer, Palmer, Agran, Mithaug, and Martin (2000) to teach children with ASD to engage in goal-setting, decision-making and problem-solving—key components associated with self-determination. The Self-Determined Learning Model of Support (SDLMS) is very similar except that it has been adapted for use by parents (Lee et al., 2006). The SDLMS consists of three phases, which lead children through typical problem-solving processes, and provide a framework from which children and their parents can work together to (1) set a goal, (2) design a plan to achieve that goal, and (3) implement and track progress towards their goal. In each of these phases, children are asked a series of questions to help them to accomplish the primary action associated with each phase. For example, to set a goal, children are asked: What do I want to learn? What do I know about it now? What must change for me to learn what I don't know? What can I do to make this happen? The SDLMI and SDLMS have been found to be effective in increasing the problem-solving and self-determination skills of children with disabilities, including young children (Lee et al., 2006) and individuals with intellectual disabilities (Shogren et al., 2012). The phases of the SDLMS and their associated questions are presented in Table 8.1.

Table 8.1 Self-Determined Learning Model of Support (SDLMS)

Phase	Question 1	Question 2	Question 3	Question 4
Phase 1: Set a goal (What is my goal?)	What do I want to learn?	What do I know now?	What must change for me to learn what I don't know?	What can I do to make this happen?
Phase 2: Take action (What is my plan?)	What can I do to learn what I don't know?	What could keep me from taking action?	What can I do to remove these barriers or problems?	When will I take action?
Phase 3: Adjust goal or plan (What have I learned?)	What actions have I taken?	What barriers or problems have been removed?	What has changed about what I don't know?	Do I know what I want to know?

Source: Lee et al. (2006). Used with permission of Sage.

Self-advocacy is another area of self-determination that has been the focus of research, particularly with regard to future planning for children with ASD. The growing awareness of the importance of self-advocacy has been labelled “the third wave” of the disability movement (Wehmeyer, Bersani, et al., 2000). Shore (2004) argues that self-advocacy begins with self-awareness. As an individual develops an awareness of their own self, including their physical, mental and social characteristics, they develop a knowledge of their own strengths and needs. As they move towards becoming an advocate for their own support, they must disclose these needs to others. Shore also suggests that, by participating in their own future planning, children and adolescents with ASD have the opportunity, with support and instruction, to practise the critical self-determination skills they will need to become independent adults who can set their own goals and take action to achieve them. Furthermore, Barnard-Brak and Fearon (2012) confirm the need to individualise instruction in self-advocacy for children and adolescents with ASD, as their ability to self-advocate is closely tied to their sense of self-identity. These researchers maintain that by learning to self-advocate, adolescents with ASD are constructing a positive self-identity.

In the following section, we present one mother’s story of how she utilised the steps in the CoL framework to develop her son’s self-determination, enabling him to self-advocate for his own needs and take charge of his own CoL.

8.3 What Can Be Done? Sara and Mitchell’s Story

Mum has helped me by letting me do more things by myself and letting me have a say in my life. This makes me feel happy and like I can have a more successful future. (Mitchell)

Parenting a child with autism is a journey that includes much joy, frustration, and hard work. Sara’s instinct told her early on that Mitchell’s development was not

progressing along typical lines. While other children played on the swings and the slippery slide in the park, Mitchell would spend his time lying on the ground, pushing the wheels on strollers backwards and forwards. He would spend hours rolling a ball down a slope, becoming distressed if his game was altered in any way. Their family life became very restricted and routine bound, as any deviation from the norm would cause a tantrum or much upset for Mitchell. Nobody was able to give Sara clear answers.

