

# Evidence Briefing on Respite Services for People with Intellectual or Developmental Disability

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## Overview

This report will provide a summary of the current state of respite on a global scale, and provide research evidence to support the potential St.Amant respite service expansion. Respite is a range of services aimed at supporting families and individuals with developmental or intellectual disabilities with/without complex health needs. For decades, these services have arranged short-term breaks or admissions of these individuals which provides relief to families or caregivers from the demands of care. All around the globe, respite is provided under various programs, including weekend, overnight, holiday, and day care programs. Services are available in settings in the community, hospitals/institutions or in the recipient's own home. The literature review conducted was a scoping review that aimed to integrate the findings from reports of both quantitative and qualitative studies of respite services or respite related information around the globe. The majority of the literature collected from this study originated in the UK and Ireland.

Respite has been proven to have many benefits, not only for families, but also the clients receiving the respite care. The increase in stimulation from activities and interaction for recipients results in improved social and independence skills. Families overall experienced improved functioning due to significantly decreased caregiver stress levels and the addition of time for other activities. However, families using respite services also expressed frustration from encountering some obstacles. The majority of these obstacles were related to the limited availability, accessibility and flexibility of respite services, and the high expenses associated with it. In part, all of these difficulties result from the mismatch of global supply and demand for respite. This is a paramount issue, as this population of individuals with intellectual or developmental disabilities are extremely vulnerable, and are more likely to experience marginalization and poverty. Recent changes in population trends have resulted in a larger and on average older aged global population. This directly contributes to the growing number of those who are in need of and consequently denied respite services, thus increasing the urgency for change. This large change must first begin with small steps. The first step is to expand and restructure respite services within our own communities in order to meet these increasing demands. Currently, respite services are provided within St.Amant's large main residence, Red River Place (RRP). There are currently six beds designated for respite. Respite is scheduled on a 'first come first serve' basis and can be booked up to once per month for stays up to seven consecutive days. In the 2012/13 year, respite care was provided to 29 adults and 10 children, resulting in 2051 days requested and 1878 days actually provided. 173 requested days could not be accommodated. The current wait list for respite services is 25 individuals (16 children and 9 adults), resulting in a wait time of approximately two years. These numbers will continue to grow, unless action is taken promptly. It is estimated that St.Amant will require an additional eight beds in order to meet this need, in addition to widening the range of respite options to include fun holiday experiences.

### Evidence Briefing on Respite Services for People with Intellectual or Developmental Disability

There are over 650 million people living with disabilities around the globe (United Nations, 2006). Respite was first introduced in Canada in the late 1960s as a response to a de-institutionalization movement (Canadian Healthcare Association [CHA], 2012). The ideal was to shift those with intellectual or developmental disabilities from a hospital/institutional setting, and back into the community. This was according to the belief that care for a person with a disability is best provided in the family home and community (CHA, 2012). Respite is intended to provide family members who are caregivers to these individuals a break, thereby significantly reducing stress levels. Research has shown that significant benefits of respite are evident in not just the individual level but also the community level. Unfortunately, the respite services that are currently available to the public are unable to meet the growing demands of our population on a global scale. Waiting lists are continuing to become longer, and an increasing number of families are unable to access services. This report will provide a brief overview of respite services across the globe, discuss the benefits and obstacles associated with respite, provide a brief cost analysis, discuss the importance of restructuring and expanding respite, and the barriers preventing these changes.

### **Respite Services across the Globe**

The following section describes the variations of respite services across the globe found in the literature. These services are segregated according to geographical region. See Global Respite Services Table in Appendix A for a summarized table of services.

#### **Canada**

Regional care centers (such as St. Amant or Red Roof Retreat) currently offer respite to a limited number of children and adults with multiple disabilities and significant/complex needs. In St. Amant specifically, there are currently 6 beds designated for respite. During admission, the individual receives care appropriate to their needs and may access limited recreation activities. Where possible, individuals are encouraged to continue programs in the community (for example, school or day care program). Respite is currently booked on a 'first come first serve' basis, and can be booked up to once per month for stays of up to seven consecutive days (St. Amant, 2012).

The Red Roof Retreat is another example of a Canadian organization that offers respite to children, youth and young adults with intellectual or developmental disabilities. Located in Ontario, they have a range of programs to choose from, including weekend respite, adult day programs, summer camps, teen nights, horseback riding, educational and recreational school trips (Red Roof Retreat [RRR], 2013). Currently, 70% of the Red Roof Retreat's \$420,000 budget is supported by charitable donations from third-party events (RRR, 2013). The cost to the facility for providing respite to five individuals per weekend is over \$3,000; however the Red Roof Retreat only charges families \$130 per weekend (RRR, 2013).

#### **United States of America**

American literature divides respite services in the US into in-home and out-of-home services. The in-home services (Whitlach, 2006) can be broken down further as informal or formal (Caldwell, 2003; 2007). Informal respite consists of family, friends or neighbors hired as support workers. Formal supports

(Whitlach, 2006) are other hired staff, which provides care in or out of the home. Out-of-home services (Mullins, 2002) consist of community or institutional based services.

### **Singapore**

Literature sourced in Singapore outlines the following respite services available: home support, day-care service, short stay in institution and emergency/overnight in institution (Ng, 2009).

### **South Africa**

South African literature describes respite services as community clinics which provide care to both children and adults with disabilities (Sandy, 2013).

### **Taiwan**

Respite care was legislated as a community service for adults with an intellectual disability in 1993. It was intended to “provide family members who care for an adult with a disability with short-term breaks and so avoid/delay the out-of-home placement of those adults” (Chou, 2008). These short breaks can consist of care within the client’s own home, or out of home care (Chou, 2008).

### **Australia**

Respite services in Australia are generally divided into two categories; in-home and out-of-home (Chan, 2008). The in-home services consist of activities in a variety of settings; a personal care attendant, home-care and child-minding services (Ridley, 2003). The out-of-home services are day programs held in short-term respite center-based services, and institutional care (Chan, 2008; Nankervis, 2011).

### **Ireland**

The literature sourced in Ireland describes an impressive spectrum of respite services. All services can be first divided into informal or family and friend care-givers, (Merriman, 2007) and formal services. These formal services can be provided in home (McConkey, 2004) or out of home in either community “homey” settings (Black, 2010; Hartrey, 2003; McConkey, 2010; 2011), or hospital/institutional settings (McConkey, 2000). Beechfield Services is a community based out of home program that provides both overnight and domiciliary services for families (McConkey, 2000). Opening Doors is another community based out of home service that provides holiday programs for clients and entire families (McConkey, 2000; 2006). Weekend respite is also available for families (Wilkie, 2008).

