Chapter 19

Transition: More Than An Event

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'The only constant in life is change' (Heraclitus, c. 535 - 475 B.C.)

Introduction

All people experience transitions in the course of their lifetimes. Transitions are important and often complicated periods of change and adjustment in the lives of any child, young person or adult. However when the child or young person at the centre of the process also has an intellectual disability, the transition may become more complex and challenging as a range of factors and systems interact (Jacobson & Wilhite, 1999; Janus, Kopechanski, Cameron, & Hughes, 2008; Teeters Myers, 2006). Whilst it is debated whether people with intellectual disability experience more transitions than their typically developing peers (Coe et al., 1999; Emerson & Hatton, 2007; Hatton & Emerson, 2004), exposure to this process of change is a certainty. As such, practitioners have an opportunity, if not a responsibility, to support the children and young people with intellectual disability with whom they work to negotiate these periods of transition successfully.

What Is Transition?

The concept of transition is not new. However much of the existing transition literature adopts a narrow scope by focusing on specific life events and contexts (Kralik, Visentin, & van Loon, 2006). Life change events commonly studied in the lives of people with intellectual disability include starting school (Janus et al., 2008; McIntyre, Blacher, & Baker, 2006), moving from primary to high school (Repetto & Correa, 1996), leaving school and commencing work or post-school programs (Boardman, 2003; Heslop, Mallet, Simons, & Ward, 2002; Kohler, 1996; Nuehring & Sitlington, 2003; Rapanaro,

Bartu, & Lee, 2008), moving out of home (Bigby, 2000), and moving from paediatric to adult healthcare services (Blum et al., 1993; While et al., 2004). Whilst periods of transition are associated with these and many other events across the lifespan, it can be limiting to conceptualise transition as an event alone.

Transition is more than an event. It is not the day a child with intellectual disability starts school or begins to access respite services. It is a dynamic and interactive process of change and adjustment that occurs as the child or young person moves from one phase, condition, place or set of circumstances to another. Whilst transition is always embedded in a particular context, it is not a discrete event in itself (Department for Children, Schools and Families/Department of Health, 2008; Department of Health/Department for Education and Skills, 2006; King, Baldwin, Currie & Evans, 2005; Kralik et al., 2006). As shown in Figure 19.1, transition involves three phases over time: (1) planning and preparation; (2) the provision of individualised supports and systemic linkages; and (3) integration and follow-up in the receiving context.

[Insert Figure 19.1 here]

All transitions involve change, often across multiple domains of life and functioning. These may include changes in the individual's environment, relationships, roles, expectations, affect, emotional wellbeing and/or behaviour (King et al., 2005; Kralik et al., 2006; Szymanski, 1994). However transition is not simply another word for change. Instead, it is the *process of adapting* to these life changes that is central to the conceptualisation and understanding of transition (Kralik et al., 2006). Transitions

both influence and are influenced by the individual and others in their support network. Therefore, transitions may necessitate a period of significant change and adjustment not only for the individual but also for a range of stakeholders (King et al., 2005).

Transition And Mental Health/Wellbeing

In terms of the clinical significance of transition, it has long been established that stressful life change events, such as moving house or the death of a loved one, can place an individual at increased risk of physical and mental health issues (Hulbert-Williams & Hastings, 2008; Paykel, 2001; Tiet et al., 2001). Life change events have been identified as a risk factor for mental health issues across the lifespan for people with and without an intellectual disability. For example, Emerson and Hatton (2007) found that exposure to two or more negative life events significantly increased the likelihood of conduct disorder, emotional disorder and hyperkinesis in children with and without an intellectual disability. Further, they found that exposure to these events was significantly higher for children with intellectual disability. This supports Hatton and Emerson's (2004) earlier finding that children with intellectual disability were more likely to experience a greater range of adverse life events than their typically developing peers.

Owen et al. (2004) found that the life change events most commonly reported by individuals with intellectual disability included staff changes, moving house, relationship changes, family bereavements, injury, and illness. Exposure to these and other life change events has been associated with mental health issues in children, adolescents and adults with intellectual disability (Cooper, Smiley, Morrison, Williamson & Allan, 2007; Hatton & Emerson, 2004; Owen et al., 2004; Tsakanikos,

Bouras, Costello, & Holt, 2007). In particular, exposure to negative, stressful or adverse life events has been found to increase the risk of affective, emotional and conduct disorders in individuals with intellectual disability (Esbensen & Benson, 2006; Hastings, Hatton, Taylor, & Maddison, 2004; Hatton & Emerson, 2004). Furthermore, the risk of having mental health issues appears amplified if the individual has experienced multiple adverse life events (Hatton & Emerson, 2004). However, it is also important to be mindful that there are other risk factors beyond life change events that may contribute to an individual's vulnerability, and/or the likelihood of emotional and behavioural disturbance.