Mitchell is now 14.6 years of age. He was diagnosed with ASD at 2.5 years of age, and was assessed as having significant developmental delays in his social skills, self-help skills, fine motor skills and his overall communication, as well as speech and language skills. As a mother, Sara found it was an immense relief to finally have a definitive label for what she had been seeing. As daunting as it was, Mitchell's diagnosis helped Sara to seek out specialist support to help her understand ASD, and started both Mitchell and her on a journey towards identifying different goals and plans from the ones she had originally anticipated when Mitchell was born. Along the way, Sara learned about the CoL, and realised that this provided her with a model to help Mitchell to develop a vision and plan for his future. Since that time, Sara has worked with Mitchell in a variety of ways to develop his self-determination, including his self-awareness and self-advocacy skills. While the road has been a bumpy one, with many barriers along the way, there have been a number of small steps, critical people and strategies that have allowed Mitchell to develop into an increasingly independent, self-determined teenager with clear hopes and dreams, and a vision for his future. As he relates:

I want to do well at high school. I need to get good marks so I can go to university and study game design. Then I can study IT and learn how to make games for consoles, get a job, earn lots of money and be rich.

Even prior to his diagnosis, Sara's primary goal was for Mitchell to be happy in life and to reach his full potential, whatever that may be. Ultimately, she wants Mitchell to be as independent an adult as possible, with the confidence and self-determination to be an active participant in his community. Sara hopes Mitchell will have a fulfilling career, and establish social networks that provide both functionality and enjoyment. Over the past few years, Mitchell and Sara have discussed their collective hopes and dreams for his future. Together, they have regularly identified barriers that would prevent Mitchell from achieving these dreams, and brainstormed and planned specific goals and strategies to make these dreams become reality. Sara supported Mitchell to realise that there will be a number of steps he will need to face and achieve before his vision can be realised. His overall priorities will need to be broken into small, manageable goals and actions as he moves through high school, and later university. When working on these smaller goals, Sara has recognised the importance of remembering Mitchell's strengths and interests, in addition to his dislikes and triggers.

As Mitchell has matured, he has become more able to articulate his own vision and identify the priorities that are important to him. His current goal is to improve his self-help skills in order to fit in at high school and to achieve to a high standard

academically. He hopes to realise his 5-year dream of securing entry to university, where he wants to study IT, learn to make games for consoles and become very rich. With his mother's support, Mitchell has considered potential obstacles that will prevent him from reaching his goals, and has discussed with her how he might overcome them. Sara and Mitchell have recognised that the biggest potential barriers for Mitchell at this time are his high stress and anxiety levels. In order for him to be successful in his goal, Mitchell must learn to manage his anxiety and stress levels. When Mitchell was three, he and Sara made a 'calm kit' that contained a stress ball, a variety of stretchy lizards and animals, and small manipulative toys, which travelled between home, school and community settings. Over time, Mitchell and Sara have modified this strategy to suit his age. Currently, he utilises strategies such as having a piece of Blu-Tack in his pocket that he is able to squeeze, listening to music on his iPod, looking at a photo of his dog and having regular breaks built into his day. He has found this to be very effective, saying, "When I start to feel stressed there are things I can do. I can listen to music on my iPod, look at a photo of my dog, squeeze Blu-Tack that I keep in my pocket, or take a break."

Throughout Mitchell's life he has had a support network of school staff, friends, family and other professionals. This support team has performed the essential role of helping Mitchell to determine meaningful, appropriate strategies that will benefit both him and his family. He relates, "A good team helps me because it makes problems more minute. It helps me reach my goals better because I feel more encouraged and supported." From an early age, Mitchell has been supported and encouraged to make choices, advocate for himself and develop independence and self-help skills. Mitchell has always been a visual learner. With the team's support, Mitchell began to use simple visual schedules, made from visual symbols and incorporating a "finished box", to independently file tasks and activities he had finished. Mitchell also utilised visual symbols to make requests and communicate his needs. Choice cards allowed Mitchell to practise independently choosing tasks and making decisions, giving him some control over his life. Visual social stories with simple text were effective in helping him to understand concepts, rules and expectations of different social and school environments. Mitchell's visual schedules and social stories have gradually become more complex, and now contain predominantly text, with few images. They remain effective strategies to help ensure that Mitchell fully understands the expectations of different environments, thereby allowing him the best chance of success while minimising his stress and anxiety levels. In addition, Mitchell has always benefited from watching his peers, and as he has developed his social awareness, using them as models for his own behaviour. Peer-mediated instruction has become a powerful teaching and learning tool, as concepts and expectations become clearer to Mitchell when they are modelled by his peers.

