

Young People with a Disability: Independence and Opportunity A Literature Review

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Young People with a Disability: Independence
and Opportunity

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Contents

Executive Summary.....	4
Introduction.....	6
Definitions.....	7
The issue of independence.....	8
The changing social context for young people today.....	8
Methods.....	10
Findings from the Literature.....	11
Identity development.....	11
Resources and supports.....	21
Attitudes.....	24
Conclusion.....	28
References.....	30

EXECUTIVE SUMMARY

In recent decades there has been considerable research into and debate on the changing nature of transitions to adulthood for young people. Within this context of late-modern uncertainty, and in the wake of widespread adoption of philosophies of normalisation, de-institutionalisation and integration, an extensive body of research has also emerged on the transitions of young people with a disability. Much of the existing research into enhancing or maximising the independence of people with disabilities has tended to focus on the macro-structural factors that are barriers to an individual's functioning (such factors as physical access, availability of transport, level of skill development and quality/availability of supports). To address these gaps in research the current review focuses on personal, familial and social factors that impact, as barriers/enablers, on an individual's opportunities to maximise independence. The research question is: What are the important factors that impact on opportunities for independence for young people with a disability?

Methods

The Literature Review synthesises international and Australian literature related to the personal and social factors that impact on the opportunities of young people with disabilities to maximise their independence and successfully transition to adulthood. The review draws on a comprehensive range of materials from across multiple academic disciplines, most notably sociology, health, social policy and education. Sources include government reports, conference proceedings, relevant monographs, journal articles, unpublished PhDs and online resources.

Findings from the literature

Three themes emerged in regard to the research question. The themes discussed include:

- Identity development
- Resources and supports; and
- Attitudes

We explore how these themes highlight factors that facilitate or hinder meaningful choice and control for young people with a disability through having a range of opportunities at the level of the: individual; family; community; and through interaction between the 3 levels.

Identity development

Social relations: Research reveals how the work that young people do to shape identities is revealed in their narratives, or stories they construct, and are made possible by the social networks to which they belong. So what are the implications here for young people with a disability? The literature emphasises that young people with a disability have less opportunities for developing social networks and less opportunities to develop stories or narratives of themselves that draw on a wide range of resources and social interactions. They have fewer opportunities to develop identity narratives that enable them to negotiate their own way as much of their social interaction is mediated by a third person (either a carer of family member) despite finding that they in fact need more opportunities/time than young people without a disability to develop meaningful relationships.

Hopes and aspirations: Young people with a disability have the same aspirations and hopes as other young people. There was little overall difference between young people with and without a disability in aspirations such as accessing more training or education, making a lot of money, accessing sports and hobbies and having a long-term relationship or marriage.

Decision making: Identity development is also linked to opportunities for meaningful decision making. In particular, young people need to have the capacity to embrace decision-making ('choice') and accept responsibility for building their own futures. The extent to which decision-making processes acknowledge and include young people playing a role studies highlight the 'lack of voice'. Young people with a disability are not properly involved in decision-making at crucial points in their journeys to adulthood.

Managing risk: Sociological frameworks tend to focus on the conditions that place young people at risk with the literature showing there is a direct association between a young person's level of social support and the number of health risk factors they exhibit. Correspondingly studies show that young people with a disability are more likely to engage in risk taking behaviour. The literature reveals that families face a dilemma in deciding what is an acceptable risk but in order to be able to make informed decisions, young people with disabilities, like their peers without disabilities, need to be able make mistakes and learn from them. This finding highlights the need for information and support to assist families and young people with a disability to make informed decisions.

Resources and supports

Parents, siblings and close community connections play an important role to support young people with a disability. Added to this are aspects of parenting and familial relationships enhance attainment of independence including:

encouragement and the balance of nurturing with provision of opportunities to undertake independence; parents fostering high expectations; and parents having the skills to negotiate with professionals. Underlying all of this is the impact of socio economic resources with families with a young person with a disability with young people with a disability are much less likely to be engaged in education, work and community and families and carers also less likely to be fully engaged socially and economically and are more likely to be experiencing social isolation and poor health.

Attitudes

The literature reveals the ongoing work that still needs to be done particularly in regard to attitudes in school, the workplace and the community to foster inclusiveness and promote independence and opportunity for young people with a disability. Through the review of the literature comes a picture of the success of promoting an inclusive culture (see section on attitudes in school) but also outlines the further work that needs to be done to educate all people about disability.

Conclusion

Wellbeing as well as having the capacity to exercise choice and control over one's own life, is strongly associated with having strong social connections. However, evidence on the situation of young people with a disability suggests that they are more likely than their peers without a disability to be socially isolated and that they take longer to forge strong relationships of trust. Closely related to this is the impact of community attitudes and perceptions as they are the most frequently reported barriers to social inclusion. This argues strongly for social policy programming (and expenditure) that actively educates the community about the experiences of people with a disability.

INTRODUCTION

In recent decades there has been considerable research into and debate on the changing nature of transitions to adulthood for young people. As Stokes and Wyn (2007) have noted, social developments since the 1970s have significantly complicated youth trajectories and life options. Faced with educational systems and policies that remain committed to an essentially industrial model, young people have needed (and are needing) more and more to personalise their pathways, consciously construct their identities, even reinvent themselves, in order to live and thrive in a context of uncertainty. Within this context of late-modern uncertainty, and in the wake of widespread adoption of philosophies of normalisation, de-institutionalisation and integration, an extensive body of research has also emerged on the transitions of young people with a disability.

In the 1990s sociologists and educators began to look at the extent to which individuals exercised agency in negotiating risks and opportunities (Beck 1992). This generated an over-emphasis on the power of agency as a predictor of social and individual outcomes, and although individual agency is important, many researchers on youth transitions pointed out that the impact of families and other key relationships tend to be ignored (Tisdall 2001, Stokes 2012, Witz 1995, Wyn et al 2008, Wyn et al 2010). Peng Yu (2009) also notes the trend to overlook the influence of familial and social factors on the transition processes for young people with a disability.

Much of the existing research into enhancing or maximising the independence of people with disabilities has tended to focus on the macro-structural factors that are barriers to an individual's functioning (such factors as physical access, availability of transport, level of skill development and quality/availability of supports). Mirfin-Veitch (2003) and Townsley (2004) note that the literature tends to focus on progression to higher education and employment, with an overall emphasis on (a) shortcomings in provision or administration of services and supports, (b) conclusions drawn from personal accounts, or (c) employment outcomes. For example, Tisdall (2001), notes that research on youth transitions in the 1980s focused on structural factors (class, educational attainment and labour market conditions) rather than on individual characteristics.

To address these gaps in research the current review focuses, therefore, on personal, familial and social factors that impact, as barriers/enablers, on an individual's opportunities to maximise independence. The research question is: What are the important factors that impact on opportunities for independence for young people with a disability?

The review draws on national and international sources to (a) compare and contrast the situation for young people and in particular for young people with disabilities and (b) focus on what

the situation means for young people with a disability. The review first addresses definitions of disability, independence and the age range of what constitutes a young person. We then briefly address the issue of independence and why it matters for young people with a disability. We explain the changing social context for young people today and provide a description of our methods. The findings from the literature are presented under three main themes: identity development, resources and supports and attitudes. In each of these sections we highlight factors at the individual, family and community level. Under the theme of identity development sub themes include: social networks, social relations with peers; changing dynamics with family members; relationships with the community (including online participation); hopes and aspirations; decision making; risk; and self confidence. The theme of resources and supports explores: family resources; sibling support and community resources and under the theme of attitudes we explore family attitudes, attitudes to sexuality; community attitudes; attitudes in schools and the workplace.