Whilst transitions occur across the lifespan, adolescence is known to be a period of rapid and widespread change (Tur-Kaspa, 2002). For some young people with intellectual disability, the multitude of transitions experienced during adolescence will prove challenging, perhaps even overwhelming. Moreover, as the risk of mental health issues increases with exposure to more life change events, adolescence may present a period of particular vulnerability. However, it is apparent that the way an individual experiences transition and adjusts to life changes, irrespective of their age, can have significant implications for their mental health and wellbeing. Therefore the provision of supports through these times of change is one way of enhancing an individual's coping mechanisms, moderating the risk of mental health issues, and promoting quality of life for children and adolescents with an intellectual disability.

The Child/Young Person Experiencing Transition

It is widely acknowledged in the literature that a person-centred approach to transition is needed when supporting children and young people with intellectual disability (Attfield, 2009; Department for Children, Schools and Families/Department of Health, 2008; Department of Health/Department for Education and Skills, 2006; King et al., 2005; Kohler, 1996; Michaels & Ferrara, 2005). A person-centred approach is an individualised and flexible approach that draws on the strengths, needs and desires of the individual with intellectual disability. However in practice, transition planning continues to be done *for* children and adolescents with intellectual disability rather than with or by them. For example, Heslop et al. (2002) explored the transition experiences of young people aged thirteen to twenty-five years. They found that, despite the existence of legislation and guidance on transition, more than forty percent of children and young people surveyed had little or no involvement in their transition planning. Moreover, they found that one fifth of young people had left school without a transition plan. This highlights the need for practitioners and educators to listen to the views of individuals with intellectual disability, facilitate their active participation, and foster their self-determination skills in this process (King et al., 2005; LaCava, 2005).

One way of assisting the child or young person to participate in transitions is through the use of Augmentative and Alternative Communication (AAC) systems (Beukelman & Mirenda, 2005; Brewster, 2004; LaCava, 2005) such as Talking Mats® (Cameron & Murphy, 2002). AAC systems provide the young person with a helpful scaffold for expressing their needs and making decisions and choices at points of change. In turn, these resources can be used to identify key actions and communicate information to the child or young person throughout the process.

Other People Involved In Transition

The impacts of transition are not limited to the child or young person with intellectual disability. Rather, a broader view is needed to consider the influence that transition has on the child or young person's support system (Hudson, 2003). This system may include family, friends, peers, professionals, and members of the community (Kim & Turnbull, 2004; Szymanski, 1994). These stakeholders both contribute to, and are affected by, the transition process in varying ways and to varying degrees (Jacobson & Wilhite, 1999; King et al., 2005). For example, significant points of change (such as starting or finishing school) can be a source of stress and even sorrow for parents as they are reminded of the discrepancies between normative expectations and their child's circumstances (Hanline, 1991). King et al. (2005) suggested that factors such as caregiver isolation, burnout, and stress can also complicate transitions, contributing to and/or being an outcome of the transition process. Attfield (2009) offered a personal account of her experience of supporting her son through a period of transition. She described her son's move to a residential special school as 'probably the most stressful time of all ... [that was] a huge 18-month battle ... finally achieved ... when he was 14, but only at considerable detriment to our own mental health' (Attfield, 2009, p. 36).

Attfield (2009) suggested that whilst an individualised and person-centred approach to transition is vital, it is also important to consider the views of the individual's family and friends to promote the wellbeing of all. Transitions present a significant period of change and adjustment for children and young people with intellectual disability, their families, and other stakeholders. Therefore ensuring good communication, coordination, and collaboration is essential in good transition practice (Attfield, 2009; Heslop et al., 2002; Hudson, 2006; Kim & Turnbull, 2004; Nuehring & Sitlington, 2003; Stoner, Angell, House & Bock, 2007).