As Mitchell has grown older, become more confident and developed his communication skills, his self-determination skills have taken a more sophisticated form. Mitchell now seeks to have his voice heard, and expresses a strong desire for a say in, and control over, his life. Although Mitchell finds oral communication to be stressful and confronting, with support from his mother, he has become adept at

communicating his needs and advocating for himself in alternative ways. He designs posters to let others know his needs, wants, challenges, interests and general information about himself. Before formal meetings, Mitchell and Sara brainstorm topics, ideas and strategies that they feel are important to share. Mitchell has moved from using Sara as 'his voice' to being able to record the information he wants to share on his iPad, or typing it on his laptop. He is learning that email is a powerful communication tool that, with practice, will be a manageable system he can use in the long term. As he relates, "It is my life. I want to have a say in my life. I am getting better at typing important information. It is a good feeling to have control over things."

Positive behaviour support has always been, and continues to be, critical to Mitchell's successful learning. As a young child, reinforcement for Mitchell was based on extrinsic rewards, which were given frequently. With encouragement and practice, Mitchell has learnt to self-evaluate and self-reinforce his own achievements. By setting goals and documenting the steps he takes to achieve these goals, Mitchell is now able to enjoy the intrinsic rewards of self-accomplishment and the personal satisfaction of a job well done. Mitchell's team has helped him to monitor his progress and to evaluate the effectiveness of the strategies that have been implemented. As he gets older, Mitchell is learning to evaluate his own progress and to revise strategies when needed. As Mitchell is rigid about the ways in which he learns, and tends to have difficulty generalising skills, behaviour and knowledge, he is provided with multiple opportunities to practise skills and strategies across contexts, thereby increasing the functionality of each priority skill he learns.

The strategies Sara introduced to Mitchell as a 2 year-old have changed as he has aged, gradually taking on a more socially and age-appropriate form. As a result, Mitchell is now a teenager with increased independence and self-management skills who, with support, is able to advocate for himself. Developing his skills in self-awareness, self-management, self-regulation and self-advocacy has been of tremendous benefit at high school, as Mitchell manages his daily school life, negotiates routines, makes choices and participates in extra-curricular activities. Using the CoL has enabled Sara and Mitchell to construct a plan that enables Mitchell to develop a sense of self-worth, feel positive about himself and become a successful learner, both academically and emotionally, as he works towards his ultimate goal and vision. Behind Mitchell's success has been a strong team of people who advocate, provide support and therapy, develop and implement strategies, and communicate regularly to ensure consistency and effectiveness of practices. Mitchell's desire and drive to fit into a society that is not always easy for him to understand is astounding. With continued support, Sara has every confidence that Mitchell will become a happy, independent, self-determined adult working to his potential while enjoying a high quality of life in his community.

8.4 Why Does This Work? Strategies for Parents to Promote Self-Determination

Mitchell's story illustrates what was achieved when one parent employed the elements of the CoL framework to help her son to develop his self-determination. Through this process, Sara was able not only to prioritise self-management and self-regulation as key skills that Mitchell would need to achieve his vision, but his engagement with her around the CoL enabled him to develop his self-determination as he identified his priorities and needs, and formulated a plan of action. Researchers have found that when children participate in their own education planning, their overall self-determination is increased, resulting in an improved level of skills needed to manage their life in different environments (Held, Thoma, & Thomas, 2004; Wehmeyer, Palmer, Lee, Williams-Diehm, & Shogren, 2011). Researchers have suggested that, even at an early age, parents can begin to develop their child's self-determination (Lee et al., 2006), by helping them to start to communicate their wishes while also building their capacity to identify their own strengths and needs.