Definitions

Disability and Independence

The definitions of both disability and Independence are contested and evolving. For the purposes of this paper we endorse:

(a) The finding by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2008) that “disability results from interaction between impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” and

(b) Rock's (1988) contention that “Independence for young people with a disability means having choice and control in the management of their life and their environment”.

In the context of disability, the concept of independence does not confine itself to such traditional criteria as living on one's own, or being employed in an appropriate job. The UNCRPD emphasises that independence for persons with disabilities encompasses:

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

For independence to be achieved, it is essential that young people have access to a range of opportunities and resources so that they can make meaningful choices and decisions about the management of their life and environment. Without maximum opportunities, it can be argued, independence as defined above will not be achieved.

Young people

Based on Muir et al (2009) the age range of young people with a disability was selected as 15-24 years. However, it should be noted that youth is a social concept and there is a trend to recognise the blurring of boundaries between childhood, youth and adulthood (Wyn 2009).

For the purposes of this literature review we acknowledge that young people with disabilities do not live in isolation. They live within the context of their communities, which may include families and other diverse communities. Families are defined as including immediate and extended family members and communities are defined as immediate, relational communities that young people would be in contact with on a day to day basis.

The issue of independence

On all indicators (Muir et al 2009) young people with disabilities fare worse than other young people in the population. While policies and programs exist to support young people with a disability through their late teens and early twenties, governments need more advice regarding: a) how to engage young people with a disability, their families and communities to take up the available opportunities, and b) to identify what additional supports are needed.

Why does it matter?

A significant proportion of young people have a disability, although as Dubois and Trani (2009) note, the total number of people with disabilities is not known. Young people with a disability are much less likely to be engaged in education, work and community which has social, family and economic implications. Families and carers are also less likely to be fully engaged socially and economically and are more likely to be experiencing social isolation and poor health. Therefore young people with disabilities require appropriate supports at this key time in their lives to develop independent living skills and to maximise their opportunities for independence.

The changing social context for young people today

To assist our discussion of how to maximize the independence of young adults with a disability we present a summary of recent thinking about the nature and meaning of youth transitions in general. Two of the key concepts that are the focus for this project, independence and choice, have also become central to recent theories on young people and change. The meaning and experience of youth has changed significantly over the last quarter of a century, and therefore so has the idea of transition to adulthood. Social theorists,

including Bauman (2001) and Beck and Beck-Gernsheim (2002), identify the changing meaning of independence as family structures change and the life course becomes destandardised. They also provide insights into the idea of choice, highlighting the increasing need for individuals to take personal responsibility for decisions in relation to actions over which they have little control.

Economic change (particularly globalization) and political economic change (the shift from Keynesian to monetarist economic frameworks) have impacted on many aspects of life in developed countries from the mid-1970s onwards (a period commonly referred to as late modernity), and particularly on the lives of young people. In late modernity, they argue, young people have little choice but to learn how to live with new realities such as labour market unpredictability and the fragmentation of traditional pathways through education and work. The meaning of transition has been affected by processes such as the increasingly targeted provision of welfare, workplace restructuring, changes in family structures and a reduction in community ties. Furlong & Cartmel (2010) and Leccardi & Ruspini (2006) show how young people struggle to manage changing circumstances across many different societies. Gerson (2010) writes about the way in which changes we refer to above have impacted on the nature of family, work and on gender in the United States. These studies document the changes in family structures over the last quarter of a century, and in particular the trend for young people to rely on family resources (social and material) until they are well into their twenties. It is increasingly common for young people to live in the family home until they have completed their education and found stable employment. This means that the kinds of transitions that were available to the Baby Boomer generation are not possible for subsequent generations (Wyn & Woodman 2006). Furthermore, the increasing need for young people, with and without a disability, to rely on family resources

to navigate the early post-secondary school years impacts on the reproduction of social and economic inequalities; insofar some individuals from high socio-economic background can draw greater resources from their families than their counterparts (Cuervo & Wyn 2012, Stokes 2012).

For young people, at an individual level, the personal management of uncertainty and risk is experienced as a pressure to make choices in a context where traditional certainties and institutional supports are disappearing. The widespread use of the idea of choice with reference to young people (for example, the idea of 'choice biographies') is sometimes understood as meaning that young people are free to make choices. As Woodman (2009) points out, the reality is the other way round. Young people are compelled to make decisions about things in which they have relatively little choice. For example, in an era of mass post-secondary education, a young person decides which educational course they will 'choose' on the basis of fairly limited options. The actual decision is compelled by the necessity of gaining further education and limited by the young person's ability to pay as well as the level of material and cultural support their family can provide. Hence, while young people may appear free to choose in regard to future careers and imagining their futures they are also 'obliged to be free and enact their lives in terms of choice' (Rose, 1999:87).

METHODS

The Literature Review synthesises international and Australian literature related to the personal and social factors that impact on the opportunities of young people with disabilities to maximise their independence and successfully transition to adulthood. The review draws on a comprehensive range of materials from across multiple academic disciplines, most notably sociology, health, social policy and education. Sources include government reports, conference proceedings, relevant monographs, journal articles, unpublished PhDs and online resources.

The authors have attempted to concentrate the literature survey around current or recent research (i.e. work published since 2000) with a focus on finding more recent material published from 2004 onwards. Preliminary analysis having confirmed the existence of a number of strongly pertinent earlier studies, however, we have had no hesitation in enriching our findings by consulting and citing such important sources as Rock, Ryan, Arnett or Furlong & Cartmel.

Relevant texts were identified using a range of methods, including general internet searches (GOOGLE SCHOLAR, etc), systematic keyword searches of educational and sociological databases (ERIC, CIJE, Medline, the Cochrane Library, Campbell Collaboration, National Centre for the Dissemination of Disability Research data base, ARACY, SSCI, AIDD Online Journals), general indexes (PAIS, APAIS), bibliographic 'trawling', and – primarily – the University of Melbourne

Supersearch facility¹. Abstracts, where available on-line, were scanned for possible inclusion. A number of key references were located through consultation with stakeholders and through 'snowballing'. Some attention was also paid to findings in 'grey literature', i.e. material not yet published or the interim results of projects still in progress.

The literature has been analysed to (a) identify and detail factors impacting, at a personal and/or social level, on young people with disabilities, their families and communities during the young person's journey or transition to adulthood, and (b) identify and detail factors likely to facilitate or enable opportunities for the young person to maximise independence, choice and control.

¹ In order to locate as much relevant material as possible, Keyword searching of databases made use of multiple descriptors, focusing on the three key areas of individual, family and community in relation to young people with a disability. Accordingly, searches typically consisted of combinations or 'strings' of terms denoting the population of interest (e.g. adolescents, youth, young people, disability/disabilities, family/families, siblings, extended family, community, neighbourhood, peers) and factors (eg. social adjustment, aspirations, social interaction, social isolation, social attitudes, peer relations, personal characteristics, resilience, parental attitudes, coping strategies, information, attitudes, choice, control).

FINDINGS FROM THE LITERATURE

In researching the literature, three themes emerged in regard to the research question: What are the important factors that impact on opportunities for independence for young people with a disability?

