



Agencies and Professions in the Provision of Care

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Background

With the move away from institutionalisation to community participation, inclusion, human rights, and person-centred supports, the need for systems and services to meet the needs and aspirations of people with intellectual disability (ID) and their families is essential. However, supporting people with ID who are described as having complex needs is often regarded as challenging to systems, services and individuals, leading to difficulties in having those needs met effectively. Supporting people with ID and complex needs requires multiple safeguards as well as service coordination between multiple agencies and service systems. This chapter provides an overview of the issues associated with complex needs for people with ID, and best practices in supporting them.

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What Is Meant by Complex Needs?

There is inconsistent understanding of what is meant by “complex needs” and it is often used to describe people with ID who have additional needs (Cooper & Ward, 2011) or multiple needs that span issues, services and systems (Rankin & Regan, 2004). *Complex needs* is a term described by Rankin and Regan (2004) as:

“A framework for understanding multiple, interlocking needs that span health and social issues. People with complex needs may have to negotiate a number of issues in their life, for example learning disability, mental health problems, substance abuse. They may also be living in deprived circumstances and lack access to suitable housing or meaningful daily activity. As this framework suggests, there is no generic complex needs case. Each individual with complex needs has a unique interaction between their health and social needs and requires a personalised response from services.” (p.i)

Accordingly, there is no universal understanding or definition of the term complex needs. For instance, a person may have complex *disability support* needs that are associated with impairment, such as having profound intellectual and multiple disabilities. In other cases, a person may have complex needs that are associated with having needs that span services and systems, not just disability services. As proposed by Rankin and Regan (2004) complexity of need can involve multiple and interlocking problems that have

depth (severity of need) and/or *breadth* (range of need). Thus, complexity of need can arise from: (1) the severity of impairment and disability for the individual and/or (2) needs that require system and sector coordination due to multiple needs (such as co-morbidity), circumstances (abuse, neglect, trauma), or complex situations (such as inadequate appropriate accommodation). Table 13.1 presents some examples of the depth and breadth of complex needs for people with ID.

However having breadth or depth of need alone may not be complex. While some people with ID have severe and pervasive disability support needs, or multiple needs that span organisational boundaries, where adequate, appropriate and coordinated services and supports are readily available meeting those needs may not be complex. A person’s support needs can also become complex unpredictably especially where crisis arises such as carers’ or services unexpectedly no longer able to provide care or where challenging behaviour results in placement breakdown, leading to potential homelessness or inappropriate

accommodation. Thus, complexity of need is associated with any difficulties in having those needs met. Such difficulties include the timely availability of required supports and services or systems that are able to work together in a responsive and integrated fashion.

Service and System Responses and Outcomes for People with Intellectual Disability and Complex Needs

While the vision for people with complex needs is the same as for everyone—inclusion and participation, independent living and paid work, people with ID and complex needs often experience lower levels of quality of life, adverse life outcomes, and social isolation. They are disadvantaged in health, housing, independent living and employment (Cooper & Ward, 2011) and there is an overrepresentation of children with disabilities in child protection systems (Hill, 2012) with a contributing factor being increased likelihood of being abused and neglected (Horner-Johnson & Drum, 2006; Spencer et al., 2005).

Rankin and Regan (2004) state that those with the greatest (most complex) needs are at greatest risk of getting the least services. Also, that where care systems fail to recognise the interconnected nature of people’s complex needs, they fall through the gaps between services. For people with complex needs there can be a lack of supports coordination, fragmentation of services, and poor information flow at government and local service level (Rosengard, Laing, Ridley, & Hunter, 2007). Accordingly, service systems and processes need to ensure that complex needs are met in an integrated fashion.

There are a number of factors that contribute to poor outcomes for people with ID and complex needs (Collings, Dew, & Dowse, 2016; Mansell & Beadle-Brown, 2012 ; Rosengard et al., 2007). These include:

- People with complex needs and their families/ carers being daunted by complex service systems that span numerous agencies and are

Table 13.1 Examples of complex needs associated with severity of need (depth) or range of need (breadth)

Severity (depth)	Range (breadth)
Intense and pervasive level of support needs associated with profound intellectual and multiple disabilities	Residing in inappropriate accommodation such as young people in residential aged care, long stay hospital settings or precarious and unstable accommodation
ID and high physical, and/or medical needs	Multiple, socio-economic disadvantage and social isolation
ID and challenging behaviour	Social exclusion with few opportunities for engagement in meaningful activities
Multiple and co-occurring disabilities and conditions	Co-existing conditions with ID such as mental health, alcohol, and/or drug misuse
Mild to moderate ID and a history of offending (forensic disability)	A background of trauma or neglect
Children with ID in out of home care with high physical disability or extreme challenging behaviours	

difficult to navigate, know what is available and how to go about gaining access (Mansell & Beadle-Brown, 2012; Rosengard et al., 2007). Gaps in required services and supports can occur where there is a lack of collaboration and integration by services and systems or inability to meet complex needs such as co-occurring mental health and intellectual disability. Other gaps and challenges people with ID and complex needs face arise where services and systems are too inflexible to respond to a breadth and depth of needs (Collings et al., 2016) and have administrative or bureaucratic barriers that must be crossed.