### **United Kingdom**

Similar to Ireland, the respite services in the UK are first divided into informal (Robinson, 2001) and formal services. These formal services are then divided further into in-home (Hayes, 1996; MacDonald, 2004; Miller, 2002) and out of home services. These out of home services (MacDonald, 2004; Miller, 2002; Shared Care Network, 2008) can be held in institutional settings (Robinson, 2001) or in another home or residential setting (Hayes, 1996; Stalker, 1994). Respite services are primarily referred to as “short stay” or “short break” in the literature (Collins, 2014; MacDonald, 2004; McConkey, 2013; Preece, 2007). These short stays can be during the day, similar to day care, or provide “special holiday” breaks

(van Exel, 2006). There are also overnight services/breaks available for families (MacDonald, 2004; Mansell, 2009). Staley (2008) identified several programs that provide these in or out of home services:

- Saturday play schemes
- Summer holiday play schemes
- School holiday play schemes for children with complex medical needs
- Youth clubs
- 'Transitions' summer holiday camp
- Home-based care
- Home-based palliative care
- Home-based support worker
- Residential units

The Aiming High for Disabled Children (AHDC) program was implemented in the UK in 2007 as a transformation program for disabled children's services that is jointly delivered by the Department for Children, Schools and Families (DCSF) and the Department of Health (DH) (nef Consulting, 2009). Its features include:

- Short breaks
- Childcare
- Parent participation
- Transition support
- Palliative care
- Core offer and national indicator

### **Benefits of Respite**

The following section discusses the benefits of respite found in the literature. These will be separated according to whether they benefit the recipient of respite, the family/support people of the individual receiving respite, and the respite workers.

#### **For Recipients**

Respite services have been documented in the literature to have a range of benefits for recipients. These benefits are most evident in children and young people (McConkey, 2013), and are most successful when the respite is individualized to the client, and catered to the families (Barnard-Brak, 2009; MacDonald, 2004). Two primary benefits of respite are the increase in sensory stimulation and activities for the recipient (Gent, 2012; McConkey, 2004; 2006; Staley, 2008; Truesdale-Kennedy, 2006; Wilkie, 2008; Withers, 2003; Yoong, 2012); and the opportunity for social interaction (Robertson, 2011; Wilkie, 2008). The increase in activities and interaction provides the opportunity for other benefits including increased independence (Caldwell, 2007; Merriman, 2007; Robertson, 2011), improved social skills (Black, 2010; Gent, 2012; McConkey, 2006; Merriman, 2007; Truesdale-Kennedy, 2006; Wilkie, 2008), improvement of practical life skills (Gent, 2012), the development of relationships and friendships (Robertson, 2011; Yoong, 2012), and in some cases even aspirations for greater inclusion, for example seeking employment (Black, 2010). One study found that there was a positive correlation between receiving respite care and academic achievement in children (Barnard-Brak, 2009). Having the respite

worker as an emotional support or companion for the child was noted in one study (McConkey, 2004). A reduction in challenging behaviors or behavior modification was seen in some children receiving respite care (Black, 2010; McConkey, 2011). Respite breaks also enhanced the safety of the child, as it decreased the risk of abuse or maltreatment as a result of parental/caregiver stress (O'Brien, 2001; McConkey, 2004). Overall, an improved quality of life was reported by respite recipients (Robertson, 2011; Yoong, 2012). A study conducted by the Shared Care Network (2008) with parents of children with an autism spectrum disorder (ASD) utilizing respite across the UK reported the following:

- 92% of parents agreed breaks helped their child make friends
- 80% of parents agreed breaks helped their child take part in social activities
- 67% of parents agreed breaks helped their child learn independence skills
- 75% of parents agreed breaks helped their child feel happier overall
- 100% of parents agreed breaks helped their entire family cope with demands of caring
- 100% of parents agreed breaks helped their entire family live 'normal' lives; 75% said it helped their child experience this normality specifically

### **For Family/Support People**

Overall, respite care contributes to strengthened family coping and functioning. The most commonly sourced benefits for family members of those receiving respite is a significant decrease in stress levels (Black, 2010; Brown, 2005; Caldwell, 2007; Chan, 2001; Chou, 2008; Cowen, 2002; Cotterill, 1997; Gent, 2012; Hartrey, 2003; Merriman, 2007; O'Brien, 2001; Robertson, 2011; Shared Care Network, 2008; Stalker, 1994; van Exel, 2006; Whitlach, 2006) and more spare time for recreation (Wilkie, 2008). Recreation time was used for social activities (Hartrey, 2003; Stalker, 1994) and the ability to spend time with their other children or family members (Robertson, 2011; Shared Care Network, 2008; Stalker, 1994); two things that family caregivers often expressed that they didn't usually have time for. The reduction in overall stress levels provided other benefits for parents, including improved marital status (Withers, 2003), an increased sense of control in their life (Nankervis, 2011), a reduction in the development of dysfunctional behaviors (Cowen, 2002) and an improvement in sleep patterns (Nankervis, 2011). The bond between the parents/caregivers and the respite support staff was also valued, as it provided a source of emotional support for parents (Jeon, 2005). Families expressed that they benefitted from the individualized services that met their specific needs (Wilkie, 2008), and valued how it allowed them to still provide care for their child without having to seek an out-of-home/institutional placement (McConkey, 2004). Respite also provided families with the opportunities to network with other parents and to access information about other services in the community (Jeon, 2005; McConkey, 2004). A gained sense of 'normality' was a benefit expressed by parents from receiving respite care (Ashworth, 2000).

### **For Respite Workers**

Literature which discusses the benefits of respite for the respite workers is rather limited. Benefits that were identified included job satisfaction/enjoyment (McConkey, 2005; Tarleton, 2003) and valued relationships with the recipients and their families (Stalker, 1994; Tarleton, 2003).

### **Obstacles Associated with Respite**

The following section discusses the obstacles associated with respite services found in the literature. These will be divided into difficulties experienced by the recipients, the family/support persons and respite workers.