The themes discussed include:

- Identity development
- Resources and supports; and
- Attitudes

We explore how these themes highlight factors that facilitate or hinder meaningful choice and control for young people with a disability through having a range of opportunities at the level of the: individual; family; community; and through interaction between the 3 levels.

Identity development

The years around late teens to early adulthood for young people in industrialised countries are characterised within the psychological literature as years of change that focus on identity development (see for example Brown, 2004), although it is recognised in other literature that identity development occurs throughout life (see for example Kehily and Nayak, 2008). Taking a traditional psychological approach, Arnett describes the period from ages 18 – 25

as emerging adulthood. He argues that young people have left the dependency of childhood and adolescence but have not yet undertaken the enduring responsibilities of adulthood that then allows young people to 'explore a variety of possible life directions in love, work and world views' (Arnett 2000:469). He describes this as a period when many different directions remain possible and little about the future has been decided. Arnett argues that these years involve young people undertaking the character development necessary for the transition to adulthood including the acceptance of responsibility and making independent decisions (Arnett 1997).

However others, including Beck (1992), Giddens (1991), Hall and Du Gay (1996) and Melucci (1996) argue that in late modernity, identity development has become a task rather than a 'given'; growing up is about becoming rather than finding a fixed (or adult) identity. The implications of this are that in a changing and unpredictable world, young people need to develop identities that enable them to negotiate their own pathways. From this perspective, the task of maintaining and re-developing identity is ongoing, not limited to particular life phases and not completed.

Social networks

Research reveals how the work that young people do to shape identities is revealed in their narratives, or stories they construct, and are made possible by the social networks to which they belong (Stokes 2012). So what are the implications here for young people with a disability? As Wierenga (2009) notes, young people's stories reflect the worlds to which they have been exposed and in which they have already engaged. Other theorists provide insights into the ways in which social relationships are the key to performing identities and to having these performances recognised and reinforced (Davies 2006). Hence, although identity is seen as an individual task, identity is made possible through social relations.

The evidence suggests that for young people with a disability, having opportunities for meaningful social relationships is more difficult to achieve than for their peers without disability. There are a number of difficulties associated with developing these relationships including the time taken to develop face to face relationships, opportunity and the mediation of most social interactions by another person (either through the family or a carer). Furthermore, the dominance of the assumption that "growing up" necessarily means shifting the focus of identity development to non-family members obscures the extent to which it has become normative (amongst Generation X) for new forms of inter-generational relationships to occur (see Gerson 2010). The impact of changing notions of inter-generational relationships on families with a child or young person with a disability is almost entirely unexplored. It is significant given the finding that young people with a disability are more socially isolated than their peers. Muir et al (2009) found, compared to young people without a disability, young people with a disability spend more time alone and four hours per week less with friends.

Yueng, Passmore and Packer (2008) conducted a study with nine young people with cerebral palsy

(CP) to ascertain their views about citizenship. They found that even where these young people were living in the community they faced isolation and loneliness as a result of having limited social networks. Yueng et al noted that it takes a long time to develop social relationships and that a young person might have to engage in an activity many times before they were recognised by others and social interactions began to occur. It was noted that opportunities to form social networks were often mediated and dependent upon paid carers who may be more informed by duty of care than promoting social interaction. They stressed that simply having people in their lives (for example, paid carers) does not equate to having social networks and friendships.

De'Ath and Walls' (2003) study of young people with an intellectual disability in Ireland highlight the important part that social relationships play in the process of identity development. They found that during transition to adulthood, friendships and peer relationships:

- Provide support in the task of adjusting to new environments;
- Function as a mirror, helping adolescents to gauge how others see them and assisting in development of self-identity;
- Assist in negotiating relationships by establishing norms of behaviour; and
- Provide a sounding board for exploring values and aspirations.

The literature emphasises that young people with a disability have less opportunities for developing social networks and less opportunities to develop stories or narratives of themselves that draw on a wide range of resources and social interactions. They have fewer opportunities to develop identity narratives that enable them to negotiate their own way as much of their social interaction is mediated by a third person (either a carer or family member) despite finding that they in fact need more opportunities/time than young people without a disability to develop meaningful relationships.

Social relations with peers

Both young people with and without a disability express the importance of peer relationships. As with young people without a disability young people with a disability expressed a desire to have relationships with those experiencing similar and also different life experiences. Engagement with peers and friendships are nested structures that support young people in their developmental processes.

Throughout the literature there was an identified need for both young people with a disability and their family members to have friendships and peer relationships but also an acknowledgement that there were difficulties associated with making friends and engaging with peers. Kampert and Gorenczy (2007) stress the frequent desire of the cohort for more opportunities to make new friends. As one young woman in another study (Yueng et al 2008: 71) described:

I am bored out of my brain. I am ready to go out but have no one to go clubbing with. Nobody is there to go out with...I don't want to take my carers. I don't have enough friends.

In regard to concerns expressed by family, parents interviewed for the 2003 Quality of Life survey in Ireland, insisted that friendships were crucial for their children's happiness and well-being and that lack of friendships was a source of deep frustration to the young people (NFVB 2003). Another Irish study (Smyth and McConkey 2003a: 54), conducted with 51 special school leavers with severe levels of disability who had undergone transitions planning activities in Belfast, underlined the importance for both parents and the young people of purposeful occupation and friendship networks.

- 85% of the young people expressed a wish for more friends.
- 90% of parents expressed the desire for their children to have more involvement with friends of their own age.

McVilly et al (2006: 191), in their study conducted in Tasmania and New South Wales, emphasise the important influence of stable and rewarding relationships on quality of life, and benefits associated with interpersonal networks (and, conversely, of adverse consequences associated with poor social networks and loneliness). Based on a Loneliness Scale, administered to 51 participants, and interviews with a sub-set of those participants, the authors reported (a) that respondents valued both social and emotional dimensions of friendship; (b) that loneliness was least evident among young people who felt they were part of a network, and (c) that they valued relationships with peers who shared life experiences associated with their disability.

Most importantly, given the findings about the importance of peer relationships for young people, Solish, Perry and Minnes (2010) suggest that a shortage of opportunities for social interaction, rather than a lack of desire to participate, distinguishes young people with disabilities from their peers without a disability. Lack of opportunities can be compounded by lack of transport, lack of autonomy, and inaccessible telecommunications technology. In regard to telecommunications technology, a recent review of social media by Cahill and Hollier (2009) found that some sites are more accessible to people with a disability than others depending on the level of accessibility features available. Facebook was rated the most accessible site for people with a disability followed by Skype and YouTube. Flickr was somewhat accessible and Twitter and MySpace had few or no accessibility features built into the design.

Changing dynamics with family members through transition

One of the times of greatest change to family dynamics has been identified as during the transition for young people with a disability from school to post school options. Ryan (1997) and Mirfin-Veitch (2003) highlight the conflicting

emotions felt by many young people at leaving school, emotions that echo those of young people without a disability. Ryan cites typical responses from young interviewees, ranging from 'I can not wait to leave school ... I'm gonna have a party' through 'Part of me says I'm glad but another part asks why' to 'It's frightening when you leave school ... when you've got to go into the big world, it's really frightening'. [Ryan (1997), quoted by Mirfin-Veitch (2003:7)]

As Mirfin-Veitch (2003) notes, rarely do parents of young people with a disability regard transition simply in terms of moving from school to work. Murray (2007), in her study of parents of young people with severe disabilities in outer metropolitan Melbourne and regional Tasmania, describes transition from school to post school options as a continuation rather than a transition with less available options than for young people without a disability. More often than not it is regarded as a major family event involving change for everyone concerned (parents, the young person, siblings), as they come to terms with the reality that, contrary to the experience of young people without a disability, demands on the family are likely to increase rather than decrease during this life-stage as the support once provided by the school diminishes.