- Not being able to access the services or ending up in inappropriate services due to the nature of the person complex needs. Complex needs associated with severe disability, co-occurring mental health problems, autism and/or extremely challenging behaviours can lead to higher levels of out of area placement, associated with higher costs, lack of choice and control, social isolation and difficulties in transitioning back to their community of origin (Mansell & Beadle-Brown, 2012; Pritchard & Roy, 2006; Rosengard et al., 2007). People with complex needs are more often in long-stay hospital settings, “stuck” due to a lack of supported housing that meets their needs, level of risk and level of support required to live in the community (Sergeant & Brown, 2004). Additionally, they can find themselves in group accommodation where there is incompatibility between co-residents including resident to resident physical and verbal assault resulting in people with ID reporting that they feel unsafe in their home environment (Gatfield, 2016).
- Barriers to accessing required services and systems due to inflexible service criteria that may use ID or challenging behaviour as exclusion criteria (Mansell & Beadle-Brown, 2012; Rosengard et al., 2007) or have obscure or inconsistent entry criteria. Fragmented and siloed service systems that lack coordination and integration limit the person’s ability to receive coordinated service provision and have

their range of needs met (Mansell & Beadle-Brown, 2012; Rosengard et al., 2007).

- Resource constraints that prevent early and proactive supports, leading to crisis driven responses. Examples of such resource constraints include lack of respite care or short breaks for families or early intervention for younger children with challenging behaviour (Mansell & Beadle-Brown, 2012; Rosengard et al., 2007).

As can be seen, services and systems are critical to the quality of life outcomes for people with ID and complex needs. Therefore disability agencies and professions in the provision of supports to people with complex needs must be able to assist people with ID and their support networks to negotiate service systems to ensure needs are met and human rights are safeguarded.

Special Case: Family Crisis Resulting from Poor Service Response

While caring for a person with ID (regardless of age) can be a rewarding experience for parents and families (e.g. Corman, 2009 ; Grant, Ramcharan, McGrath, Nolan, & Keady, 1998 ; Hastings, Beck, & Hill, 2005), it can also be challenging for a multitude of reasons including the restrictions placed on the family’s opportunities for social engagement (e.g. Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009 ; Edwards, Higgins, & Zmijewski, 2007), and the long-term impact on the physical and/or mental health of parents in particular (e.g. Burke, Patton, & Taylor, 2016 ; Burton, Lethbridge, & Phipps, 2008 ; Emerson, Robertson, & Wood, 2004 ; Miodrag & Hodapp, 2010). Consequently, some parents and families can experience a “crisis of caring” resulting in a request for a disability service to take over the day-to-day care of their family member with ID (*out-of-home care*).

Typically families requiring out-of-home care for their child with ID will go on to a waitlist for accommodation services in their jurisdiction. When a placement becomes available, the family

usually works in collaboration with the service provider to implement planned transition to the accommodation arrangements.

However, there are instances where families seek immediate, unplanned emergency out-of-home care for their family member with ID as a result of family crisis. In these cases, the family member is often placed in temporary, emergency accommodation until the family agrees to resume the caring role, or an accommodation service is sourced if the family is unwilling to provide care on a continual basis.

Illustrative Case Study

Sam, a 12-year-old boy with autism and Down syndrome, lives at home with his mother. His mother wants him to continue to live at home; however, she needs assistance due to Sam's high levels of challenging behaviours. In-home supports are funded as well as some clinical services, including speech therapy to increase his communication skills. However his aggression has been escalating and Sam's mother does not believe that she can keep her other children safe from harm. While Sam has been supported in the family home by a disability service provider, that provider withdrew involvement due to assaults of workers and a lack of behaviour assessments or supports in place. Despite considerable efforts, a new service provider could not be engaged. A serious incident where Sam injured his mother led to the police being called and Sam being removed from the family home. Sam's mother refused to have him return home and crisis meetings were called by the government agency to find emergency accommodation. Sam lived in a number of short-term respite accommodation houses for 6 months until a longer term, more stable accommodation placement could be found.

Multiple studies have been conducted to investigate the reasons why families have sought out-of-home care for a family member with ID, with only a handful of studies specifically focusing on families who have sought unplanned, emergency out-of-home care during a period of family crisis. There is a noticeable overlap in the reasons reported by families who sought planned out-of-home care, and the families who sought immediate, emergency out-of-home care, with three groupings evident across the identified reasons. The first grouping relates to the *family member* with ID, who typically presents with complex needs due to severe disability, limited communication, challenging behaviour, and/or health problems (e.g. Ellem, Wilson, & Chenoweth, 2016; Essex, Seltzer, & Krauss, 1997; Grey, Griffith, Totsika, & Hastings, 2015; Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999; McConkey, Nixon, Donaghy, & Mulhern, 2004; Nankervis, Rosewarne, & Vassos, 2011). The second grouping specifically relates to the *parent and other family members*, with parent inability to cope with the parenting role (e.g. Alborz, 2003; Mirfin-Veitch, Bray, & Ross, 2003; Victorian Equal Opportunity and Human Rights Commission [VEOHRC], 2012), poor parent health and/or mental health (e.g. Duvdevany & Vudinsky, 2005; Ellem et al., 2016; Nankervis et al., 2011), parental concern for their other children (e.g. Hostyn & Maes, 2007; Llewellyn, McConnell, Thompson, & Whybrow, 2005; VEOHRC, 2012), family conflict (e.g. Ellem et al., 2016; Hostyn & Maes, 2007; Llewellyn et al., 2005; McConkey et al., 2004; Nankervis et al., 2011), and financial strain (e.g. Chui & Hung, 2006; Ellem et al., 2016) cited as reasons leading to the decision to seek out-of-home care (or emergency out-of-home care).