#### **For Recipients**

The primary source for the majority of respite care obstacles is a mismatch of the supply and demand (Caples, 2010; McConkey, 2000; 2010; Nankervis, 2011). One complication resulting from this is a limited availability of, or a greater need for services/programs, such as weekend and holiday breaks (Abelson, 1999; Burton-Smith, 2009; Jeon, 2005; McConkey, 2000; 2005; Nageswaran, 2009; Robinson, 2001; Wilkie, 2008; Wodehouse, 2009). Another complication is limited service flexibility and poor convenience for recipients and their families (Brodin, 2006; Burton-Smith, 2009; Caples, 2010; Chan, 2008; Jeon, 2005; Nageswaran, 2009; Robinson, 2001; Thurgate, 2005). Limited accessibility to resources is another obstacle that stems from this supply and demand issue (Abelson, 1999; Mansell, 2009; McConkey, 2005; Thurgate, 2009; Stalker, 1994). As a result, parents are often unaware of certain programs, or respite services in general (Brodin, 2006; Chadwick, 2002; Hayes, 1996; Stalker, 1994). All of these factors have contributed to long wait lists, ranging from weeks to years (Cramer, 2008; McConkey, 2005). There is also a need for equity in the provision of respite services to ensure that care is fairly distributed to those who are most in need of it (Brodin, 2006; Doig, 2009; McConkey, 2005; 2010; Nankervis, 2011; Thurgate, 2005; van Exel, 2006). This equity of provision should look at all aspects of the applicant, including the details of the disability and family dynamics (ie. single parent home; elderly caregiver) (McConkey, 2011). One notable result from this lack of equity is that often children with challenging behavior are excluded from respite care (McGill, 2006). It is due to this that children with an autism spectrum disorder (ASD) often wait the longest to receive respite services (Shared Care Network, 2008). Three sources from the literature found that the process of separating the child from the parent/caregiver during respite caused distress in some children; manifesting as crying, screaming, or uncharacteristic withdrawal (Radcliffe, 2008; Robertson, 2011; Stalker, 1994). Respite care provided in a hospital/institution setting that may already be familiar to the recipient as a place where they received unpleasant treatments, has the potential to further distress the child (McConkey, 2010; Robinson, 2001; Stalker, 1994). Another obstacle was that in some cases, respite services may not be individualized enough to meet the client's specific needs (Thurgate, 2005). Specifically, children with ASD may prefer solidarity, have no concept of 'friends', and cling to predictability/routine. Due to this they may not find enjoyment in respite services (Preece, 2009).

How has this impacted respite service distribution at St.Amant?

- According to the St.Amant Expansion Summary Report (2013), during the 2012/13 year, River Road Place (RRP) provided respite care to 29 adults and 10 children, resulting in 2051 days requested and 1878 days actually provided. 173 requested days could not be accommodated. The current wait list for respite services is 25 individuals (16 children and 9 adults), resulting in a wait time of approximately 2 years (p.1).

### **For Family/Support People**

A major obstacle with respite that was evident in the literature was the high expense and a lack of government financial support (Burton-Smith, 2009; Black, L. 2010; Caldwell, 2003; 2007; Chan, 2008; Nageswaran, 2009). Despite health care coverage (in some countries), many families still faced high direct and indirect out-of-pocket ‘opportunity’ costs (Burton, 2009). Another common obstacle was that often there was a mismatch in the definition or goals of respite care between the families and workers. As a result, some families expressed that they didn’t feel their needs were properly being met (Chan, 2001; MacDonald, 2004; Mansell, 2009; Radcliffe, 2008). Due to the poor accessibility, availability and flexibility of respite care, families were often given short notice of schedule changes (McConkey, 2013) and often found the complex application process distressing and frustrating (Doig, 2009). In one article, parents expressed that accepting respite care was difficult for them, as they felt it signified a failure to cope with their child/family member’s disability (Ashworth, 2000). Other obstacles for families were difficulty with staff recruitment (Caldwell, 2003), a sense of guilt related to removal of the child (Hartrey, 2003), and a dislike of sending their children to hospital/institutional settings (Robinson, 2001). One study found that caregivers/families tended to become overly dependent on the professional aids that provided the respite care (Ng, 2009). A majority of the literature found that respite services were effective in reducing parental stress levels; however one article instead found that there was a lack of impact on the health of parents whose children were receiving respite (Truesdale-Kennedy, 2006).

### **For Respite Workers**

Obstacles with respite for the workers include lack of training (Chan, 2008; McConkey, 2004; Tarleton, 2003), lack of role clarity (Tarleton, 2003), and lack of knowledge, specifically regarding the ecological issues/triggers in children with autism spectrum disorder (Preece, 2009). A common cause for these issues was explained as a lack of other staff time to provide training/information (Tarleton, 2003). Staff also had difficulties in trying to meet the needs of a wide range of children with differing needs/abilities within one setting (Preece, 2009). One complaint that was sourced from staff was discontent with low level of payments (McConkey, 2004).

### **Cost Analysis**

The following section provides a summary of the different costs associated with respite care for both families and organizations. These costs are separated according to geographical region. A summary table with conversions to Canadian currency will be provided at the end of this section.

#### **Canada**

- Canada’s universal health care covers the service fees associated with respite; however there are still significant out-of-pocket costs Canadian families must cover for ‘opportunity fees’. These fees are a mean annual of \$1,159 (Burton, 2009).
- Biggest predictor of out-of-pocket expenses is the severity of the child’s disability (Burton, 2009).
- In a study conducted across the 10 Canadian provinces, 44.7% of parents felt their child did not receive some equipment due to high costs (Burton, 2009).

### United States of America

- Family support services are available to help families cover the costs of respite; however funding allocated for these support services accounts for only 2.8% of all funding within the developmental disability service system (Caldwell, 2003). One example of these support services is the Illinois Home Based Support Services Program, which provides individualized monthly budgets of approximately \$1,656 to adults with intellectual and developmental disorders (DD) living at home with their families (Caldwell, 2007). Families expressed how important these services were; stating the financial support they received helped them ‘dig out of debt’ (Caldwell, 2007).
  - In the fiscal year of 2006, annual nationwide family support spending per family averaged \$5,376, ranging from \$232 - \$10,000 per family in 11 states (Rizzolo, 2009). From the years 2000-2006, the number of individuals receiving family support services increased 34% (by 108,000 people). The total adjusted expenditures increased from \$1.3 billion to \$2.3 billion (Rizzolo, 2009).
- In a 2001 National Survey of Children with Special Health Care Needs, 22% of 767 individuals stated the reason for their unmet respite needs was due to high cost (Nageswaran, 2009).
- From 2004-2005 in the state of California alone, a combined total of individual expenditures on Medicaid home and community based services for individuals with a DD reached \$15.7 billion for 416,546 families (Kang, 2008).
  - Of this population, 138,336 individuals received regional center services, totaling \$1.8 billion in expenditures (Kang, 2008).
  - In home (49, 600) and day programs (48, 883) were the next most frequently used services; 7,834 used out-of-home services (Kang, 2008).
  - The average yearly expenditure was \$13,323 per person. The most expensive service was the out-of-home programs which totaled \$23,529 yearly per person. The day program and in-home respite recipients paid an average yearly total of \$10,123 and \$2,561 respectively (Kang, 2008).
- Parents often stated that in the absence of respite services, they would have to refuse employment opportunities in order to care for their child. Taking an economic standpoint, this harms the family as an individual unit, and negatively impacts the entire community on a larger scale (Abelson, 1999). In the long run, respite services would save tax-payers money as it is less expensive to have people with DD living at home, rather than in group homes or in hospitals (Abelson, 1999).