Although still relying on family resources, young people without a disability may have options to distance themselves increasingly from family in favour of peer group, or, as is increasingly the norm, to manage to blend ongoing close familial relations (especially through living in the family home) with strong peer friendships. Young people with a disability have more limited options in regard to their interactions. Lack of friends or social networks tends to reinforce the young person with a disability's reliance on family.

Based on an in-depth Australian survey of 218 parents, Davies & Beamish (2009) highlight the impact of the young person's journey to independence on family dynamics and also

engagement with the community through work and geographical location. Almost half of their respondents (n=102) reported that the transition from school of a family member with a disability had entailed "considerable" family adjustment, much of it related to increased support demands. Many of the parents (more often mothers) had been required to cease work (or reduce work-hours) in order to be home during the day (often resulting in financial hardship).

Other parents reported disruption to family life brought about by:

- Increased caring requirements;
- The need to move from country to city because of the rigours of transporting a young person daily to a distant adult service; and
- General frustration at a lack of viable post-school options.

While the authors concede that their study was compromised by a low (27%) response rate and over-representation of parents of young adults with high support needs, Davies & Beamish (2009: 253-256) believe that their findings still offer a useful insight into the 'substantial disruption to family routines and responsibilities' that frequently distinguish the young person's journey to adulthood.

Relationships with other people in the community

The literature confirms the importance of community connection for young people and that they value having the capacity to participate in, contribute to and play a role in their community. Yueng, et al (2008) in their study with young people with cerebral palsy found that the young people felt that involvement in the community was important because it helped demystify the many misconceptions about young people with disabilities. Involvement gave them a greater

sense of agency and reason to be involved in the community. They felt that it was important to be an advocate for other people with disabilities, as well as a role model for others so that they would participate in the community in the future. There was a recurring theme that young people with cerebral palsy felt they had a valuable story to tell others about their experiences. Their role as an educator to people without a disability was one they often had to take on when in the community and it added to their sense of being part of the community and valued by the community.

According to Solish et al (2010) "*Research with young adults with disabilities suggests that among the things that they desire most, their first priority was more community involvement and activities*". This priority is confirmed by Lewis et al (2007:194) who report concern at a lack of "*informal activities based outside school, home, and involving other young people*" as a consistent and recurring theme in their interview feedback. Wedgewood (in press), in her qualitative study of sport and the identity development of young men with physical impairments, highlights engagement in sporting activities as one way to develop social capital and gain both peer and family acceptance. Acceptance for these young men with a disability was played out both within the family, particularly in relationships with male siblings and fathers, and with peers in school.

Online participation

As discussed above, an important site for community involvement for young people with a disability is online or virtual communities as well as the geographic communities of which they were part. Schindlmayr (2007) points to the value of technological innovation, particularly the internet and software adaptations, in helping young people make contact with their peers, giving them a sense of belonging and breaking down barriers. In the literature about online participation for people with a disability there

is a view that people who experience physical impairments or the visual 'stigma' of disability are able to construct identities not related to their physical existence, to hide aspects of themselves and so remove their disability from the forefront of interaction (see for example: Dobransky and Hargittai 2006).

Bowker and Tuffin (2002) completed online interviews with 15 participants with sensory and physical impairments in New Zealand on their engagement in social media. They found that online communication offers another medium for presenting the self in which the visual cues for evaluating others were not necessarily accessible. The anonymity available to people online included the choice to disclose or not disclose their disability meaning that they did not have to deal with explanations and assumptions about their disability as part of routine interactions. They noted that the opportunity to experience anonymity is subjectivity rarely accessible to people with a disability. As one participant noted: *I value being able to exercise that choice as it is not one I can exercise in my daily life*. The participants discussed having a disability as one part of their identity. As one participant commented: *Although CP is an intrinsic part of who I am, there is more to me than just that*. Further work has found that this analysis is problematic. Moser (2006), in her study of the uses of new technologies in the lives of people with a disability in Norway, questions the binary that still exists between 'abled' and 'disabled' and the ways that the use of new technologies have contributed to this. She has found that, while new technologies are transformative and enhance the competence of people with a disability, they also reproduce the existing boundaries that constitute some people as disabled in the first place. Goggin and Newell (2006) note that it is important to look critically at the power relationships inherent in technology, and that focus tends to be on people's individual bodies as the problem rather than on the structures in society. As they comment further, 'people with disabilities are expected to cut their

cloth to fit the temporarily able-bodied world, and its new media technologies'...in its desire for the same, inclusion always requires the 'other' to stay in its niche as it is pressed into the mould of the normal rather than engaging with the real alterity and difference in an 'us' relationship (Goggin And Newell 2003:149).

A recent evaluation of the Livewire Online Community for young people living with chronic illness or a disability (Third and Richardson 2009) found that young people were able to positively integrate their embodiment and their identity, with many disclosing their disability to others while participating in online chat forums. This positive integration of embodiment and identity impacted on the density of online friendships established on Livewire.

Hopes and Aspirations

The literature reveals that young people with a disability have the same aspirations and hopes as other young people. Drawing on data from the Household Income and Labour Dynamics in Australia survey (HILDA) 2004, Emerson, Honey, Madden & Llewellyn (2009) deduce little overall difference between young people with and without a disability in aspirations such as accessing more training or education, making a lot of money, accessing sports and hobbies and having a long-term relationship or marriage. Other studies on young people without a disability (Wyn et al 2008) have found that young people valued financial security, personal and self fulfilment, having and caring for a family, having a special relationship with someone and being able to travel.

Yueng et al, (2008) conducted a study of young people with cerebral palsy (focusing on their civic participation) and found that these young people's aspirations were related to attaining independence

and having the right and capacity to exert control over their lives. As one young woman commented:

I want to be a normal person in a normal environment, have my own house,...not renting, I'd like to have my own home, my own car, a husband and children (Yueng et al (2008:69).

In common with the wider youth population, some young people with a disability may have strong aspirations for their future (realistic or otherwise), others may be quite undecided. Lewis et al (2007) emphasise the highly individualised nature of the experiences and views of young people with disabilities.

Decision making

Identity development is also linked to opportunities for meaningful decision making. In particular, young people need to have the capacity to embrace decision-making ('choice') and accept responsibility for building their own futures. But "while most young people may speak the language of individual choice, control and agency, many studies reinforce the fact that it is only for some that the rhetoric of choice, control and agency is accompanied by the requisite resources and opportunities" (Thomson, Bell, Holland, McGrellis and Sharpe, 2002:351) and is related to the political and social condition under which young people live.

What then does meaningful choice and decision making mean for young people with a disability? The extent to which decision-making processes acknowledge and include young people playing a role studies highlight the 'lack of voice'. Young people with a disability are not properly involved in decision-making at crucial points in their journeys to adulthood. In a British survey of 250-

plus families in 2000, Heslop et al (2002), recorded that four out of 10 of the young people surveyed had little, if any involvement in making decisions and a quarter had none².