The last grouping specifically relates to the *supports available* to the family to upkeep the caring role. Within this grouping, what is evident is that families who have sought out-of-home care (or emergency out-of-home care) are *reliant* on formal services available through the disability service system in order to cope with the caring role, mainly as a result of social isolation or a lack

of social supports available to the family (e.g. Hostyn & Maes, 2007 ; Mirfin-Veitch et al., 2003 ; Nankervis et al., 2011). Because of this overreliance on formal supports (especially respite care), these families report significant unmet need for services, which then influences their ability to cope with the caring role on a long-term basis (e.g. Ellem et al., 2016 ; Llewellyn et al., 2005 ; McConkey, McConaghie, Barr, & Roberts, 2006 ; Mirfin-Veitch et al., 2003 ; VEOHRC, 2012). In addition, many families who have sought out-of-home care (or emergency out-of-home care) indicated that the services made available to them were of poor quality in their opinion (e.g. poor support practices in use, poor staff), resulting in more stress for the family as opposed to a sense of relief and assistance (e.g. Mirfin-Veitch et al., 2003 ; VEOHRC, 2012).

Coupled together, the known reasons for families to seek out-of-home care (or emergency out-of-home care) paint a picture of families who are experiencing many stressors, demands and hardships related to providing not only for the family member with ID, but the entire family. However, it should be noted that not all families caring for people with ID who have high support needs will seek out-of-home care. This is where formal service delivery and access to supports is crucial to families, and cannot be underestimated. Resilience is a notion widely discussed in the psychology research literature, with *parental resilience* recently defined by Gavidia-Payne, Denny, Davis, Francis, and Jackson (2015) as a parent's capacity to deliver quality parenting and care to their children despite adverse circumstances within the family. Gavidia-Payne et al. (2015) identify many protective and risk factors that are associated with parental resilience, with social connectedness being a crucial protective factor for the family (i.e. parental resilience is associated with greater levels of support). Also, resources such as social support and access to effective formal services allow a family to maintain their desired family social system, and if these resources are limited, family crisis can ensue (McCubbin & Patterson, 1983). Given the above, when it comes to conceptualising family crisis within the disability service system, the

role of the service system and the supports available to a family cannot be neglected.

So what can agencies and professionals do to prevent family crisis? Recommendations from the research literature around the early identification of parents at-risk of seeking emergency out-of-home care (Nankervis et al., 2011; VEOHRC, 2012) have merit. Specifically, the VEOHRC (2012) advocate that systems must be put in place to accurately *identify* families at-risk of seeking emergency out-of-home care, with a focus on providing coordinated, early intervention supports to prevent these families from reaching a stage where they feel that crisis-driven, out-of-home care is their only viable option to cope. These recommendations for future practice were endorsed by parents who had sought emergency out-of-home care in the past (Vassos, 2017). Early identification of families at risk of crisis constitutes a proactive and prevention-based approach to ensure assessment of need processes that inform service allocation and support planning.

The Role of Agencies and Professions in the Provision of Care to People with ID Who Have Complex Needs

Systems, agencies and professionals are critical in supporting families and ensuring that people with ID's high and complex needs are appropriately met. The challenges in accessing the supports and services required must be addressed to avoid poor outcomes such as social isolation and poor quality of life. This necessitates an understanding of the depth and breadth of a person's needs and the implementation of a carefully targeted approach that understands and addresses the interaction between those needs and those that span systems (Rankin & Regan, 2004). An integrated approach to understanding complex needs and spans systems and processes enables the early identification of supports and interventions required to prevent crisis or other adverse outcomes.

The essential elements for such an integrated and coordinated approach to meeting complex

needs are listed below (Carnaby & Pawlyn, 2009; Hudson, Dearey, & Glendinning, 2004; Rankin & Regan, 2004; Rosengard et al., 2007), and will be discussed further in this section:

- Understanding the needs of the person, especially their complexity.
- Access to information and advice.
- User and carer empowerment and co-design.
- Single point entry and access to required supports.
- Coordinated service delivery.
- Integrated systems.
- A proactive and preventative approach.
- Monitoring and measuring outcomes.

Understanding the Needs of the Person

In order to understand the person, a comprehensive, person-centred approach is essential, as well as understanding what constitutes complexity for the individual and their support network. An understanding of the whole person needs to be at all stages of service delivery and requires an exploration of the breadth, depth and interaction between needs (Rankin & Regan, 2004). By understanding the person and the basis of their complex needs, services can be tailored to the person, their circumstances and their needs. This requires comprehensive needs assessment that considers the whole person, and enables a person-centred approach where services are designed around the person rather than the person “fitting in” with the services that are on offer (Hudson et al., 2004; Rankin & Regan, 2004; Rosengard et al., 2007). Service planning and delivery should be designed to meet the needs of the person, not those of the service or system.