### South Africa

- Government grants are offered to families of children with learning disabilities, however many stated that the money offered was not sufficient to meet daily economic needs of the children (Sandy, 2013).

### Taiwan

- One full day of respite cost families 1,500 New Taiwan Dollars; one month of respite care cost on average 45,000 New Taiwan Dollars. Institutional care expenses were higher, and cost 75,000 New Taiwan Dollars monthly (Chou, 2008).

### United Kingdom

- The national average payment for respite workers in the UK was £44 for a twenty-four hour overnight period (Cramer, 2008).
- The following table shows information presented in Holmes' (2010) *The Costs of Short Break Provision* study (p.9). This table breaks down the costs of respite services according to service type:

Service Type	Costs
Residential overnight	£69.97 - £373.00 per child per night (24 hour period)
Family based overnight	£140.36 - £226.26 per child per night (24 hour period)
Day care	£99.21 - £204.83 per child per session (8 hours)
Domiciliary home care	£16.74 - £25.60 per family per hour
Home support	£17.54 - £25.60 per family per hour
Home setting	£10.98 - £26.07 per family per hour
General groups	£296.68 - £430.61 per session
Afterschool clubs	£239.77 - £331.17 per session
Weekend clubs	£296.68 - £324.17 per session
Activity holidays	£113.38 (for 2 day break) - £3,701.15 (7 day break)

*\*Costs of the services also varied according to the provider, the type and number of staff required, the time duration, number of children and the individual needs of the child/children.*

- Ongoing support costs: children's social care departments provide ongoing support to families receiving respite care. This ongoing support consists of supports visits, as well as reviews (Holmes, 2010).
  - Support visits: costs per visit range from £54.17 - £99.32; visits last approximately one hour on average (Holmes, 2010).
  - Reviews: costs of reviews range from £186.90 - £260.63 (Holmes, 2010).
- Aiming High for Disabled Children (AHDC) program identified short breaks as the highest priority service for families with disabled children. Of the £430 million allocated to new investment in disabled children's services during 2008–2011, £370 million was devoted to short breaks (nef Consulting, 2009).
  - Childcare – £35 million
  - Transition Support Programme – £19 million
  - Parent Forums – £5 million.
- According to a report commissioned by the Action for Children and Every Disabled Child Matters campaign (nef Consulting, 2009), effective delivery of short breaks to those eligible with full coverage from the state could produce potential savings in the region of £174 million yearly.

- Decreased cost of long-term residential care from reductions in children placed outside of family homes: £135 million.
- Decreased cost to health services from reduction in parent/family/carer stress (combination of general practitioner visits and sick time from work): £18 million.
- Decreased cost to school of educating siblings with behavioral and emotional difficulties: £21 million.
- The government has already announced a continued investment in short breaks by providing over £800 million over the 2011 to 2015 period as part of the Early Intervention Grant (Department of Education, 2011).

### Ireland

- Family income appears to be an influential factor on the type of respite services the family receives; more affluent families utilized family-based services, while the lower income families were more likely to use hospital/institutional services (McConkey, 2000).
- For the financial year, the Health and Social Services Board spent approximately £1.59 million on respite services; 41% on residential homes, 35% on hospital-based services, 15% on domiciliary services, 5% on family-based schemes and 4% on leisure activities/residential holidays (McConkey, 2000).
- A complaint among some respite workers is that payment levels are too low for their services (McConkey, 2004).

### Australia

- According to the Australian Institute of Health and Welfare, funding for respite across Australia makes up 8% (\$A196.7) of the total national budget for disability services (\$A3.6 billion) (Chan, 2012).
- Direct health care costs for children with Down syndrome decreases with age. Mean annual cost was \$A4,209 for direct health care (hospital, medical, pharmaceutical, respite and therapy) (Geelhoed, 2011).
- Fees per respite service ranged from a minimum of \$A1 - \$A725, to a maximum of \$A2 - \$A75 (Chan, 2008).
- In 2007, the unit cost of a residential or respite place was €80,000 (€219.18 per night) (Chan, 2012).

The following table provides a cost summary in Canadian dollars for the individual and organizational costs of respite in the UK, Ireland and Australia. These three geographical regions were selected based on the similarities of their respective health care systems to the Canadian health care system.

	UK	Ireland	Australia
Individual Costs	<u>Types of Respite:</u> <ul style="list-style-type: none"> <li>- Residential overnight (\$125.94 – \$671.36)</li> <li>- Family based overnight (\$252.63 - \$407.25)</li> </ul>	2007 unit cost of a residential or respite place: \$114,456 or \$313.58 per night.	Fees per respite service ranged from a minimum of \$1 - \$25, to a maximum of \$2 - \$76