The importance of young people's involvement in decision-making is highlighted by Stokes (2009). Her study researched young people without a disability accessing resources to make decisions about their futures. Across Australia, 169 interviews were conducted with young people at schools in years ten to twelve. Young people described the quality of the relationships that needed to be present before they were willing to access the advice and support of school counsellors. For a relationship to develop involving trust, more than one counselling session was needed. An earlier study (Stokes and Tyler, 2001) found that young people needed about four sessions with an advisor to build up enough trust to start talking about possible futures. Yeung et al (2008), who studied young people with a disability also focused on the building of trust. They found that young people with a disability need more time to develop social relationships than young people without a disability. This means that young people with a disability may need a longer time-frame to build up the levels of trust that enable them to access the resources that will enable them to make sound decisions about their futures.

Another study, by Pilnick et al (2010) illustrates how challenging it can be to create the conditions that enable young people with a disability to have the capability to make decisions. A longitudinal study of 28 young people with learning disabilities aged 18/19 years who were leaving two special schools in England, it shows that despite the best intentions of professionals, choice and control were taken away from young people with a learning disability. Pilnick et al (2010) recorded interactions during meetings undertaken in a

² Likewise the Barnado's Organisation suggests that barriers to social life can be combated through pro-active invitations by the young person and involvement in decision-making about desired activities. See Barnado's, (n.d.) My Voice, My Choice, London.

formal setting with a number of professional staff and the young person's parent. There was a lengthy agenda covering a wide range of areas to be discussed. The findings reveal that attempts to empower young people through this process can actually undermine their control. When the young people failed to make "appropriate" decisions (as defined by the professionals and according to a limited range of options available) their decisions were overruled. They found that young people were guided towards options that others felt were in their best interests, rather than options they aspired to or imagined they would enjoy.

There is also evidence that lack of choice does not necessarily decrease as young people with a disability get older. In a UK study of choice about housing needs, 72 adults with learning disabilities articulated their choices about preferred housing options (McGlaughlin, Gorfim with Saul, 2004). The study found that while the people with learning disabilities were able to describe their needs, would like to be able to choose their housing options and were aware of the support they required, they also felt powerless because decisions were often made on their behalf by professionals or carers. It was found that people with learning disabilities were reluctant to speak about their wishes for independent living if they felt it would put them in conflict with their families. The researchers noted that to be able to make decisions, people with learning disabilities needed to be provided with opportunities to try out independent accommodation options, be allowed to make mistakes and learn skills after moving (in effect to be able to take risks). The study also recommended that people with learning disabilities who had succeeded in achieving independent living arrangements be used as role models for others. As noted previously, young people develop positive narratives of self through the worlds and ideas they are exposed to.

The same social processes have been noted in studies of sexuality and young people with a disability. Bedard et al (2010) interviewed 32

people with developmental disabilities. This study explored sexuality issues for young people with developmental disabilities. The research found that there is a perception that people with developmental disabilities are not competent at making decisions, particularly regarding their sexuality. Most of the young people interviewed identified as heterosexual with a small number identifying as bisexual or homosexual. The authors concluded that it is important to respect the sexuality choices these people have made.

In contrast to the documentation of barriers to choice and control for young people with a disability, the internet has been identified as a site where these young people are able to act on the opportunity to make decisions and choices. An evaluation of the Livewire Online Community for young people living with chronic illness or a disability (Third and Richardson 2009) found that young people's opportunity to make decisions and sense of empowerment and accomplishment were further enhanced when the young people as users were able to contribute to the design of the site and upload user generated content. A recent review of social media accessibility (Cahill and Hollier 2009) notes that social media allows anyone with an internet connection to publish digital content and share in online networks, conversations and debates.

Managing Risk

The literature on risk is divided, falling into discipline-specific categories. The idea of risk and the definition of risk-taking behaviour are both contentious. Literature that draws on psycho-social frameworks assumes that risk-taking is a particular characteristic of adolescence and is located within individuals. Risk-taking is seen within this framework as both normative (i.e. a normal part of development) and something that should be prevented. For example, Steinberg (2010) argues that while risk taking behaviour in adolescence is associated with poorer health

outcomes, it is also viewed as a developmental hallmark of typical adolescent behaviour. Ponton (1997) argues that risk behaviours can have benefits because they are associated with the development of independence and survival without the benefit of parental protection. Risk taking behaviour, it is also argued, can also help foster independence in adolescence and is viewed as assisting with identity formation (Le Breton, 2004).

Literature that draws on sociological frameworks points out that risk-taking behaviour occurs throughout life, and is not empirically limited to any particular age group. Sociological frameworks tend to focus on the conditions that place young people at risk. For example, drawing on research by the Australian Institute of Health and Welfare (2007), Wyn (2009) points out that there is a direct association between a young person's level of social support and the number of health risk factors they exhibit. Around 30% of young people who lacked social support were daily smokers compared with 17% of other young people. Thirty per cent of young people who lacked social support did not participate in social activity or did so less than once a week, compared with 20% of other young people. Eleven per cent of young people living in the most disadvantaged areas lacked social support compared with 5% of those living in the least disadvantaged areas (AIHW, 2007: 105). In other words, a lack of social supports places young people at risk, and increases the likelihood that they will engage in risky behaviour.

The finding that lack of social support is associated with greater risk-taking behaviour by young people may be the explanation for the findings of a recent Canadian study by Raman, Boyce and Pickett (2009). This study surveyed 7235 students from grades 6-10 and found that students who reported having a disability experienced significantly higher rates of injury from similar amounts of risk taking behaviour by students who did not report having a disability.

Student with a disability engaged in risk taking behaviour more frequently than their peers who did not report having a disability. As the students with a disability grew older (years 9-10) their risk taking behaviour increased and they reported higher levels of injury.

Other research has also concluded that young people with a disability are more likely than their peers without a disability to engage in risk-taking behaviour. Brunnberg, Bostrom and Berglund (2009) compared the sexual behaviour of young people with a disability (hearing impaired) with young people without a disability. All 15-16 year olds in mainstream schools in the county of Orebro, Sweden, (numbering 3084) completed the survey, with a completion rate of 85.5 percent. The survey was also completed by young people from a special school for deaf and hard of hearing students. Brunnberg et al (2009) found that 15-16 year old boys and girls with a disability were more likely to report they had engaged in sexual activity at a younger age than those without disabilities, even though conventional ideas often consider disability equates with an asexual status.

A number of writers have highlighted the impact of parental concerns about safety and risk as inhibitors in the young person's journey to independence. Heslop et al (2002) conducted a questionnaire survey with 283 families and interviews with 27 young people with a disability and 27 parents and carers in England. More than half the parents interviewed for the Bridging the Divide project spontaneously raised concerns about safety and risk. A quarter of the young people interviewed for the project had experienced bullying, assaults; others expressed concern about personal safety.

Smyth & McConkey (2003b), compared parents' perceptions of risk with those of their children. They argue that parents typically see the young person with a disability as vulnerable, unable to stay alone in the house, use appliances or catch public transport. Fear of sexual abuse or concerns

about the young person's sexuality can impact on their opportunities to develop friendships or relationships. However, danger-avoidance inevitably tends to restrict the young person's freedom of choice. The research highlighted problems faced by parents with children with a disability in obtaining advice about sexuality issues and cite a clear need for more support and information in this area (Heslop et al (2002); Townsley (2004), Smyth, & McConkey (2003b).