The Impact Of Transition Across Life Domains

In the same way that transition not only affects individuals but also their support network, the impacts of transition are not limited to one area or aspect of an individual's functioning. Transition can affect multiple domains of life and functioning including the individual's environment, relationships, roles, expectations, affect, and behaviour (Department of Education, 2008; King et al., 2005; Stewart, Antle, Healy, Law, & Young, 2007; Szymanski, 1994). These domains need to be considered in the planning, development, and provision of comprehensive transition supports for children and young people, irrespective of the actual life change event.

Whilst the impact of transition across life domains will be explored below with reference to the individual with intellectual disability, it is important to highlight that these domains apply equally to others within the support network. For example, when a child or young person begins to access centre-based respite for the first time, their family also experiences a significant period of transition. Parents and siblings may find that their home environment, relationships, interactions, and behaviour change as a consequence of the role of caregiver being transferred to a service provider, albeit for a brief period of time. Families may also experience a wide range of contrasting emotions such as guilt and relief as the expectations of the family as individuals, and as a unit, shift and evolve.

Transition And The Environment

People do not exist in a vacuum; they grow, develop, and live in constant interaction with the world around them. The environment provides both a physical space and a link

with personal histories, culture, experiences, relationships, memories, and a sense of self (Jacobson & Wilhite, 1999). People and their environments have reciprocal effects on each other and therefore must be considered as interdependent (Brofenbrenner, 1979).

The degree to which the environment adequately meets the needs, desires, and preferences of the individual has important implications for adjustment (King et al., 2005). When a good 'fit' exists between children with intellectual disability and their environments, then positive outcomes can be expected (e.g., participation in meaningful activities). Conversely, a poor 'person-environment fit' is likely to result in negative outcomes, such as dissatisfaction or the presence of challenging behaviour (Swanson & Fouad, 1999). The 'person-environment fit' can become compromised during periods of transition due to direct changes in the physical environment (e.g., home renovations or moving house) or changes in other domains which then impact on that environment (e.g., addition of a new sibling at home or a new child in the classroom).

When supporting children and adolescents with intellectual disability, it is important to inform them about and prepare them for changes in their environment and/or routine. This could be achieved through the use of AAC systems such as Social Stories TM (Gray, 1995), Comic Strip Conversations (Gray, 1994) and routine schedules. Lifestyle and Environment Reviews, which identify discrepancies between the individual's needs and their supporting environments, may also provide a mechanism for the development of strategies to achieve an optimal 'person-environment fit'.

Transition And Relationships

Relationships are critical in the lives of all people. They can provide safety, support, stimulation, confidence, self-esteem, a sense of self, and historical affiliation (Forrester-Jones et al., 2006; Jacobson & Wilhite, 1999). At times of transition they can also offer a significant source of support, which aids in coping and wellbeing and provides a buffer against stress (Hanline, 1991). For this reason, it is paramount that individuals with intellectual disability and their families are supported to maintain relationships and utilise both their informal and formal networks through periods of transition. It is also important to be sensitive to the implications of transition for the broader system of support (as discussed earlier).

In some situations, transition can signal the end of relationships (Bridges, 2004; Jacobson & Wilhite, 1999). For example, when a young person changes or leaves school, their relationships with teachers typically end and friendships with peers may also be lost or weakened. The significance of such losses is often overlooked and individuals may report feeling lonely or missing particular people (Jacobson & Wilhite, 1999; Runnion & Wolfer, 2004). This may be further complicated if the child has a history of loss, bereavement or unresolved grief. To help a child or young person with intellectual disability to adjust to these changes it is important to provide opportunities to say 'goodbye'. Acknowledging and recording significant and changing relationships in a child or young person's life using life story books, scrap books, photo albums or memory boxes can also be of help (Runnion & Wolfer, 2004).

Transition may also signal the beginning of new relationships (Bridges, 2004; Jacobson & Wilhite, 1999). For some children with intellectual disability the process of forming new friendships can be particularly difficult (Runnion & Wolfer, 2004). Again, AAC systems, such as a 'Chat book' or 'A book about me' (Bloomberg, West &

Johnson, 2004) can be helpful ways of supporting a child or young person in interactions to share information about themselves.