By regularly discussing Mitchell's hopes and dreams for his future, Sara and Mitchell began to explore what it would take for Mitchell to become an independent, successful adult, designing games for consoles and living a fulfilling life. Over time, Sara was able to develop Mitchell's capacity to evaluate his own strengths and needs, to set specific goals and to identify the actions he could take to reach these goals. Sara helped Mitchell to learn to brainstorm the skills needed, and to break his goals into small, manageable steps, remembering his strengths, needs, goals, and learning style. He explains this process, "I feel I achieve things best when I break the main goal into many sub-goals. It helps me when I just have to manage one tiny task at a time." This approach is consistent with the Self-Determined Learning Models of Support and Instruction advocated by Lee et al. (2006) and Wehmeyer, Palmer and colleagues (2000). Similar to this model, Sara used the CoL to help Mitchell set goals for himself, take action to achieve the goals and then evaluate his progress and adjust his action plan if needed. Moreover, Sara not only assisted Mitchell in setting goals for himself, but provided him with opportunities to try new strategies and solve his own problems. Researchers consistently have emphasised that self-determination develops not just when individuals learn specific skills, but also through the opportunity to learn what works for them through trial and error (Eisenman & Chamberlin, 2001; Wehmeyer, Shogren, Zager, Smith, & Simpson, 2010). Most importantly, Sara helped Mitchell to connect the skills he learned to meaningful outcomes and to applying these skills to solving problems as he worked towards his goals. By doing this, Sara ensured that Mitchell was not just learning a set of rote skills, but was also developing strategies and knowledge that would help him to set and achieve goals in many stages of his life.

After helping Mitchell to identify his vision and priorities, Sara also began to facilitate Mitchell's self-awareness of his own strengths, interests and needs. Shore (2008) emphasises that self-awareness is the first step towards a person's ability to self-advocate. Shore (2004) also suggests that a fundamental flaw in most education

planning processes is that the child with ASD is marginalised as just one of many participants in a team. Shore advocates that students be placed at the centre of the process, as they are the people who will most benefit from the plan. Playing an integral part in designing their own education plans prepares students with ASD to become advocates for their own needs as they move out of school and into the adult world. This is evident in Mitchell's story. As Sara worked with him and Mitchell developed his abilities to articulate his wishes and desires, he began to take a more active role in advocating for himself at school and home. Sara also found that Mitchell was responsive to instruction in choice-making and problem-solving, even from an early age. This is consistent with research that has found even young children can identify their own goals and make choices about actions and strategies that will help them to achieve those goals (Shogren & Turnbull, 2006).

As Mitchell moved through primary school and into adolescence, Sara was able to identify strategies that had helped him in the past, and worked with him to reflect and revise these strategies as needed. This ranged from changing his earlier strategy of using sensory toys to manage his anxiety to keeping a small object in his pocket or using music to control his agitation and self-calm. Additionally, Sara involved Mitchell in creating his own strategies throughout his childhood. This is consistent with the research on effective interventions that have been demonstrated to be beneficial in the development and promotion of the key skills linked to self-determination (Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009; Eisenman & Chamberlin, 2001; Fullerton & Coyne, 1999; Karvonen et al., 2004; Wehmeyer et al., 2013). Researchers emphasise that selected strategies should be appropriate to their child's developmental ability, strengths, needs, goals and learning style, and reflect family values, beliefs and dynamics (Kleinert, Harrison, Mills, Dueppen, & Traylor, 2014; Shogren & Turnbull, 2006). As self-determination is a developmentally evolving skill set, with increased benefits linked to longer intervention times, individuals with ASD are more likely to become self-determined adults if parents begin building their skills in the early years, continuing throughout their child's development (Eisenman & Chamberlin, 2001). Palmer (2010) terms this a lifespan approach to self-determination. A visual model of the lifespan view of self-determination is presented in Fig. 8.2.

Sara and Mitchell identified a variety of interventions that could help Mitchell to learn the skills he needed to self-regulate and self-manage in different learning environments. Sara's research on ASD and her use of the CoL to evaluate the impact of past strategies helped her to suggest strategies such as social stories, peer-mediated interventions and self-management techniques that had an evidence base and were most likely to be effective in helping Mitchell to reach his goals. As researchers suggest, parents are generally their child's first teachers, and are well placed to help their child to develop the specific skills related to self-determination (Lee et al., 2006; Wehmeyer, 2014). Parents should support the establishment of abilities in these areas over time by structuring their child's home environment, and providing multiple, ongoing opportunities for their child to practise skills within natural environments (Palmer, 2010). Strategies and approaches will vary across an individual's lifespan as they develop skills, and their strengths, needs and goals change (Weir et al., 2014).