While some commentators argue that parental protectiveness can stifle the young person's independence, impacting on self-esteem and sense of identity, Almack, Clegg and Murphy (2008:296) concede that policy agendas of self-determination can be fraught with risk for parents and their children. They echo Fyson & Kitson (2007) who argue that, its admirable aims notwithstanding, current policy fails to fully recognise the need to protect vulnerable young people. As a consequence, parents are required to deal with "competing interpretations of risk acceptability and responsibility for their young person". On one hand, in Western societies parents are accountable for the safety and welfare of their children; on the other, increasingly, they find that policy challenges their right to make major decisions on the young person's behalf.

Based on findings from a study of 28 English special school leavers with severe disabilities, Almack et al (2008) note that parental responses can include:

- Trying to find a happy medium between letting go and being over-protective,
- Contesting or accepting expert opinion on the basis of having the "fullest knowledge" of the situation.

They also note that the difficulties faced by parents can include (a) concern that they are being undermined by professional opinion that they do not know best; or (b) concerns at being

seen or labelled as either over or under-protective while attempting to manage their child's ongoing dependency. Almack et al (2008:292-295) cite a range of parental comments as illustrative of typical dilemmas:

You just worry ... I mean, they've led such a sheltered life ... and then all of a sudden it's this big change.

I know all the new government guidance says we have to include our children ... in the decision-making process but ... he wasn't going to make a decision except to stay at home and that wasn't acceptable ... he hasn't got the bigger picture and he'll just say what he wants to do at that moment in time ... I can't let him sit around at home, stopping me going to work, watching telly and videos all day long, becoming more and more isolated.

I don't want her to feel like we're pushing her out but I was advised [moving out] would be good for her ... It doesn't bother me if she stays at home but it's not really good for her, is it?

In order to be able to make informed decisions, young people with disabilities, like their peers without disabilities, need to be able to make mistakes and learn from them. The literature reveals that families face a dilemma in deciding what is an acceptable risk. This finding highlights the need for information and support to assist families and young people with a disability to make informed decisions.

Self-confidence and self-esteem

Given the limited research available on self-confidence and self-esteem for young people with a disability, it is difficult to draw comparisons between this group and young people without a disability. The small amount of available literature suggests that there is a need for support to assist young people with disabilities to enhance their self-esteem and confidence.

One of the sources of evidence about this comes from research undertaken in the United Kingdom. The Hope Farm Trust and Norah Fry Research Centre in England (Heslop et al 2002) undertook a survey of 283 families and interviews with 27 young people and their parents/carers. The findings, which confirm those of research on young people without a disability (see Stokes 2000, Brown et al 2001, Smyth, Down and McNerney 2010), reveal that young people with a disability typically wanted (a) encouragement (b) to be treated as an individual, (c) greater responsibility and privacy, and (d) someone with whom to talk things over. Above all, they wanted consistent support to enhance their self-confidence and self-esteem.

Another source of evidence comes from a US study. Based on a cross-sectional study of 85 young Americans with physical disabilities, Antle (2004) has underlined the connection between success and a positive self-image or 'sense of self'. While she finds that most young people with physical disabilities have global self-worth scores similar to those of peers without disabilities, she acknowledges that her findings are inconsistent with earlier studies that judged young people with physical disabilities at higher risk than their peers of psychosocial adjustment difficulties. (She hypothesises that young people with physical disabilities may well need higher-than-average levels of self-esteem to compensate for the attitudinal and physical barriers they face throughout life).

Interestingly, another US study (Manuel, et al. 2003), that examined predictors of self-esteem in 50 young people with Cerebral Palsy, found, on average, that self-esteem was high with scores comparable to samples of healthy adolescents and young adults with chronic illness.

The small amount of available evidence on self-confidence and self-esteem suggests that young people with a disability have the same requirements as their peers without a disability although the situation is complex however.

The section above has outlined the many factors that impact on the identity development that young people with a disability undertake. Young people with a disability have hopes and aspirations similar to young people without a disability. Through the literature we gain a picture of the many challenges they face to develop social networks, make meaningful decisions and learn to manage risk. Throughout all this is the pivotal role that families play in these processes.

Resources and supports

It is important to acknowledge that socio economic factors for all young people, and in particular those of young people with a disability, impact on possibilities for choice. As outlined extensively in the literature young people who are able to draw on social, educational and economic resources have better outcomes than those who are less able to do so. The recent destinations data of school leavers in Victoria (Teese, Nicholas, Polesel and Helme 2006) confirms a strong correlation between socio-economic status of students and their corresponding parental education levels with their school achievement and post school destinations. Nearly two thirds of all low achievers in year 12 come from low to very low socio economic backgrounds, while two thirds of high achievers are from high to very high socio economic backgrounds. (For further international examples see Bourdieu and Passeron 1979, Furlong and Cartmel 1997, Ball, 2003 and national examples see Lamb et al 2004, Keating and Lamb 2004, OECD 2004, McGaw 2006, Teese, Nicholas, Polesel and Helme 2006, Lamb 2007).

The impact of socio economic resources is of particular relevance for young people with a disability and their families. Hayes, Gray & Edwards (2008) note that disability can impact significantly on the economic situation of the primary carer and their families particularly at transition points when young people move from

school to post school options as carers no longer have the support provided through their child being in the school setting on a daily basis.

Hayes et al (2008) also cite evidence that (a) the employment rate of primary carers was 42.8% in 2003, compared with the Australian national average of 59.2%, and (b) many unpaid carers would like to be in paid employment. A recent AIHW (2009b: 3-4) study of carers highlights finance, service provision, workforce participation, stress and burden as significant and ongoing issues confronting the cohort. According to this study, many carers reportedly:

- Experience difficulty in meeting everyday costs of living;
- Incur additional expenses associated with caring (transport, medication, equipment);
- Have restricted income-earning capacity because of their caring responsibilities; and
- Have great difficulty balancing caring and workforce participation (currently, employment of carers is mostly part-time)

Family resources

There has been an increasing understanding of the roles families play in supporting all young people through their adolescence, into young adulthood and beyond. Jones (2005:5) comments on the capacity of families to be 'mediators of external structural factors and transmitters of social and economic advantage and disadvantage' from one generation to the next. Focusing on the capacity of young people without a disability to discuss their futures with trusted adults, Stokes (2009) found that family, including mothers, fathers, siblings, uncles and cousins were most frequently mentioned as a source outside school when discussing what may happen in the future. Over 47% of the students interviewed mentioned that

they talked first with family members about their future options. The young people were selective about the family members they spoke with, seeking out family members who were interested in similar areas or, in the case of siblings, were older and had made the transition from school to post school options and could provide advice about the steps to take. This was compared with 20% who mentioned they would discuss future directions first with their friends. These findings concur with other research on parental involvement in the gathering of information and making decisions about the future which has found that the information is very specific and based on the life experience of the parents and therefore highly trusted (Bryce and Anderson, 2008; Kennedy and Haines, 2008; Rainey et al 2008).

For young people with a disability, family support, as the single most important contributor to a young person's being able to maximise independence and transition successfully to adulthood, is a recurrent theme in the literature. Beresford (2004: 583), for instance, insists that, wherever or whenever positive transition outcomes occur, it is usually 'very much down to the role played by parents'. Dyke, Leonard & Bourke (2007) argue that – of all predictors of success – having parents involved in all aspects of the transition process and experience is critical. They see an obvious correlation between the young person's success at achieving transition to adulthood and parents who are supportive and encouraging, are strong advocates and have clear expectations of their child's abilities. (They concede that socio-economic variables can also be influential, acknowledging that parents who are privileged economically and educationally often have more time, resources and skills to provide support through the process). Heslop et al (2007:65) concur: 'Putting families at the heart of decision making is more likely to mean paying proper attention to the wishes and views of the young person who is the whole focus of the transition.' Based on an in depth study of 128

young adults, Neece, Kramer and Blacher (2009) relate transition satisfaction to multiple measures of family well-being, and argue the need for considering the broader family situation when planning for the young adult's future.