Access to Information and Advice

In order for people with ID to have their needs met, they need to be aware of what is available to them, both disability specific and mainstream. Commonly there is a lack of accessible informa-

tion for people who have complex needs, and they have low awareness of what is available (Rosengard et al., 2007). Therefore information and advice for people with ID and their families must be accessible and understandable (e.g. written in Easy English, using plain language; translated into other languages), as well as readily available.

User and Carer Empowerment and Co-design

With human rights generally, and the UN Convention on the Rights of Persons with Disabilities (2006) specifically, giving primacy to a person’s will and preferences must be actively supported (Carney, 2015). The best outcomes are where the person with ID is involved in planning their supports recognising and building on their strengths as well as those of their support network. As such, users of social services need to be recognised as co-producers of their own care (Rankin & Regan, 2004), and the experts about their own lives (Hudson et al., 2004). Involving people with ID and their carers at all levels of service planning, development and delivery as well as facilitating access to advocacy as required recognises the contribution the person with ID can make, and views them as the experts (Rosengard et al., 2007).

For people with complex needs and ID, choice, control and decision-making are important; however, due to the complexity of their needs (including severity on ID), decisions about the person’s life may be undertaken by others, often under formal arrangements for substitute decision-making such as guardianship. Supporting a person with ID to participate in decision-making includes involving them right at the start; avoiding a tokenistic approach; allocating the necessary time, resources and commitment; and being clear about what exact decisions can be made (Hudson et al., 2004).

There is a growing focus on supported decision-making in response to overreliance on formal systems of substitute decision-making (Jameson et al., 2015). Supported decision-

making aims to empower people with cognitive impairments, including ID, by recognising that they are the decision-maker, but are provided support for decision-making from one or more others from their network of support, giving them the assistance they need (Kohn, Blumenthal, & Campbell, 2012). This support is individualised to the person (Jameson et al., 2015) and may involve explaining issues and options in ways that are understandable to the person, or interpreting the individual's words or behaviours to identify preferences (Kohn et al., 2012). People with ID who exercise greater self-determination and have more control over their lives have greater independence and quality of life (Jameson et al., 2015). A reciprocal model emphasises the contribution that can, or could be made by the people in receipt of services and support (Hudson et al., 2004), recognising them as valued persons who have valued social roles. A person's level of participation in decision-making can range from being provided with information about decisions to be made, services and supports available, through to the individual having the authority and ability to make decisions for themselves (Hudson et al., 2004).

Single Point Entry and Access to Required Supports

Navigating complex and fragmented service systems is a significant barrier to people having their complex needs met. Users of service systems should be able to access the entire system of support through a single point of entry (Rankin & Regan, 2004). Single point entry can involve the ability to access appropriate services to meet different needs, information about available services (Rosengard et al., 2007) without the need to identify and then have contact with multiple agencies. Additionally, multiple legitimate routes to a variety of services from a variety of sectors that reflects diverse needs and circumstances are required (Hudson et al., 2004).

Coordinated Service Delivery

For a person with ID and complex needs in the context of service fragmentation, the roles of "service navigator" (Rankin & Regan, 2004; Rosengard et al., 2007) or "systems wranglers" (Madden, Fortune, Collings, & Madden, 2014) are needed to assist the person with ID and their family to identify needs and goals, plan their supports, and coordinate access to the required supports and services. Such a role needs to have knowledge of both specialist and mainstream services, as well as knowledge of specific issues, such as dual disability (Madden et al., 2014; Rankin & Regan, 2004). Case management is used to address situations where a person has complex needs and a single service response will not be adequate (Gursansky, Kennedy, & Camilleri, 2012). An essential element is a skilled coordinator, working across sectors and services, who is an active negotiator who understands the needs of the person who acts as the central point of linking services and other sectors (Madden et al., 2014).

Integrated Systems

An integrated systems approach is based on a holistic view of the person and a comprehensive, whole system model where all relevant services are involved in joint processes for information sharing (with the person's/family's permission) to prevent service users having to repeat information, facilitate pathways through services (Rosengard et al., 2007). Joined up and integrated service systems do more than just share information. They serve to enhance the supports provided by each other as well. Joint working is essential in order to have a "whole systems" approach (Hudson et al., 2004) rather than partnerships that are ad hoc or fragmented. In an integrated system working relationships are built around shared service user goals rather than organisational frameworks and existing systems (Hudson et al., 2004).

A Proactive and Preventative Approach

Early and proactive supports to meet identified needs and prevent escalation and crisis is essential. This implies identification and provision of supports and services to meet the needs of adults and children with ID in a timely manner rather than crisis driven responses. For example, children with intellectual disability are at increased risk of developing emotional and behavioural difficulties at an early age and carers experience stress related to the behaviours of the child (Gore, Hastings, & Brady, 2014; Nankervis et al., 2011). An early, preventative approach to providing behaviour supports, including parent education, can have a positive impact on the child's behaviour as well as carer stress and coping (Hudson et al., 2003). Without an early intervention approach, emotional and behavioural difficulties will persist over time into adulthood (Gore et al., 2014).