	<ul style="list-style-type: none"> <li>- Day care (\$178.57 - \$368.67)</li> <li>- Domiciliary home care (\$30.13 - \$46.08)</li> <li>- Home support (\$31.57 - \$46.08)</li> <li>- Home setting (\$19.76 - \$46.92)</li> <li>- General groups (\$533.99 – \$775.05)</li> <li>- Afterschool clubs (\$431.56 - \$596.07)</li> <li>- Weekend clubs (\$533.99 - \$583.47)</li> <li>- Activity holidays (\$204.07 [2 days] - \$6,661.70 [7 days])</li> </ul> <p><u>Ongoing supports:</u></p> <ul style="list-style-type: none"> <li>- Support Visits (\$97.50 - \$175.77)</li> <li>- Reviews (\$336.40 - \$469.11)</li> </ul>		<p>Mean annual direct health care costs for children with Down syndrome: \$4,273</p>
<p>Organizational Costs</p>	<p>~\$774 million investment in disabled children’s services (2008 – 2011):</p> <ul style="list-style-type: none"> <li>- Childcare – ~\$63 million</li> <li>- Transition Support Programme – ~\$34.2 million</li> <li>- Parent Forums – ~\$9 million</li> </ul> <p>Potential savings of effective short break delivery ~\$316.9 million from decreases in:</p> <ul style="list-style-type: none"> <li>- decreased cost of long-term residential care ~\$243 million</li> <li>- decreased cost to health services from reduction in parent/family/career stress: ~\$32.4 million</li> <li>- decrease cost to schools of educating siblings with behavioural/emotional difficulties ~\$37.8 million</li> </ul> <p>Government announced continued investment in short breaks by providing over \$1.44 billion CAD) over the 2011 to 2015 period as part of Early Intervention Grant.</p>	<p>Health and Social Services Board spent approximately \$2.86 million on respite services:</p> <ul style="list-style-type: none"> <li>- 41% residential homes</li> <li>- 35% hospital-based services</li> <li>- 15% domiciliary services</li> <li>- 5% family-based schemes</li> <li>- 4% leisure activities/residential holidays</li> </ul>	<p>Funding for respite: 8% (\$199.71) of total national budget for disability services (\$3.66 billion)</p>

### **Prioritizing Respite**

The following section discusses why respite expansion and restructuring should be of priority. Firstly, the importance of respite to ensure the health equity of this vulnerable population is discussed. Second, current population trends are examined to explain how there is an urgency for changes to our respite service delivery.

#### **Why is respite worth the investment?**

##### **a) Vulnerability of children/adults with intellectual and developmental disabilities**

Children and adults with intellectual or developmental disabilities are an extremely vulnerable population. According to the World Health Organization (WHO) (2012):

*“All over the world, people with mental disabilities, intellectual disabilities and substance abuse problems are subject to poor-quality care and violations of their human rights. The stigma associated with these conditions means that people experience exclusion, rejection and marginalization by society.”*

Around the globe, there are over 650 million people living with disabilities (United Nations [UN], 2006). Due to the stigmatization and marginalization of this population, many members find themselves economically disadvantaged, and are more likely to live in poverty (UN, 2006). During the Convention on the Rights of Persons with Disabilities (2006), the United Nation stated that these results of ignorance and neglect are “reinforced in government and development policies and programs that ignore, exclude, are not accessible to or do not support the rights of persons with disabilities to be included in the socio-economic life of the country”.

##### **b) Health Equity and government responsibility**

The WHO has recognized that a fault in the health care services aimed to serve this population is that they “often intend to keep people and their conditions under control, rather than to enhance their autonomy and improve their quality of life” (WHO, 2012). Respite care was first introduced in Canada in the late 1960s as a response to a de-institutionalization movement (Canadian Healthcare Association [CHA], 2012). This was based on the belief that care for a person with a disability is best provided in the family home and community. The literature has shown that respite care produces an abundance of benefits for not just the recipient, but also for their family/caregivers as well. Overall, respite has been shown to better the quality of life of its recipients and strengthen family functioning. In one study, recipients of respite also displayed an aspiration for greater inclusion, such as attending classes and finding employment (Black, 2010). Government involvement in the funding and distribution of respite services is crucial to ensure its survival, and is therefore legislated in many parts of the world. In the UK, the Equality Act was passed in 2010, and states that “local authorities are required to ensure their services are accessible to disabled people, to promote equality for disabled people, and to encourage their participation in public life” (Department of Education, 2011). In Australia, the National Disability Agreement commits all jurisdictions to work towards the objective of “people with a disability and their carers have an enhanced quality of life and participate as valued members of the community” (Australian Institute of Health and Welfare [AIHW], 2011). The United Nations (2006) has acknowledged that government involvement in the development of policies and

programs ensuring the inclusion of disabled individuals in the community, and the protection of their rights.

### **Why is restructuring and expanding respite service delivery a priority?**

The literature has indicated that there is a supply and demand mismatch of respite care. This is due to the trends and consequential changing needs of our population. The first trend is that people are living longer due to technological advances. According to Statistics Canada (2009), “between 1921 and 2005, the average life expectancy at birth rose substantially in Canada from 58.8 to 78.0 years for males, and from 60.6 to 82.7 years for females” (CHA, 2012). Not only are respite recipients living longer, but the growing cohort of aging family members caring for disabled individuals globally only heightens the importance of enhancing family support services (Rizzolo, 2009). The second trend is that our population as a whole is growing and consequently so is the number of those requiring respite services. In Australia, the number of respite service users across all service groups increased almost 50% between 2003-2004 and 2008-2009 (to 279,000 individuals) (Australian Institute of Health and Welfare [AIHW], 2011). In America, from 2000-2006, the number of individuals receiving respite increased by 34% or over 108,000 individuals (Rizzolo, 2009). The supply and demand mismatch often means that more families are placed on growing waiting lists that can last anywhere from weeks to years (Cramer, 2008; McConkey, 2005). In the 2012-2013 fiscal year, St. Amant was only able to provide 1878 days out of the requested 2051 days of respite care, and their current wait list is approximately two years long (St. Amant, 2013). The final trend is the changing dynamics of today’s modern family unit. These changes include decreasing extended family networks, families no longer living in the same geographical area, and fewer two-parent households (CHA, 2012). These changes contribute to decreased supports for those caring for someone with a disability, therefore increasing the likelihood they seek external supports, such as respite.

### **Barriers to Change**

One of the primary barriers to change in restructuring and expanding respite services is insufficient funding. Programs and organizations can only grow up to a certain point according to the funding they receive, and resulting in the exaggerated supply and demand mismatch. The major disadvantages of respite were described earlier in the literature as limited availability of services or desired programs, limited flexibility or poor convenience and difficulty accessing respite. This, in combination with a continuously growing and aging population results in more and more families being denied services. Another barrier to address would be the difficulty in staff recruitment for respite support staff (Caldwell, 2003). Issues related to this topic are a lack of training and/or applicable training (Chan, 2008; McConkey, R. 2004; Tarleton, 2003) and low payments (McConkey, 2004). Public knowledge of respite services is another barrier worth addressing. There are families who are unaware of what respite services are, where facilities exist, the types of support services there are and how respite protects the dignity of the recipient (MacDonald, 2006). These families who could utilize these services may be oblivious to their existence, or choose to not access them. There are also social economic barriers that influence whether or not someone seeks respite. Families with lower education levels, living in low income areas where they have limited access to resources and a poor social network are less likely to use respite services (Chou, 2008; Hayes, 1996; McGill, 2006). Geographic location is another barrier to respite care, as respite is generally utilized more by those located in urban communities rather than those located rurally (Chou, 2008).