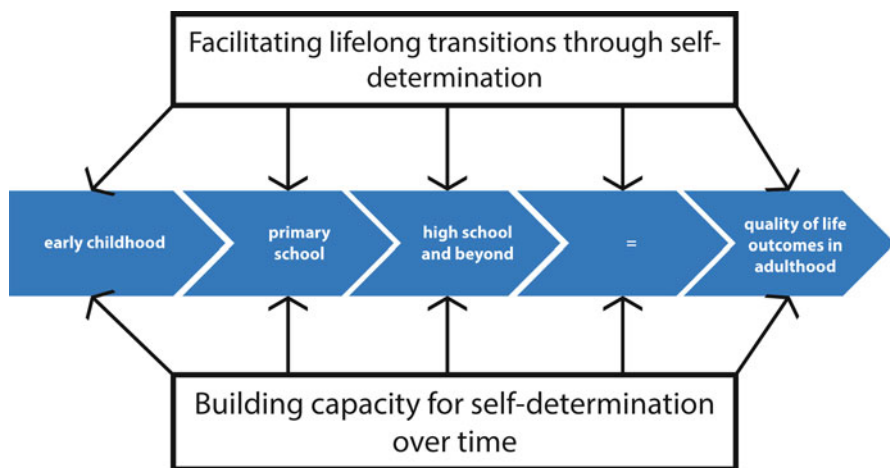


Fig. 8.2 A lifespan view of self-determination

Efforts to promote self-determination are more likely to be successful when collaborative partnerships are formed (Lee et al., 2006; Palmer, 2012). Throughout Mitchell's life, he has had a support network of school staff, friends, family and other professionals who, along with Mitchell himself, have made up an essential team that works together and allows Mitchell to develop into a teenager with ever-growing self-determination. Mitchell's team helped him to monitor his progress, set achievable goals and establish effective strategies and supports, providing a model for Mitchell to follow. This unified approach remains critical in ensuring the steps towards reaching Mitchell's goals and long-term vision are based on accurate information, effective communication, thoughtful planning and consistency.

When provided with strategies, instruction, guidance and adequate support, researchers have established that individuals with varying abilities and needs can learn the skills associated with self-determination (Palmer, 2010; Palmer & Summers, 2012). Sara's use of evidence-based strategies with Mitchell from an early age has resulted in a teenager who can now set goals for himself, communicate his strengths and needs, self-advocate for supports and strategies that will help him and solve problems in his daily life. These skills have been of tremendous benefit to Mitchell as he has faced new challenges in high school, and has enabled him to be an active participant in extra-curricular activities. Using the CoL has allowed Mitchell to develop a sense of self-worth, and to become a successful learner—both academically and emotionally—as he works towards his goals and ultimate vision. While the strategies used with Mitchell have been effective for him, parents need to consider the strategies that are best suited to their own child and family.

Sara has also been on a learning journey. Her use of the CoL has not only enabled her to facilitate Mitchell's self-determination in identifying his future vision and his plan to achieve this vision; it has also empowered her to help other parents to work with their children. Sara has translated her learning into key strategies that parents can utilise to help their children develop the component skills of self-determination. These are presented in Table 8.2. Researchers have identified a range of individual