Additional to early interventions, timely and proactive identification of a person with ID as having complex needs and the provision supports is required. Systems, agencies and personnel need to reconsider approaches that prioritise access by urgency of need (crisis-driven) to ensure that reasonable and necessary supports are provided in a timely manner.

Monitoring and Measuring Outcomes

Continuous monitoring of how services are being provided and the outcomes for the person is critical so that progress in meeting their needs can be monitored and acted upon. Monitoring enables the identification of difficulties and barriers, identifying what is working well and achieving desired outcomes, which is essential to informing any reassessment of the person's needs and objectives. Monitoring the implementation of planned actions avoids implementation gaps that lead to poor outcomes, such as inappropriate accommodation or homelessness.

Monitoring should also focus on outcomes that are meaningful for the individual, be measured and the tools and ways of measuring should be individualised to the person's needs and goals (Carnaby & Pawlyn, 2009; Rosengard et al., 2007).

Hudson et al. (2004) draw on the evidence of the outcomes that service users contribute to a good quality of life as:

- (a) Being healthy.
- (b) Staying safe.
- (c) Enjoying and achieving, including feeling valued and having access to social contact and company.
- (d) Making a positive contribution.
- (e) Economic well-being.

Of course, the role of agencies and professions in the provision of integrated and effective supports for people with ID who have complex needs is dependent on the skills, knowledge and experiences of the staff involved. The next section of this chapter will concentrate on the required competencies for the professions involved in service provision to people with ID and complex needs.

Professional Competencies

All professionals involved in planning and service delivery for people with ID who have complex needs require training to ensure that they are able to recognise and relate effectively to people with complex needs and their families, and assist them in navigating systems of services and supports available (Rankin & Regan, 2004). Given this, the concept of professional competence is fundamental to any discussion regarding service quality in the disability service sector, and will receive extensive focus.

In 1999, Hoffman stated there are three main approaches when it comes to defining *competencies*: (1) *observable competence*, (2) *standard of performance*, and (3) *underlying attributes*. In the first notion of observable performance—one

must be able to witness performance on a task in order to attribute if someone can competently complete the desired task. The second approach is to conceptualise competency as a standard, i.e. a minimum standard of performance a person need to demonstrate in order to be deemed competent to complete the desired task. The third and last approach is to conceptualise competency in terms of a person's underlying attributes, i.e. the knowledge, skills or abilities that allow competent performance on the desired task. Hoffman also indicated that the approach to competency adopted will depend on context and requirements. When exploring the notion of professional competencies in the disability service system, the second and/or third conceptualisations will be focused on specifically.

When it comes to supporting people with complex needs, three professionals working in the disability service system have key roles to play to ensure quality service for people with ID—disability support workers, behaviour support practitioners, and case managers. The essential competencies associated with these three work roles, starting with disability support workers is discussed further.

Disability Support Workers

With regard to disability support workers, also referred to as disability support professionals, consistent conceptualisation of worker competency is difficult due to the variability of this role. Generally speaking, the role of a disability support worker is to ensure that support plans related to client personal care, health, behaviour, community access, and other relevant needs are effectively implemented on a consistent basis (Bogenschutz, Hewitt, Nord, & Hepperlen, 2014; Hewitt & Larson, 2007; Iacono, 2010). This may involve varying levels of direct care/support, ranging from supporting clients to complete daily living tasks to the best of their ability, to undertaking daily living tasks for their clients. Additionally, disability support workers can also be employed within various service settings such

as supported accommodation, day programs and respite services, or within the clients' home. Given the heterogeneity of the intellectual disability population and the various service options available, the disability support worker role is diverse, with individual work duties and tasks typically determined by the worker's place of employment and the support needs of their clients (Bogenschutz et al., 2014). Given this, defining a universal framework for support worker competency may be difficult.

However, some researchers have attempted to piece together an all-encompassing set of competencies related to the disability support worker role. In line with Hoffman's (1999) third conceptualisation of competency, Taylor, Bradley, and Warren (1996) focused on understanding the skills, knowledge, abilities and personal characteristics that disability support workers require in order to effectively perform their role. Taylor et al. (1996) conducted focus groups with support workers working within various support services, and identified 144 relevant skills, knowledge and abilities within twelve competency areas (see Table 13.2). These competency areas are also reflected in a more recent competency analysis conducted by the National Disability Authority (2018) (see Table 13.2 also). The National Disability Authority (2018) reviewed ten competency frameworks regarding the disability support worker role from various countries, and uncovered 18 common competency areas. Eight of Taylor et al.'s (1996) competency areas were directly comparable with competencies reported by the National Disability Authority (2018). In comparison to Taylor et al. (1996), the National Disability Authority (2018) emphasised additional competencies related to staff behaviour (e.g. ethical practice, respect, resilience, safety and cultural awareness/practice, innovation) and specific work tasks (e.g. focus on client health/wellness, providing specific clinical support, working from a person-centred practice perspective, focusing on quality improvement). While the National Disability Authority (2018) mentioned staff behaviours as specific areas of competency, Taylor et al. (1996)