Transition And Roles

Like all people, individuals with intellectual disability fulfil a range of roles in different contexts of their lives. These may include child, sibling, friend, student, worker, housemate, and partner. These roles bring both privileges and responsibilities and are critical in the construction of a positive sense of self, self-esteem and hopefulness (King et al., 2005). For this reason, continuity of roles throughout transition is beneficial. The alignment of roles with the strengths, skills, needs and goals of the individual and their circle of support is also considered vital.

As roles influence the way in which events are perceived and responded to, they have significant implications for an individual's adjustment to transition (King et al., 2005; Stewart et al., 2007). Transition often leads to the adoption of new roles and responsibilities, as well as changes to existing ones (King et al., 2005; Stewart et al., 2007). Therefore the provision of information and skill development opportunities can assist an individual to prepare for and adjust to these changes in roles. This may also assist to resolve discrepancies between new role demands and existing skills, knowledge, and resources (King et al., 2005).

Transition And Expectations

All people hold expectations for themselves, others, their routine, and the world around them. These are based on existing schemas and influence the way individuals anticipate, interpret, and participate in daily life (Parkes, 1993). Change is interpreted in relation to

these existing expectations and schemas. Therefore knowledge of an individual's history can offer helpful clues about how he/she might respond to future points of change. This may also offer intervention and support ideas to promote the individual's adjustment and wellbeing (i.e., drawing on what has worked well in the past).

During periods of change, information is often acquired which is at odds with an individual's existing schemas or expectations (Parkes, 1993). This can prove challenging for any individual, but particularly for individuals who rely on the predictability and consistency provided by familiarity and a structured routine. As such, it is essential that children and young people with intellectual disability are prepared for transition to reduce discrepancies between their expectations and experienced reality. This preparation includes communicating to children and young people about what changes they should expect, what others will do, and any specific requirements or things that they may be asked to do. AAC systems such as calendars, checklists, and illustrated transition books, can be helpful means of communicating and clarifying expectations. Providing opportunities for questions, acknowledging concerns, and highlighting aspects that will remain constant during the transition can also be a source of reassurance for individuals.

Transition, Affect, And Emotional Wellbeing

During periods of transition, individuals with intellectual disability can experience a wide range of emotions, including excitement, apprehension, anxiety, and loss (Jacobson & Wilhite, 1999). Parkes (1993) noted that in transition, the familiar becomes unfamiliar and this can affect an individual's sense of security and emotional wellbeing.

Even positive life changes, such as making a new friend, can result in stress (King & Anderson, 2002).

Researchers have found a strong association between life change events and an increased risk of mental health issues, including the presence of mood disorders in both children and adults with and without intellectual disability (Emerson, 2003a; Esbensen & Benson, 2006; Hastings et al., 2004; Hatton & Emerson, 2004; Owen et al., 2004; Tiet et al., 2001; Tsakanikos et al., 2007). Emerson (2003a), for example, found that exposure to potentially stressful life events increased the likelihood of emotional and anxiety disorders in children and adolescents with intellectual disability. Interestingly, Esbensen and Benson (2006) found an association between life change events and depressive symptoms was present regardless of whether the individual perceived the event as negative or positive. They also found that as more negative or positive events were experienced, more depressive symptoms were reported.

To support children or young people to adjust to the emotional impacts of transition it may be useful to develop a toolkit of strategies that promote wellness. Strategies might include:

- Ensuring opportunities to talk with others about how they are feeling, and offering validation and empathy;
- Providing a structured routine, encouraging exercise and participating in enjoyable activities;
- Teaching problem solving skills and relaxation strategies;
- Promoting a healthy diet and good sleep hygiene; and,
- Seeking professional help and advice about medication and other therapeutic options.

Transition And Behaviour

Given the observable nature of behaviour, changes in this area of life are often the first to be noticed when individuals experience difficulty coping with transition. For children with intellectual disability and Autism Spectrum Disorder (ASD) these behaviours may reflect their resistance to and/or difficulties adjusting to the change (Sterling-Turner & Jordan, 2007). Life change events have been found to be positively correlated with challenging behaviours including irritability, lethargy, stereotypical behaviour, hyperactivity, non-compliance, inappropriate speech, and aggressive/destructive behaviours (Esbensen & Benson, 2006; MacHale & Carey, 2002; McIntyre et al., 2006; Owen et al., 2004). Changes in everyday patterns of behaviour, such as sleeping and eating, have also been observed during periods of transition (Jacobson & Wilhite, 1999). Interestingly, whilst stressful life events are associated with an increased risk of behavioural difficulties, positive life events are not (Esbensen & Benson, 2006). This suggests that the way in which an individual perceives a change (i.e., as positive or negative) has implications for the likelihood of behaviour problems.