**Conclusion:**

Globally, there is an unmet need for respite services. These families are placed under tremendous emotional, social and financial stress. Our growing and aging population is only increasing the urgency for a change in order to meet the needs of this extremely vulnerable population. Provision of respite services helps alleviate caregiver stress and improves overall family functioning, while also provides the recipient with sensory stimulation in an interactive environment. It should be a priority for organizations to expand and restructure their current model of respite service delivery, and a priority for governments to restructure funding models.

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## Appendix A: Global Respite Services Table

Country	Canada	USA	Singapore	South Africa
<b>Types of respite services</b>	<ol style="list-style-type: none"> <li>1. School</li> <li>2. Day care</li> <li>3. Holiday</li> <li>4. Weekend respite</li> <li>5. Adult day programs</li> <li>6. Summer camp</li> <li>7. Over nights</li> <li>8. Educational</li> <li>9. Recreational school trips/activities</li> </ol>	<ol style="list-style-type: none"> <li>1. In-home               <ol style="list-style-type: none"> <li>a. Informal (family, friends or neighbors)</li> <li>b. Formal (hired staff)</li> </ol> </li> <li>2. Out-of-home               <ol style="list-style-type: none"> <li>a. Community</li> <li>b. Institutional</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>1. Home support</li> <li>2. Day care</li> <li>3. Short stay in institution</li> <li>4. Emergency/overnight in institution</li> </ol>	<ol style="list-style-type: none"> <li>1. Community clinics</li> </ol>
<b>Exemplary programs</b>	St. Amant (Manitoba) Red Roof Retreat (Ontario)			

Country	Taiwan	Australia	Ireland	UK
<b>Types of respite services</b>	In or out-of-home care services.	<ol style="list-style-type: none"> <li>1. In-home                             <ol style="list-style-type: none"> <li>a. Activities in/out of home</li> <li>b. Personal care attendant</li> <li>c. Homecare</li> <li>d. Child-minding services</li> </ol> </li> <li>2. Out of home                             <ol style="list-style-type: none"> <li>a. Day programs in respite centers</li> <li>b. Institutional care</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>1. Informal</li> <li>2. Formal                             <ul style="list-style-type: none"> <li>- In-home</li> <li>- Out-of-home                                     <ol style="list-style-type: none"> <li>a. Hospital/institutional</li> <li>b. Community settings   <ol style="list-style-type: none"> <li>1. Overnight</li> <li>2. Domiciliary</li> <li>3. Holiday</li> <li>4. Weekend</li> </ol> </li> </ol> </li> </ul> </li> </ol>	<ol style="list-style-type: none"> <li>1. Informal</li> <li>2. Formal                             <ol style="list-style-type: none"> <li>a. In-home                                     <ol style="list-style-type: none"> <li>i. Home-based care</li> <li>ii. Home-based palliative care</li> <li>iii. Home-based support worker</li> </ol> </li> <li>b. Out-of-home                                     <ol style="list-style-type: none"> <li>i. Short stay   <ol style="list-style-type: none"> <li>1. Day care   <ol style="list-style-type: none"> <li>a. Saturday services</li> <li>b. Youth clubs</li> <li>c. Summer holidays</li> <li>d. Summer holidays for children with complex medical needs</li> </ol> </li> <li>2. Special holiday   <ol style="list-style-type: none"> <li>a. ‘Transitions’ summer holiday camp</li> </ol> </li> <li>3. Overnight   <ol style="list-style-type: none"> <li>a. Residential units</li> </ol> </li> </ol> </li> </ol> </li> </ol> </li> </ol>
<b>Exemplary Programs</b>			Beechfield Services Opening Doors	Aiming High for Disabled Children

**Appendix B: Literature Data Extraction**

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Abelson, A.G. (1999) USA	Focus on Autism and Other Developmental Disabilities	Survey Quantitative	Identify the respite care needs, and the impact of lack of respite care, among families of children with developmental disabilities.	574 families in Iowa with children with developmental disabilities completed the surveys.	Results documented a void in the availability and accessibility of respite services regardless of demography, income level, or extent of disability.	<p>Respondents expressed that they perceived that the availability of respite care services would improve overall family functioning.</p> <p>Need for care exacerbated in summer when schools are closed.</p> <p>Often, parents needed to refuse employment opportunities with economically harms the family unit and the entire community. Therefore cost-effectiveness of not providing respite services must be seriously questioned.</p> <p>Respite care is cheaper for tax-payers; people with intellectual disabilities living at home with their families cost the taxpayers less than those in group homes and hospital</p>

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>settings. -Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Ashworth, M. (2000)  Netherlands	Health and Social Care in the Community	Interview  Qualitative	Determine what caregivers themselves said about the benefits or otherwise of respite care.	26 caregivers (aged 14-85 years old and whose dependents were aged between 32 and 93 years old) currently using respite care were interviewed about their experiences of respite care and qualitative themes were derived from the transcripts.	Major benefits had 2 themes: normality and freedom were both facilitated by respite care. Overall perceived as service that facilitated informal care and enabled care to continue at home for longer than what would have been otherwise possible.  Problems with respite care were predominantly expressed in the themes of quality and adjustment.	There was an uncomfortable realization by many that this care might be viewed as a signal to the patient, family and local community that they were no longer able to cope.
Australian Institute of Health and Welfare (2011)  Australia	Disability series	Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement	This report presents information about people who used disability support services during 2008–09, and the agencies and outlets that provided services. Key trends in service provision are also examined using six years of national data collected	N/A	The number of service users across all service groups increased by nearly 50% between 2003–04 and 2008–09 (to 279,000 individuals). Employment and respite services registered the highest increases in service users over this period (70% and 67% respectively)  More than 11,000 outlets delivered services under the CSTDA in 2008–09—an increase of more than a third since 2003–04. Most service outlets are from the nongovernment services sector	More males than females were recorded as disability services users and nearly one in twenty service users were Aboriginal or Torres Strait Islander. More than 6% of total service users were aged less than 5 years. Intellectual disability continues as the predominant primary disability, reported by more than a quarter of service users in 2008–09.
Barnard-	Child Youth	Woodcock	To examine the	Special Education	Positive association between	Linking respite care