Pascall and Hendey (2004: 170-171), who interviewed both young people with a disability living independently and with their parents, cite responses from young people living independently that confirm that a balance of parental nurture, encouragement, support and, in particular, expectations that the young people with a disability could achieve in all spheres of their lives as, far and away, the biggest contributors to successful journeys to adulthood and living independently. For example:

[Mum] expected me to do and have exactly the same things that everybody else was expected to have.

Mum was all for me going out and making a life.

My mum ... would sort of push me into going out and about and making my own life really.

The young people with a disability who were living independently described a 'style of parenting that prepared them for living in an individualistic world' ...and 'gave accounts of parents who cared, fought and negotiated for them, but also ensured that they could care, fight and negotiate for themselves' (Pascall and Hendey 2004: 173).

Pascall and Hendey (2004) echo Dyke, Leonard and Bourke (2007) in acknowledging that the most independent young people are generally those with parents in higher socio-economic strata whose parents had 'skills, time and money'. They found that what they called 'unusual conditions' underpinning these young people's move to independent living including having received compensation payments, having socially advantaged and professional parents with a

knowledge of networks and negotiation, and having parents who had prior experience of disability either personally or through having another sibling with a disability. In an earlier article Hendy and Pascall reported '[o]ur most independent respondents described a hard-edged care that fostered independence. But those parents also had a relatively high level of social, economic and cultural resources' (2001: 12). In comparison the group still living with parents had parents from lower occupational categories and had fewer economic, social and cultural resources. Respondents from this group described equally close relationships with their parents but recognised that these close relationships could provide a barrier to independence. The young people both relied on their families for emotional support and, in turn, were relied on by their parents. As one respondent commented:

My Mum would miss me if I left home because she would have nobody to look after

Hendy and Pascall (2001) and Pascall and Hendey (2004), from their study identify qualities of parenting likely to maximise their child's prospects of independence including:

- Encouragement, support, assistance (both in terms of practice and engendering attitude of mind),
- Balancing of nurture with strategies to foster independence,
- High expectations,
- Implicit confidence in the child,
- Ability to negotiate with (and, when necessary oppose) professionals, and
- Resources.

Sibling Support

In terms of maintaining parental well-being and ability to support, Neece et al (2009) emphasise the importance of sibling involvement and support. Based on a series of interviews with six young adults regarding their relationships with sisters or brothers with dual disabilities, Harland & Cuskelly (2000) note that sibling support can include providing respite for mothers (generally the primary carer), assistance with practical activities, provision of communication support, supporting the young person's personal development by offering encouragement, providing companionship and emotional support, keeping up social contact. While they concede the limitations of their study, and while they acknowledge that relationships can be influenced by such variables as feelings of obligation, guilt at lack of input, anxiety about the future, Harland & Cuskelly (2000) highlight the important (albeit secondary) support role played by many siblings in assisting their parents especially their mothers.

Community resources

With regard to community resources and young people in general, support for families from small community support circles and parent self help groups is often mentioned. In general there are clear benefits for the whole family (in terms of emotional support, practical information-sharing, even such day-to-day issues as sharing transport) in parents being able to maximise their connections with other parents (going through a similar situation) and with key professionals. Parental self-help groups, providing advice based on shared experience, are also recommended by Smyth & McConkey (2003b). Heslop et al (2007: 65) note that pro-active, advocating parents can contribute to better outcomes for their child, conceding that parents from "more privileged" (meaning socio-economically wealthier) backgrounds generally have an advantage in this regard. Parents interviewed by Lewis et al (2007)

typically reported the value they derived from small familial and community support circles (rather than from a large, impersonal network of supports).

This section on resources outlined the important role that parents, siblings and close community connections play to support young people with a disability. It also outlines aspects of parenting and familial relationships that enhance attainment of independence including: encouragement and the balance of nurturing with provision of opportunities to undertake independence; parents fostering high expectations; and parents having the skills to negotiate with professionals.

Attitudes

Family attitudes

As is the case for parents with children without a disability, Mirfin-Veitch (2003:13) notes that parents with a child with a disability usually have a vision for their child's future. But with this vision come some dilemmas as the young person with a disability moves to post school options. These dilemmas include:

- Wanting, on one hand, to create opportunities for the young person while, on the other, seeking to ensure he/she is safe;
- Wanting to ensure the young person has a good life while wanting their own separate lives;
- Wanting to ensure the young person has a separate and fulfilling social life while wanting to be less involved in that social life themselves;
- Wanting to maximize their child's potential while wanting to accept him/her for who he/she is.

Parental views regarding sexuality

While there is not a significant body of literature in regard to family attitudes to sexuality for young people with a disability it is an important area to be addressed in regard to attitudes to independence and opportunity. Ballan (2004) found that the sexuality of people with developmental disabilities has been both denied and feared, with views such as they were asexual or "breeders" of disability. This has led to parents of such children experiencing anxiety over their children's sexuality and often leading to overprotection of their children, inhibiting independence. Isler et al (2009), who surveyed 40 Turkish parents (mostly mothers (87.5 per cent) who had children with an intellectual disability, aged 15 years and older, found that parents of children with an intellectual disability had had no education on sexuality and that some of their beliefs about their children's sexual activity were wrong. The authors concluded that, given the umbrella opinions about disability and asexuality, adolescents with a disability needed to be given the opportunity to express their sexuality in a healthy way.

Community attitudes

Heightened visibility of people with disabilities, as a consequence of policy transformations throughout the western world over the past 30 years or so, has made significant inroads into educating the general community and changing negative attitudes and prejudices against disability. In this context, Wynn et al (2006:90) describe community relationally rather than geographically, as representing "*the ongoing transactional relationship between persons, objects and space within the environment ... a community should provide a setting in which individuals experience a sense of belonging and oneness with others and where they feel safe to explore and achieve their unique potential*". A comparative study of community inclusion of young people

with and without disabilities living in regional Queensland found there was a lack of substantive difference in the experience of both cohorts (Pretty, Rapley and Bramston 2002).

Even so, negative attitudes have persisted (and continue to do so) in the community and have, in fact, been ranked by Johnson (2000:31-2) (along with aspects of access to resources and services) as the 'most commonly mentioned external barriers' to participation in favoured activities. Yueng et al (2008:70) also found that stereotypical assumptions, low expectations and misunderstandings about the particular impairments had impacted on the young people they interviewed. As one young person with CP commented:

People think we're stupid but we are not... they think we are not intelligent.

Morris (2001) argues that strong experiences of social exclusion felt by many young people with disabilities closely relate to a generalised lack of respect. She suggests that the invisibility of more severe levels of disability has been compounded by community pre-occupation with integration into the labour market. Young disabled people themselves have underlined their concerns at being shut out of society, not being listened to, having no friends, being made to feel they are a burden, feeling unsafe or bullied and being dependent.

Community attitudes towards sexuality

Based on common assumptions and those of the medical model about the sexuality of people with a disability, Rembis (2010) argues that the common and medical assumption is that sex and disability are incompatible terms. He argues that the social model of sexuality for people with

a disability is limited and the new scholarship that challenges assumptions about sexuality for people with a disability actually reinforces heterosexuality. Much research assumes either heterosexuality or asexuality, thus impeding opportunities for independence for people with a disability.