Table 8.2 Strategies to promote the components of self-determination

<p>Make informed choices/decisions</p> <ul style="list-style-type: none"> • Model choice-making—think out loud as you make decisions (Weir et al., 2014). • Allow the child to choose toys, outings, food, clothes and after school/leisure activities as appropriate—use supports as necessary (e.g. visual supports, PECS symbols, choice boards, alternative communication) (Lee et al., 2006; Palmer, 2010; Palmer & Summers, 2012). • Begin by offering limited options, then gradually increase the number of options as the child's skills improve (Loman, Vatland, Strickland-Cohen, Horner, & Walker, 2010). • Involve the child in family discussions and decision-making, encouraging them to express opinions and ask questions (Wehmeyer, Davis, & Palmer, 2012). • Guide the child to make good decisions and to take responsibility for outcomes—ask questions that allow them to anticipate consequences and possible outcomes (Lee et al., 2006; Palmer, 2010). • Reflect with the child on decisions and outcomes—it is okay for the child to make mistakes and learn from these. Share examples from their own life (Weir et al., 2014).
<p>Set and attain goals</p> <ul style="list-style-type: none"> • Help the child to set realistic goals from early childhood, and establish the steps needed to work towards these (Wehmeyer et al., 2012; Weir et al., 2014). • Begin with very short-term goals over a day or week to promote success—provide visuals to represent goals and the steps or plan to achieve them. Display these where the child can easily and frequently see them (Carter, 2012; Weir et al., 2014). • Gradually help the child to set more complex goals as their skills and confidence increase—help them to break these into small steps and to set priorities. Encourage them to ask for help as needed (Lee et al., 2006; Weir et al., 2014). • Help children to identify potential barriers to goals, and to consider supports they may need to overcome these (Carter, 2012; Lee et al., 2006). • Support the child to become a partner in their education, being actively involved in educational meetings, decision-making and planning. Find ways for them to communicate to have their voice heard (Grigal et al., 2003; Karvonen et al., 2004; Wehmeyer, Agran, & Hughes, 2000; Wehmeyer et al., 2011; Wehmeyer & Schwartz, 1997). • Use person-centred planning tools such as Planning Alternative Tomorrows with Hope (PATH) or Making Action Plans (MAPS) to help the child set goals and plan for their future. (Visit http://trainingpack.personcentredplanning.eu/index.php/en/inclusive-training-course/module-5 for more information.)
<p>Operate with self-knowledge and awareness</p> <ul style="list-style-type: none"> • Help children to recognise their interests, strengths, limitations, needs, likes and dislikes (Carter, 2012; Lee et al., 2006). Help them to communicate these to others (e.g. through a drawing, or a poster they make on the computer). • Allow the child to participate in activities based on their strengths and interests (Weir et al., 2014). • Help the child to become aware of how their behaviour impacts others. Encourage self-reflection and self-evaluation. Allow the child to take responsibility for actions and decisions—help them to plan future decisions accordingly (Lee et al., 2006). • Teach self-management strategies, including strategies for self-calming (Carter, 2012).

(continued)

Table 8.2 (continued)

<p>Problem-solve</p> <ul style="list-style-type: none"> • Model problem-solving strategies in your own life (Weir et al., 2014). • Help the child to identify barriers, and to develop strategies and supports to prevent or overcome these—write or draw problems and solutions so they are visible (Carter, 2012). • Use visuals to directly teach problem-solving (e.g. social stories) (Weir et al., 2014). • Use appropriate media and books to start discussions about problem-solving (Carter, 2012). • Help the child to identify the magnitude of a problem and appropriate reactions (Weir et al., 2014). • Support the child to solve problems—ask questions and provide choices of possible solutions to support the process of logical problem-solving (Lee et al., 2006; Weir et al., 2014). • As the child becomes more skilled, allow them to solve problems on their own, intervening when necessary (Weir et al., 2014). • Let the child know that they can ask you for assistance (Weir et al., 2014). Model asking for help (Carter, 2012).
<p>Self-regulate behaviour</p> <ul style="list-style-type: none"> • Model and teach the child how to manage their feelings and behaviour. Role-play with them. • Use social stories to teach differentiating appropriate from inappropriate behaviour, as well as management strategies (Palmer, 2010). • Allow the child to reflect on and evaluate their behaviours, and take responsibility for both their successes and failures (Wehmeyer et al., 2012). Encourage them to consider choices they will make next time (Weir et al., 2014). • Reinforce appropriate behaviours (e.g. sticker chart, verbal praise, preferred activity) (Weir et al., 2014). • Give consistent consequences for inappropriate behaviours (Weir et al., 2014). • Introduce strategies to allow the child to self-manage their behaviour (e.g. calming techniques to use when stressed, a weighted lap bag to use when restless) (Weir et al., 2014).
<p>Demonstrate independence</p> <ul style="list-style-type: none"> • Support exploratory activities—allow the child to take safe risks and explore their world. Let go as the child develops confidence (Wehmeyer et al., 2012). • Create visual schedules with the child, which they can follow to independently complete daily tasks. Encourage them to self-monitor their progress. Start simply—for example, use a picture strip with one or two pictures; allow the child to file pictures in a “finished box” as completed. Gradually, as the child is ready, make strategies more complex—for example, a list of homework tasks that can be ticked off when completed. • Let the child decide on a plan they feel will work for them—consider the supports they will need. • Talk with the child about possible reinforcements, ultimately encouraging self-reinforcement. • Scaffold tasks for the child, gradually removing support as they become more confident and capable (Weir et al., 2014).