Behavioural difficulties can interfere with a child's functioning and participation in daily life and can be a source of significant stress for their family and wider support system. With this in mind, the presence of challenging behaviour may increase the likelihood of life change events occurring. For example, Alborz (2003) found that challenging behaviour was one of several factors reported by families as contributing to their decision to seek alternative accommodation for their child with intellectual disability.

When challenging behaviour is present, it is important that an assessment is conducted in order to understand the underlying function and make meaningful

recommendations for intervention and support. For those who already have existing behaviour support strategies, these should be reviewed in preparation for the transition, then monitored and updated throughout the process. Additional strategies or supports which focus specifically on the transition process may also be needed to reduce the likelihood of problem behaviours. For example, visual learners (such as those with ASD) and young people with limited verbal skills often benefit from videos about the transition, Social Stories TM (Gray, 1995) and activity schedules. These tools/strategies act as useful primers that increase the predictability of the change event (Sterling-Turner & Jordan, 2007). These AAC systems can provide an introduction and give information about new settings (e.g., how to get there, how to find your way around, who are the key new people and the activities that will occur). The option of viewing videos and reading Social Stories TM repeatedly can provide valuable learning and reassurance.

Case Study

The case study that follows illustrates some of the issues and challenges faced during transition by children and young people with intellectual disability. It also highlights many opportunities to provide creative and proactive supports that promote emotional and behavioural wellbeing.

Billy is a 16 year old young person with a moderate intellectual disability and a history of severe and persistent interpersonal and emotional difficulties. He has lived with his maternal grandparents since he was an infant; however, due to their declining health and increasing difficulty managing his behaviour, they recently reached the difficult decision to relinquish care. Billy was placed in emergency respite care whilst a more appropriate and longer term option was identified.

This accommodation change occurred at a point of crisis with little preparation and support for Billy. It was a change that provided Billy's grandparents with a much needed break; however it also caused them tremendous guilt and sorrow. Billy also struggled to adjust to the change. For him the move was much more than a change in residence. He was being cared for in an unfamiliar place, by unfamiliar people and he did not know what to expect or who he could trust. With the exception of Billy's schooling, his life and routine had been turned upside-down. The respite staff reported that Billy appeared highly anxious and withdrawn. He cried and regularly asked when he would be going home. He self-injured and attempted to assault other clients several times a day. Respite care staff did their best to support Billy with the little information they had available. However, on several occasions they needed to call for Police assistance.

This transition was anything but seamless and anything but smooth. The people in Billy's support system agreed that things needed to be done differently if future transitions were to be more successful. When a more suitable accommodation placement was identified, a transition team was established to work with Billy in preparing him for the upcoming change and to assist him with the adjustment required. This team included his grandparents, school teacher, respite staff, speech pathologist, behaviour support practitioner, and the manager of the new accommodation service. A number of goals were identified, including that Billy maintain regular contact with his grandparents as requested by his grandmother.

Using visual supports, the speech pathologist and behaviour support practitioner asked Billy about what he wanted to know about his new home. He said that he wanted to know what his bedroom looked like, whether the other people who lived in the group

home liked Harry Potter and whether the house was near his school. This formed the beginnings of Billy's transition plan.

A Social StoryTM (Gray, 1995) was developed to explain to Billy what was happening, when and why. A short video was also made to introduce Billy to his new/future home, staff and co-residents. Billy watched this video repeatedly and took great pleasure in reciting people's names. Staff were provided with training, support protocols and scripts to guide their interactions with Billy to ensure consistency in the information being conveyed. The move was framed as a positive and exciting part of growing up that many people experience as they become young adults. However, Billy's anxiety and concerns were also acknowledged and validated.

Billy's grandparents continued to have regular contact with him throughout the transition and helped him make a memory box containing small mementos and reminders of the fun times they had shared. They also included a phone card in the box so Billy could call them whenever he wanted. As Billy met and got to know the staff and residents at his new home, this memory box was often a good 'icebreaker' in establishing new relationships. Billy appeared to enjoy showing other people photos and trinkets from his life.