Brak, L. (2009)  USA	Care Forum	Johnson III (WJ-III-R) battery test was used to measure academic achievement.  Quantitative	association of receiving respite care with academic achievement for children with disabilities across time.	Elementary Longitudinal Study (SEELS) nationally representative study of the characteristics, experiences and achievement of a sample of students with disabilities who were eligible to receive or already receiving care, aged 6 through 12.	receiving respite care services and academic achievement across time for children with disabilities.	services for parents of children with disabilities to tangible outcomes such as academic achievement is very important in these days of high-stakes achievement testing. In order for respite services to be developed and promoted, these services must have some value to policy makers to justify allocation of resources.  Noted that respite care yields most successful results when care is individually catered to the family.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Black, L. (2010)  Ireland	Journal of Intellectual Disabilities	Interviews/focus groups  Qualitative	3 year formative evaluation process of a service provided to families of children/teens with severe learning disabilities, that promoted social inclusion of the young people in volunteer-run community activities, based around a person-centred plan developed	48 parents, 19 young people/recipients, 7 service volunteers, 4 community workers and 14 referring social services staff involved with the service/program.	Service was successfully implemented in all 3 delivered areas (two urban and one rural) in Northern Ireland. Helped parents to clarify individual support needs and engaged their child in ordinary community activities.	Gains of services extend beyond the activities provided; parents expressed observed improvements in their child's skills and behaviours, and how their aspirations for greater inclusion had grown (such as seeking part-time work). Parents expressed feeling less stressed.

			with child's family.			At present service is only reaching small percentage of families in northern Ireland. Government recognized need for greater investment in children's services.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Brodin, J. (2006)  Sweden	European Journal of Special Needs Education	Questionnaire and/or interview  Qualitative	Increase the knowledge of respite from care from parental perspective (quantitative and qualitative aspects of respite service) of children with severe disabilities.	Questionnaires filled out by 141 families, and an additional 25 were interviewed. All families were members of three main handicap associations to families with children, adolescents and adults with severe disabilities in Skaraborg County Council in Sweden.	Widespread perception by families that there is not enough support and that the need for respite care is not met. Also lack of information about services; more flexible, family-oriented approaches are needed.	In Sweden, respite care is legal right for families & children with disabilities. Act passed in 1994 to seal this.  Parents may not always know what the situation is in their own municipality for respite care, despite the legislation (municipalities responsible for informing citizens about social support).
Brown, J.D. (2005)  Canada	Journal of Child and Family Studies	Telephone interview  Quantitative	Examine the service needs of foster families with children who have disabilities. "What services or supports would be helpful to you?"	Those who had fostered a child with a diagnosed intellectual or physical disability, blindness, deafness, or complex health issues or a disorder	Ten major areas of services or supports foster parents perceive as helpful; support in the community, financial resources, accommodating school system, good relationships with social workers, information, comprehensive medical care,	Questionnaire from 44 foster parents and 60 responses to the question "What services or supports would be helpful to you?"  AD: Saw "respite care"

				in the fetal alcohol, or autism. A total of 44 foster parents were interviewed.	access to professionals, services for Aboriginal children and families, transitional services and respite. Described respite care needs in terms of quantity, accessibility and types of activities.	as very beneficial. There has been a significantly lower stress level found following respite care.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Burton, P. (2009)  Canada	Canadian Public Policy	Micro-data from the child component of the Statistics Canada <i>2001 Participation and Active Limitations</i>  Cross-sectional, Quantitative	Study the economic costs of caring for children with disabilities in Canada	Canadian children with disabilities living in the 10 provinces in 2001 (4,561 observations) Ages 5 – 14	Despite universal health insurance, the majority of Canadian families of children with disabilities face both direct out-of-pocket and indirect opportunity costs as a result of their children's conditions. The severity of the child's condition is the most important predictor of economic costs. Results suggest that governments should increase financial support, particularly when the child's condition is very severe.	Reported out-of-pocket expenditures associated with the child's condition (62 percent). Mean annual expenditure for those with out-of-pocket expenses was \$1,159.  Emphasize the importance of making respite available, particularly when the child's condition is long-term and very severe.  (44.7 percent) feel that their child did not receive some equipment or service because there was not enough money to pay for it.
Burton-Smith, R. (2009)	Journal of Intellectual and Developmental	Self-report survey including an adaptation of the Family Needs	The service and support needs of Australian family carers supporting one	448 family carers whose primary disability was moderate to severe	On the FNS the most frequently endorsed items were those relating to the need for information about services and, in	The majority of carers were receiving some type of respite, but almost half of these

Australia	Disability	<p>Survey (FNS) and several open-ended questions.</p> <p>A mixed method design employing quantitative and qualitative analyses.</p>	or more members with a disability at home.	ID (32% response rate)	particular, future, out-of-home accommodation. Similarly, the need for respite services was endorsed by over 80% of respondents. Comments indicated that access to and the quality of respite, day support, and therapy programs were a priority.	respondents were not very satisfied, with 47% expressing a need for more respite, cheaper respite, different types of respite, more regular respite, respite in greater “chunks,” respite in different environments, respite at different times, and greater flexibility in accessing this service.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<p><b>-Type of study (qualitative vs quantitative)</b>  <b>-Method of data collection (survey, interviews etc.)</b></p>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<p><b>-Any other outcome measures?</b>  <b>-Cost Analysis (respite)</b>  <b>-Advantages and/or Disadvantages of respite services</b></p>
Caldwell, J. (2003)  USA	Journal of Intellectual Disability Research	<p>Surveys</p> <p>Quantitative</p>	<p>How is the level of control in the management of respite/personal assistance services related to caregiver appraisals (caregiving burden, caregiving satisfaction and caregiving self-efficacy), service satisfaction, community involvement of individuals with DD and employment of the mothers?</p> <p>Who have families in the HBSSP (Home Based Support Services</p>	97 families using paid respite or personal assistance services	The present study supports the idea that there are benefits for both family caregivers and individuals with DD with increased control in managing personal assistance and respite services. More control in activities of hiring, training, scheduling, directing and negotiating the wages of staff seems to be associated with the increased community involvement of individuals with DD and the increased employment of mothers. When families are given more control in this process, becoming true ‘consumers’ of services, they are more satisfied. Families tended to hire friends, neighbours, and to a great extent, other family	<p>Within the USA, over 60% of individuals with DD live at home with family caregivers, but the funding allocated for family support accounts for only 2.8% of all funding within the DD service system</p> <p>36.1% had hired friends, 7.2% had hired neighbours, 35.1% had hired agency staff and 19.6% had hired other individuals</p> <p>Forty-six per cent of families indicated difficulty with staff</p>