(continued)

Table 8.2 (continued)

Self-advocate and act in an empowered way
<ul style="list-style-type: none"> • Model advocacy and effective communication—provide support for the child to gradually increase their own self-advocacy skills (Palmer & Summers, 2012). • Encourage the child to talk about their feelings, needs and wants (Carter, 2012). • Encourage the child to ask questions and express opinions. Encourage participation in family discussions and decision-making (Davis & Wehmeyer, 1991). • Model self-worth and confidence to the child (Davis & Wehmeyer, 1991). • Assist the child to identify information they would like to share at educational meetings, and support them to find ways to communicate this (e.g. information recorded on a iPad, or typed on a laptop, be 'their voice' when necessary) (Palmer, 2010). • Give the child a chance to be the 'leader' (e.g. in games, helping a younger child, sharing a particular skill) (Weir et al., 2014).

and environmental variables as barriers to the successful promotion of self-determination. Sara identified the barriers that might impede Mitchell's progress or serve as an obstacle for other parents and individuals with ASD. This allowed her to proactively identify a range of strategies that would help Mitchell and others to overcome these barriers. Collectively, these barriers provide reasons why the value placed on self-determination by both parents and educators is not always translated into practice, resulting in lower levels of self-determination for individuals with disabilities (Carter et al., 2013a; Grigal, Neubert, Moon, & Graham, 2003; Wehmeyer, Agran, et al., 2000). Parents should remain mindful of potential barriers in order to overcome or minimise them. Table 8.3 provides suggestions of supports and strategies parents can consider to address potential barriers, and to successfully facilitate their child's self-determination.

8.5 Conclusion

Research has shown that parents play a critical role in the promotion of self-determination for their children with ASD. Using the CoL enabled Sara and Mitchell to work together to develop a plan to help Mitchell achieve his future vision, and to develop Mitchell's self-determination skills throughout the process. Mitchell and Sara's story illustrates that parents can begin to develop their child's self-determination from an early age, and continue to progress their skills as they move from early childhood into adolescence, and eventually into adulthood. This will enable children to receive the many benefits associated with self-determination, and to utilise these skills to learn and solve problems throughout their lives. In addition,