Having been prepared for the move, Billy's anxiety was much lower than was anticipated. Whilst he continued to display self injurious behaviour in his new group home, the number of incidents was relatively low. Staff reported that he was engaging more with them and his co-residents each day. He continued to have daily phone calls with his grandparents and continued to attend school. Billy's adjustment continued to be monitored and support from the speech pathologist and behaviour support practitioner continued. It was recognised by his transition team that their coordinated, collaborative

and comprehensive approach to transition greatly contributed to the positive outcomes achieved by both Billy and his support network.

Summary And Implications For Practice

As shown in the case study above, transition goes beyond the particular point in time at which change occurs. It is a complex and interactive process of change and adjustment that involves many people and has implications across multiple domains of life.

Therefore, the scope of transition should be broad and consider the perspectives, goals, strengths, skills, and needs of individuals with an intellectual disability and their wider support systems. This requires clinicians, practitioners, educators, families, and others to identify the individuals in the support system and determine how each may contribute to and be impacted by the transition process.

Participation, information sharing, and collaborative decision making are essential during transition. These processes may be enhanced by the structuring of a safe and supportive environment, the forging of respectful relationships, and the use of communication strategies tailored to the individual's needs. Whilst a range of communication tools and AAC systems have been discussed, only those that are matched to the individual's communication skills should be used. For example, visual systems such as Talking Mats[®] and picture-based timetables or routine schedules would not be meaningful or helpful for a person with a more severe intellectual disability who does not have symbolic language skills.

Careful consideration of the potential impacts of transition across life domains, particularly for the individual with an intellectual disability, is also warranted. This will allow for the identification of actions that promote continuity and wellbeing, and reduce

or remove adverse outcomes (e.g., relationship or role losses, emotional distress or challenging behaviour).

Throughout the transition process individuals with intellectual disability and their support systems require different kinds and degrees of support. Consequently, it is neither possible nor appropriate to suggest a 'one size fits all' solution. For example, whilst some children with intellectual disability respond best when provided with considerable notice for upcoming transitions, for others this could be extremely anxiety-provoking and thus a shorter 'lead time' is preferable, albeit with other components of planning in place.

When supporting children and adolescents with intellectual disability through periods of transition, clinicians, practitioners, and educators are encouraged to focus on the unique qualities of each individual, each family/support network, and each set of circumstances. Flexibility is also important given that needs change over time, even across periods of transition.

Whilst researchers are yet to establish best practice standards in relation to transition, some features of good transitions have been described. Drawing on the current literature (e.g., Heslop et al., 2002; Kohler, 1996; Stewart, Starvness, Antle, & Law, 2006), eight guiding principles are presented for consideration when supporting a child or young person with intellectual disability through transition. These principles are listed in Table 19.1 and provide a checklist for good transition practice.

[Insert Table 19.1 here]

Putting these guiding principles into action and developing the associated transition strategies may involve a significant amount of time and commitment from a number of people from the individual's support network. Therefore it is important that transition planning commences early to allow sufficient time to undertake this work. It is acknowledged, however, that in some circumstances the timeframes for transition can be limited. Therefore, the challenge to clinicians, practitioners, educators, families, and support staff is to think creatively and with flexibility to find ways to best implement these principles of good transition practice within the available time and resource constraints.

In conclusion, this chapter has sought to identify and explore the linkages between key elements of transition. Briefly, it is suggested that an understanding of the individual with intellectual disability and their specific circumstances should be central to any transition planning or support process. A broad view that encompasses the wider support system and considers the impacts of transition across life domains is also needed. This is fundamental in promoting a holistic and comprehensive approach to any transition.

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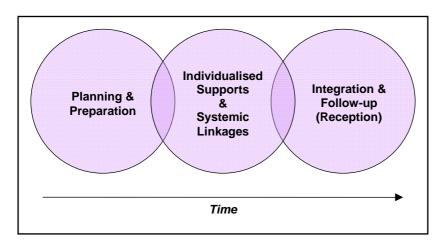
Table 19.1

Guiding Transition Principles

- 1. Be goal oriented;
- 2. Be individualised;
- 3. Incorporate choice;
- 4. Provide skill development opportunities;
- 5. Offer good information flow, communication and resources;
- 6. Be collaborative and well coordinated;
- 7. Promote continuity; and
- 8. Be comprehensive (i.e., consider implications across time, life domains and the service system).

Figure 19.1

Phases of Transition



Source: Corfield and Brearley (2009)