Table 13.2 Disability support worker competency areas (National Disability Authority, 2018; Taylor et al., 1996)

Taylor et al. (1996)	National Disability Authority (2018)
<ul style="list-style-type: none"> • Communication skills (to engage with clients) 	<ul style="list-style-type: none"> • Communication (to engage with clients)
<ul style="list-style-type: none"> • Participant empowerment (to support decision-making, choice) • Advocacy (knowledge of issues facing people with a disability, skills to facilitate advocacy) 	<ul style="list-style-type: none"> • Empowerment and advocacy (promoting clients to advocate for themselves, and supporting client advocacy)
<ul style="list-style-type: none"> • Assessment skills (in order to identify client needs) 	<ul style="list-style-type: none"> • Evaluation, observation and assessment (regarding client need and support)
<ul style="list-style-type: none"> • Education, training and self-development (to maintain skills, knowledge and abilities) 	<ul style="list-style-type: none"> • Education, training and self-development (to maintain skills, knowledge and abilities)
<ul style="list-style-type: none"> • Community living skills and supports (support to build client skills around independent living) 	<ul style="list-style-type: none"> • Community living skills and supports (appropriate assistance to support clients to engage in meaningful activities and other services)
<ul style="list-style-type: none"> • Community and service networking (skills to facilitate service use, knowledge of services and supports available to clients) 	<ul style="list-style-type: none"> • Community inclusion and networking (knowledge of services and supports available to clients, supporting client inclusion in the community and within their family and social networks)
<ul style="list-style-type: none"> • Crisis intervention (e.g. problem solving skills, conflict resolution skills) 	<ul style="list-style-type: none"> • Crisis prevention and intervention
<ul style="list-style-type: none"> • Facilitation of services (i.e. creating support plans, implementing them) 	<ul style="list-style-type: none"> • Planning and organisation (to promote partnerships, access to services for clients, and effective work practices)
<ul style="list-style-type: none"> • Vocational, educational and career support (to enable employment and participation in educational courses) 	<ul style="list-style-type: none"> • Professionalism and ethics (ensuring all practice is considered ethical and professional)
<ul style="list-style-type: none"> • Organisational participation (i.e. knowledge of their service, participation in the processes of the service) 	<ul style="list-style-type: none"> • Specific clinical support (related to behaviour support, mental illness and other clinical issues)
<ul style="list-style-type: none"> • Documentation (completion of) 	<ul style="list-style-type: none"> • Health and wellness (supporting clients to maintain good health) • Quality (focus on service improvement, and evaluating quality of care provided to clients) • Person-centred practice (providing supports in line with this framework) • Safety (ensuring that the environment around the client is safe and predictable, and using safe work practices at all times) • Resilience, positive attitude and openness to change • Cultural (values and respects diversity, and supports clients in accordance to cultural customs and beliefs) • Respect, dignity and privacy (regarding their clients) • Innovation, creativity and problem solving (to ensure positive experiences for clients)

identified these behaviours as *ideal* support worker characteristics.

Further work in developing a universal competency framework for the disability support worker role is needed, based on the views of people with ID themselves. When asked to discuss the qualities of an effective support worker, peo-

ple with ID place more emphasis on support worker skills and characteristics related to *interpersonal interaction* with clients, whereas service managers emphasise skills and characteristics that allow the worker to effectively complete their work duties (Dodevska & Vassos, 2013; Hatton, Wigham, & Craig, 2009).

Behaviour Support Practitioners

Behaviour support practitioners specialise in providing support to people with ID who exhibit challenging behaviour. According to Emerson (2001), challenging behaviours include behaviours that threaten the quality of life and/or the safety of a person with ID, or others who support the person (e.g. family members, support staff). Examples of such behaviours include self-injurious behaviours and aggressive or destructive behaviours. Behaviour support practitioners work in accordance to the principles of positive behaviour support. Positive behaviour support has its developmental roots in person-centred practice and the normalisation, social role valorisation and inclusion movements, while also intersecting the principles of applied behaviour analysis (Carr et al., 2002). Behaviour support practitioners work with people with ID, their families and their disability support workers to develop and implement a coordinated evidence-based intervention strategy that aims to enhance the person's quality of life while also minimising their challenging behaviour by addressing the function of that behaviour (Carr et al., 2002). Intervention approaches adopted in positive behaviour support include functional behavioural assessment, skill development using behavioural principles, and systematic environmental change.

Often behaviour support practitioners working with people with ID are trained in a discipline other than positive behaviour support, such as psychology, social work, nursing, occupational therapy or speech pathology. These professions will often have competency standards for registration to practice within the discipline. Because of this, behaviour support practitioners are likely assessed for competency based on the frameworks outlined by their relevant registration body, as opposed to a specific competency framework related to competently implementing positive behaviour support. Nevertheless, documenting competency to provide behaviour support services is starting to gain some traction within the disability service system, with the Positive Behaviour Support Coalition (2015) in the United Kingdom intro-

ducing a competence framework for providing best practice positive behaviour support services. In addition, to align with the introduction of the National Disability Insurance Scheme (NDIS) in Australia, the NDIS Quality and Safeguards Commission (2018) has introduced a national Behaviour Support Competency Framework. The competency framework of the Positive Behaviour Support Coalition will now be discussed in some detail.