Table 8.3 Suggestions for overcoming potential barriers

Barriers	Strategies
<ul style="list-style-type: none"> Individuals setting unrealistic, unachievable goals (Kleinert et al., 2014). 	<ul style="list-style-type: none"> Help the child set high yet realistic goals and expectations, based on individual strengths, needs, and dreams (Wehmeyer et al., 2012). Help the child rethink a goal or the action plan for reaching the goal, if necessary (Lee et al., 2006).
<ul style="list-style-type: none"> Most parents highly value self-determination skills, but report their children are generally not being taught or performing these well (Carter et al., 2013a; Grigal et al., 2003). Families want to support self-determination but are unsure how to do so (Peterson-Bese, 2012). 	<ul style="list-style-type: none"> Seek information and education about self-determination for families (Jackson, 2012). Attend appropriate workshops. Find manageable, meaningful strategies suited to the family and child. Structure/ modify the home environment (e.g. choice boards, visual timetables, goals displayed).
<ul style="list-style-type: none"> Overall, educators rate instruction in self-determination as important, although their level of instruction may not match (Grigal et al., 2003; Wehmeyer, Agran, & Hughes, 2000). Teachers report a lack of administrative support/authority/responsibility, limited knowledge of interventions and difficulty integrating self-determination content into their teaching (Karvonen et al., 2004). 	<ul style="list-style-type: none"> Be actively involved in the child's education (Loman et al., 2010; Wehmeyer et al., 2012). Liaise with educators—keep lines of communication open to share information about the child, and their goals/dreams (Palmer, 2012). Talk to the principal about professional development opportunities for staff around the concepts and application of self-determination (Loman et al., 2010). Share resources and strategies you are using at home—educators may be able to incorporate these into their programs (Loman et al., 2010).
<ul style="list-style-type: none"> Minimal or no self-determination related goals in student's Individual Education Plans (IEPs) (Grigal et al., 2003; Wehmeyer, Agran, & Hughes, 2000). 	<ul style="list-style-type: none"> Help the child to understand the purpose of educational meetings, and explain that they are an important member of the team. Their voice and dreams need to be heard. Encourage the child to consider personally meaningful goals ahead of time, and determine how these can be shared (e.g. typed up, recorded on iPad). Attend meetings with the child—share information and be an active participant in decision-making (Carter, 2012).
<ul style="list-style-type: none"> Parents and educators of children with severe/profound disabilities, generally place less importance on these children learning self-determination skills than parents of children with mild/moderate disabilities (Carter et al., 2013a; Shogren et al., 2012; Wehmeyer, Agran, & Hughes, 2000). 	<ul style="list-style-type: none"> Remember that everyone can engage in self-determination, regardless of type or severity of disability (Wehmeyer et al., 2013). Help the child to set goals and visions—advocate with the child to make these a reality. Implement strategies to gradually work towards increased self-determination.

(continued)

Table 8.3 (continued)

<ul style="list-style-type: none"> • Specific student characteristics, such as challenging behaviours, communication and social deficits (Carter et al., 2013a; Eisenman & Chamberlin, 2001; Karvonen et al., 2004). 	<ul style="list-style-type: none"> • Find and implement strategies for the child to manage their stress, anxiety and fears. • Use visual aids (e.g. social stories, comic strips) to increase socially appropriate behaviours (Loman et al., 2010). • Find a way for the child to communicate—be “their voice” when necessary. • Be actively involved in the child’s education—family involvement results in fewer incidences of high-risk behaviours (Loman et al., 2010; Wehmeyer et al., 2012).
<ul style="list-style-type: none"> • A lack of time to teach self-determination (Eisenman & Chamberlin, 2001; Fullerton & Coyne, 1999; Wehmeyer, Agran, & Hughes, 2000). 	<ul style="list-style-type: none"> • Provide opportunities for the child to practice self-determination in everyday activities. • Talk to teachers about embedding the component skills of self-determination into daily lessons (Loman et al., 2010).
<ul style="list-style-type: none"> • Failure of individuals to maintain self-monitoring/self-organisation skills (Fullerton & Coyne, 1999). 	<ul style="list-style-type: none"> • Help the child practise these skills in meaningful ways for them (e.g. computer spreadsheets, tick boxes, visual reminders/ timetables, social stories).

by using the CoL, parents and their children can identify appropriate strategies that will help them to develop the component skills related to self-determination and to provide them with opportunities to practise these skills in meaningful real-life contexts. More importantly, parents and children with ASD can work together to identify and develop strategies to address potential barriers that may prevent them from achieving their goals.

It is clear that, with the support of his mother and his support team, Mitchell has developed into a self-determined teenager, striving to meet his goals, dreams and ultimate vision. He is on the road to becoming a happy, independent, productive, self-determined adult working to his potential, enjoying quality of life outcomes. With ongoing support and continued opportunities for the development of self-determination, Mitchell has every chance of successfully completing high school and university, and fulfilling his dream of designing games for consoles.

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