This issue is raised by a study of an Australian project that was designed to develop training material for people working with young people with a disability who are gay, lesbian, bisexual or transgender in order to promote an understanding and awareness for them in the community (Noonan and Gomez, 2010). The issue of sexual consent and of the person with a disability's right to express sexual freedom and consequently some independence was raised as a matter of concern. The authors refer to people with a disability's international rights which state that people with an intellectual disability have the same range of sexual desires and needs as other people. Supporting the rights of young people with a disability to have their sexual desires/needs fulfilled is an important component in their achievement of independence.

Attitudes in Schools

Attending school and dealing with attitudes and perceptions of disability is an important area site that young people with a disability have to negotiate. Antle (2004:170) supports the role that schools can play, arguing for community initiatives that range from direct work on social skills to attitude change exercises in schools, as school is the "most influential social system outside the family".

Norwich and Kelly (2004) completed a comparative study of young people with disabilities in a mix of mainstream and specialist

school settings. They found that more than half of the sample reported bullying related to their learning difficulties, and emanating from students at other schools, neighbours and peers outside school. One young student was quoted as saying:

I don't have any much friends because, you know, I'm from a [special school]. They just think they're [sic] thick or something ... [and say] horrible things about my school.

Significantly, special school students reported considerably more bullying than did students integrated into mainstream settings³. The authors argue that the findings have implications both by underlining the pervasiveness of bullying and by identifying segregated special school students as much more likely to be bullied than their peers integrated into mainstream settings. By extension, the findings lend support to the view that bullying diminishes through exposure, familiarity and interactions between students with and without disability.

At another level, and one that potentially impacts just as strongly on the young person, is misinformation or lack of information and how that impacts on teacher attitude. Mirfin-Veitch (2003:viii), for instance, highlights the destructive nature of 'low expectations' in the classroom, and notes that assuming that a young person will not succeed in a learning environment can adversely influence both the child's performance and self-esteem. Lewis et al (2007) note the stress and discomfort felt by many young people with disabilities at having the distinction of being 'different' or 'special' reinforced insensitively in classrooms. Based on young people's input, Lewis et al (2007) differentiate between helpful and unhelpful attitudes. Unhelpful attitudes are defined as lack of sensitivity or thoughtlessness;

helpful or 'supportive attitudes' are identified as kindness, sensitivity, honesty, straightforwardness and respect.⁴ Lewis et al (2007:192) confirm clear links between the young person with a disability's self-image and the degree to which schools and communities foster inclusiveness.

The positive impact of proximity and interaction is demonstrated quite eloquently in another study, this one American. Hendrickson et al (1996) report on findings from a survey of 1100-plus American middle and high school students. The Student Friendship Perception Survey (SFPS) elicited the views of young people (i.e. students) without disabilities and their teachers on (a) the possibility of friendships with peers with severe disabilities; (b) the likely beneficiary of such friendships; (c) strategies that might help facilitate such friendships; and (d) feelings or thoughts likely to make it personally easy or difficult to develop such friendships.

Some respondents confessed that awkwardness on their part could be an impediment to facilitating such a relationship. (Comments included "I wouldn't know what to say or do", "I would be uncomfortable", "People might tease me" or "They wouldn't fit in with my friends"). Most feedback was positive though, with respondents generally agreeing that friendships with students with severe disabilities were possible, desirable and potentially personally rewarding ("It could be fun"). Approximately 38% of the student sample reported having had a friend with a severe disability, a figure the report attributed to a combination of physical integration in the schools and facilitative teaching and school culture.

⁴ Lewis et al draw their evidence from four linked projects, funded by the Disability Rights Commission, in 2004-2006. The projects, which examined experiences of disabled school students and their families across Great Britain, encompassed a parent survey (N=1776), case studies of individual children and young people (N=36), three focus groups and a series of inclusive project advisory groups. Lewis, et al, p.189- 195

³ The study extracted the views of 101 British students with Statements of Special Need for mild to moderate learning difficulties.

The overall results of the survey were seen as:

- Indicative of progress made in schools through generalised inclusion policies
- Indicative of a general willingness/preparedness by students without disabilities to interact with students with (severe) disabilities, both in and outside school, in order to promote friendships
- Confirmation of the significant role friendships play in the lives, and quality of life, of all adolescents.

Henrickson et al (1996) acknowledge the limitations of their survey, including the unrepresentative geographical focus of the sample and the potential (in common with many such surveys) of disparity between what the respondents say and what they might do in practice.

Attitudes in the Workplace

The task of changing employer attitudes about potential employees – and beliefs about customer attitudes towards 'different' employees (aged, indigenous or people with a disability) – has been identified as a primary challenge in a recent report to the Victorian Department of Communities and Workforce Participation Task Force (Meere 2009). Canadian research (Shier et al 2009) confirms that public attitudes/prejudice are the most frequently reported barrier to social inclusion, and argues strongly for social policy programming (and expenditure) that actively educates employers and employees about the experiences of people with a disability in workplaces. This need for education has been reiterated by Yueng et al (2008) who interviewed young people with cerebral palsy and reported that the young people had to prove themselves as competent in the workplace because employers lacked knowledge about and were not familiar with young people who had a disability.

Attitudes of other workers/employers can be affected by the level or type of disability. Winn & Hay (2009:105) cite (a) a greater level of satisfaction among employers with workers with mild intellectual disabilities or a physical disability (b) a less positive attitude towards employees with mental health or emotional issues or complex disabilities. They assess that a young person with a physical injury is likely to be viewed more positively by workers and (prospective) employers than a young person with an intellectual or mental health impairment. However: "The indications are that individuals with a disability still have to combat at times deep-seated prejudices in the labour market ... even when a fully functioning school-based transition process is in operation" (Winn and Hay 2009:112).

This section reveals the ongoing work that still needs to be done particularly in regard to attitudes in school, the workplace and the community to foster inclusiveness and promote independence and opportunity for young people with a disability. Through the review of the literature comes a picture of the success of promoting an inclusive culture (see section on attitudes in school) but also outline the further work that needs to be done to educate all people about disability.

CONCLUSION

The literature reveals that there is a changing and complex interrelationship between the individual, family and community factors that impact on maximising independence for young people with a disability. It supports the view that there is little difference between the hopes and desires for having choice and for exercising control in the management of their lives between young people with a disability and young people without. The research reveals little overall difference between young people with and without a disability in aspirations such as accessing more training or education, making a lot of money, accessing sports and hobbies and having a long-term relationship or marriage. All young people value financial security, personal and self fulfilment, having and caring for a family, having a special relationship with someone and being able to travel.

The review draws attention to the changing experience and meaning of youth transitions for each generation in response to emerging social and economic conditions. The capacity to build and maintain strong social ties with both friends and family is a hallmark of late modernity. These factors have very significant implications for young people with a disability.

The literature further reveals that wellbeing, having the capacity to exercise choice and control over one's own life, is strongly associated with having strong social connections. However, evidence on the situation of young people with a disability suggests that they are more likely than their peers without a disability to be socially isolated and that they take longer to forge strong relationships of trust. Closely related to this is the impact of community attitudes and perceptions as they are the most frequently reported barriers to social inclusion. This argues strongly for social policy programming (and expenditure) that actively educates the community about the experiences of people with a disability.

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