The Positive Behaviour Support Coalition (2015) framework focuses on informing what knowledge behaviour support practitioners need to know, and the tasks/duties they will need to implement in order to deliver best practice positive behaviour support. The framework is divided into three main sections that describe specific competencies that need to be achieved by behaviour support practitioners, disability support workers and supervisor/management staff. The first section of the framework relates to *creating high quality care and support environments*, the second section relates to *functional, contextual and skills-based assessment*, and the last section of the framework relates to *developing and implementing a behaviour support plan*. Table 13.3 presents the summarised Positive Behaviour Support Coalition (2015) competency framework, with the detailed framework (not shown) breaking down each individual component in the framework into knowledge and work tasks/duties relevant to the three workers. The Positive Behaviour Support Coalition (2015) indicate that their framework can be used to support the development of a whole organisation approach to positive behaviour support, to develop curriculums related to training staff in positive behaviour support, and to support staff recruitment.

It can be expected that by undertaking competent practices that ensure the implementation of evidence-based, person-centred positive behaviour support plans, by behaviour support practitioners, in conjunction with the client and their supports, will result in positive outcomes. These outcomes include (1) enhanced quality of life for the person with ID, including active participation in meaningful daily life activities, (2) increased development of skills and positive behaviours

Table 13.3 The summarised Positive Behaviour Support Coalition (2015) competency framework

Creating high quality care and support environments	Functional, contextual and skills-based assessment	Developing and implementing a behaviour support plan (BSP)
<ul style="list-style-type: none"> • Ensuring that services are values led • Knowing the person • Matching support with each person’s capabilities and with goals and outcomes that are personally important to them • Establishing clear roles and effective team work • Supporting communication <ul style="list-style-type: none"> • Supporting choice • Supporting physical and mental health • Supporting relationships with family, friends and wider community. • Supporting safe, consistent and predictable environments • Supporting high levels of participation in meaningful activity • Knowing and understanding relevant legislation • A commitment to behaviour skills training 	<ul style="list-style-type: none"> • Working in partnership with stakeholders • Assessing match between the person and their environment and mediator analysis • Knowing the health of the person • Understanding the principles of behaviour (the four term contingency); understanding the function of behaviour • Supporting data driven decision-making • Assessing the function of a person’s behaviour • Assessing a person’s skills and understanding their abilities • Assessing a person’s preferences and understanding what motivates them 	<ul style="list-style-type: none"> • Understanding the rationale of a BSP and its uses • Synthesising data to create an overview of a person’s skills and needs • Constructing a model that explains the functions of a person’s challenging behaviour and how those are maintained • Devising and implementing multi-element evidence-based support strategies based on the overview and model (antecedent strategies, alternative behaviours, increasing skill and communication, systems change and contextual interventions) • Devising and implementing a least restrictive crisis management strategy (arousal curve, reactive strategies) • Developing the plan; outlining responsibilities and timeframes • Monitoring the delivery of the BSP (procedural/treatment fidelity/integrity) • Evaluating the effectiveness of the BSP • The BSP as a live document

that are functionally equivalent and replace the challenging behaviours, (3) reduction and elimination of the use of restrictive practices (such as chemical, physical or mechanical restraint, seclusion and containment), and (4) reduction of risk for the person and their supports, including decreasing risk of placement breakdown.

Case Managers

As previously discussed in this chapter, people with ID and complex needs are likely to require support from case managers to assist them in identifying and gaining access to required services and supports. People with ID and complex needs often require high intensity case management from case managers who have specialist skills and competencies (Cambridge, 2008).

The Case Management Society of America (CMSA;, 2016, p. 11) defines case management as “a collaborative process of assessment, plan-

ning, facilitation, care coordination, evaluation and advocacy for options and services to meet an individual’s and family’s comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost effective outcomes”. The CMSA definition is an internationally recognised definition, with other case management professional bodies using this definition as the basis of their definition of the role, for example the Case Management Society United Kingdom (CMSUK;, 2015). Case management competency frameworks that are specific to people with ID and complex needs are scarce, and for that reason the more generic but widely recognised and adopted case management competencies of the CMSA (2016) and CMSUK (2015) will be the focus of this section. These frameworks are summarised in Table 13.4.

In line with Hoffman’s (1999) second conceptualisation of competency as a set of minimum standards for workers, the CMSA (2016)

Table 13.4 A summary of the CMSA (2016) and CMSUK (2015) competency standards for case managers

CMSA (2016)	CMSUK (2015)
Client selection process—Screening referrals to identify those who will benefit most from case management	Professional practice—Engaging in regular supervision of practice, practicing autonomously and within professional boundaries, self-awareness and reflective practice, and continuing professional development regarding evidence-based practice
Client assessment—The completion of a thorough, person-centred assessment that takes into account the cultural and communication needs of the client and any other relevant stakeholders	Ethical conduct—Knowledge of relevant ethical codes of conduct, practicing ethically and with integrity, advocating on behalf of clients where appropriate, implementing procedures to adequately deal with client complaints, and working in accordance to relevant legislation
Care needs and opportunities identification—The identification of client care needs that would benefit from case management intervention	Communication—Providing information to clients and relevant stakeholders, employing appropriate communication strategies, developing rapport with clients and relevant stakeholders, and building skills to deal with difficult conversations or negotiations
Planning—In collaboration with the client and other relevant stakeholders, work to identify intervention goals and document them within the client’s case management plan	Assessment—Using different methods to gather relevant information, applying relevant assessment measures for the client, and sharing (confidentially) knowledge and information for the benefit of others
Monitoring—Ongoing assessment of the client’s response to their case management interventions	Goal setting—Identifying SMART goals, setting objectives to support the achievement of goals, and measuring outcomes relevant to the goals
Outcomes—Positive health and well-being outcomes are maximised as a result of case management intervention	Planning and prioritising—Evaluating different forms of information to identify issues and draw conclusions, organising information to support goal planning, identifying client priorities for intervention, producing case management plans relevant to the client’s priorities and goals, demonstrating creativity and innovation to create the best possible plan for the client, and problem solving when faced with challenges
Closure—Undertake relevant procedures to close off case management services when appropriate	Implementing plans—Appropriate delivery of interventions, ensuring continuity in intervention, and coordinating activities in support of the client’s objectives
Facilitation, coordination and collaboration—With clients and relevant stakeholders in order to achieve client goals and positive client outcomes	Monitoring and evaluation—Monitoring client progress to achieve goals, identifying effectiveness of interventions using appropriate measures, and applying continuous improvement principles (regular monitoring, etc.)
Qualifications—Maintaining certification to practice within a health or human services discipline or in the absence of a need for certification, evidence of qualification in a relevant health or human services discipline with a relevant fieldwork component as part of the qualification	Record keeping—Maintaining objective and accurate records, ensuring confidentiality and usability of information, presenting information in clear and concise reports
Legal—Adherence to all relevant legislation when providing case management services to clients	Management—Use appropriate referral avenues, engage in teamwork to support clients, assess and manage any client risks, managing resources appropriately and managing client expectation, and ensuring all support provided abides by organisational policy
Ethics—Ensuring all practice is ethical and adheres to ethical code of conduct governing the case manager’s discipline of practice	Leadership—Making effective decisions, acting in a leadership capacity, and work in accordance to the principles of evidence-based practice in an effort to shape case management practice
Advocacy—Advocate on behalf of the client where appropriate	
Cultural competence—Maintain awareness of, and be responsive the cultural and communication needs of each client	
Resource management and stewardship—Integrating factors related to quality, safety, access, and cost-effectiveness when supporting clients	
Professional responsibilities and scholarship—Ongoing professional development to maintain knowledge and competency, and working in accordance to the principles of evidence-based practice	

and CMSUK (2015) competency frameworks provide a set of standards for case managers, with both frameworks also making explicit statements regarding how a case manager can demonstrate that they meet each standard. For example, regarding the CMSA's (2016) *monitoring* standard, case manager can demonstrate their competency by: (1) documenting their efforts to collaborate with their clients and relevant stakeholders to review client progress, (2) initiating changes to the proposed case management interventions in response to any changes to a client's circumstances, and (3) undertaking and documenting care plans reviews, and making efforts to ensure that updated intervention plans are acceptable to the client and relevant stakeholders. Comparing the two frameworks, there is overlap in content, implying that competency standards for case managers may have some universality. Of interest, competence in the areas of *assessment* of client need, *goal setting* and *outcome measurement*, *intervention planning* and ongoing *monitoring*, *effective client collaboration* and *communication*, and *ethical/professional conduct* are stressed by both frameworks.

In summary, the available evidence and information regarding professional competency for three key professionals who support people with ID who have complex needs is lacking. This is concerning given that staff competency plays a crucial role in ensuring service quality within any human service organisation. Researchers and policy makers need to prioritise the development, validation and evaluation of universal competency frameworks for key professionals working in the disability service system. This is especially the case when working with people who have complex needs as this cohort has a higher likelihood of adverse outcomes. Given that many countries are implementing significant changes to how disability services are provided to people with a disability, this task takes on extra importance as a method of ensuring consistent and effective staff practice to ensure high quality disability services that are focused on outcomes for individuals.

Concluding Remarks

Meeting complex needs for people with ID can be challenging. However these challenges can be overcome if services and systems work in ways that ensure integrated and coordinated service provision that meets human rights, provides safeguards, and improves quality of life. Often complexity of need is not associated with the individual or the need itself. Complexity arises where the right supports are not available or accessible, where service systems are fragmented and difficult to navigate, or where access to services is only prioritised where there is imminent crisis.

This chapter has highlighted the need for the early identification of families who are supporting children with ID and complex needs and are at risk of requiring out-of-home placement due to stress and inability to continue to care for their child. Such early identification enables the early and timely provision of the supports required to prevent escalation of the depth of the needs of the child and supports the family's ability to continue to care for their child in the family home.

Also discussed has been the essential elements required to be in place for social service systems, service provision agencies and professionals for best practices in providing care for people with ID who have complex needs. Having in place competent systems, agencies and professionals that understand an individual's complex needs will enable responses that result in positive outcomes that are meaningful and individualised to the person with ID and their support network.

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