			Program) hired to provide respite/personal assistance, and what have been their experiences with recruitment and staff turnover? Is hiring other relatives associated with significant differences in service satisfaction, staff turnover and the community involvement of individuals with DD?		members.	recruitment. Some families indicated that, if they did not rely on relatives or friends, they would not be able to find staff.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Caldwell, J. (2007)  USA	Disability & Society	Survey of 294 families; they were then asked to participate in an additional in-home interview (1 hour)– 9 families were selected  Quantitative	Explores the experiences of families in the Illinois Home Based Support Services Program.	9 families in The Illinois Home Based Support Services Program (recruited from 294 families in the program or on the waiting list for the program) The majority of families included their relatives with disabilities in some way.	Financial benefits, benefits from respite and personal assistance services and prevention of undesirable institutional placements were major themes that emerged and triangulated with previous research. The following themes emerged concerning barriers to the control of financial resources: provider and professional control, disability as a deserving group, fraud and abuse perceptions and familism.	The Illinois Home Based Support Services Program provides an individualized budget of approximately US\$1656 (\$1,797.92 CAD) per month to adults with intellectual and developmental disabilities living at home with their families.  Families indicated that the money from becoming paid carers

						<p>helped them ‘dig out of debt’, ‘catch up’ and ‘make life easier’.</p> <p>Families viewed this break as a ‘break from one another’, as mutually important to themselves as well as their relatives with disabilities.</p> <p>AD: Respite and personal assistance services also provided individuals with disabilities with an opportunity for growth, independence and experiences with others beside family.</p>
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Canadian Healthcare Association (2012)  Canada	N/A	Informative brief	Provides an overview of respite services in Canada (history, benefits, barriers, funding, technology, international perspectives, issues and recommendations).	N/A	The delivery of appropriate community, home, and facility-based respite services will continue to be a challenge until policy-makers realize its importance to the changing health system and focus on making access to these services more equitable across the country.	<p>An aging population and an aging family support system have major implications for respite services. There is variability in access to and provision of respite services and differences in the application of co-payments and user fees.</p> <p>Respite services in</p>

						<p>Canada, emerged in the late 1960s in response to the de-institutionalization movement and was based on the belief that the best place to care for a person with a disability is in the family home and community, rather than in a facility setting.</p> <p>Canadians are living longer. According to Statistics Canada, “between 1921 and 2005, the average life expectancy at birth rose substantially in Canada from 58.8 to 78.0 years for males and from 60.6 to 82.7 years for females</p> <p>Changing family trends: extended family networks are decreasing, no longer live in the same geographical area and there are fewer two-parent families.</p>
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<p><b>-Any other outcome measures?</b>  <b>-Cost Analysis (respite)</b>  <b>-Advantages and/or Disadvantages of respite services</b></p>
Caples, M. (2010)	British Journal of Learning	Postal self-report questionnaire	Describe the QOL of parents of children and	49 parents of children/adults with	The majority of respondents identified that family	It is evident from the findings of this study

Ireland	Disabilities	Qualitative	adults with intellectual disabilities who are availing of respite care.	an intellectual disability who were availing of respite care within a large service provider in the south of Ireland	relationships were important to them; however, despite this fact, the amount of support they received from family and others is little to none. As a result of the lack of support, parents are experiencing reduced social lives and often have to socialize separately. Whilst the majority of parents identified that they were satisfied with the support that they received for disability services, they also identified that they would like more respite, flexibility and on a regular basis.	that respite care demands far exceed supply and many families are left waiting for long periods of time. The majority of parents reported that their quality of life was either 'good' or 'excellent'.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Chadwick, O. (2002)	Child and Adolescent Mental Health	Interviews  Quantitative (?)	Separate the demand and supply aspects of respite care, firstly by examining what distinguished families who <i>wanted</i> respite care from those who did not, and secondly by examining among those who wanted it, what distinguished families who <i>received</i> respite care from those who did not.	103 children with severe ID and their families (ages 5-11) need for and receipt of respite care services	Socio-economic factors did not appear to be influential in the desire for respite care and, apart from whether or not the family spoke English at home, the only factors that distinguished families who wanted respite care from those who did not were the severity of the child's intellectual disability, the severity of his or her behaviour problems and the parents' self-reported levels of stress. Families with four or more children living at home were much more likely to receive respite care than families with fewer children, but there was little evidence to suggest they actually	Of the 72 families who had not received respite care during the past 6 months, 25 (37.3%) said they felt they did not need it, 23 (34.3%) had wanted it but had been told that no place was available, 6 (8.9%) had declined it because they were unwilling to accept an overnight placement away from home and 13 (19.4%) were unaware of respite care services.

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Chan, J.B. (2000)  Australia	Child & Youth Care Forum	Literature Review	review the literature on child and family characteristics that influence the use of respite care among families who have a child with a developmental disability.	Families who have a child with a DD	On the child side, these characteristics include severity of disability, severity of disability, level of required care, presence of challenging behaviors, age of the child, and the child's degree of communication impairment. On the family side, relevant factors include level of family stress, access to informal support networks, family size, and possibly marital status.	
Chan, J.B. (2001)  Australia	Child & Youth Care Forum	Review of studies	Reviews studies that have evaluated the effects of respite care services used by families who have children with developmental disabilities, with an emphasis on parental stress.	Families who have children with developmental disabilities who use respite services	At least in the short-term, respite care is associated with significant reductions in parental stress for the majority of parents who use it.	
Chan, J.B. (2001)  Sydney, Australia	Journal of Intellectual and Developmental Disability	Audit of case files to gather information on client history and family background. Interviews were conducted with the case managers to verify and add any	To develop a profile of individual and family characteristics that could then be compared with the profiles of respite care users identified through the existing survey and questionnaire database reviewed by Chan and	10 adults with ID living in three adult respite units for 12 - 24 months (long-term use)	In an effort to prevent unintended long-term use of respite care, it may be beneficial to undertake some proactive respite planning with families. The result of this audit suggests that this would seem especially useful for older single-parent families who have adult children with high support needs, challenging behaviour, and	The audit of case management file notes revealed that 60% of the original intake referrals had identified respite care and potential permanent residential placements as necessary considerations.

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Chan, J.B. (2008) New South Wales, Australia	International Journal of Disability, Development and Education	Questionnaire Qualitative	Profile respite service providers in NSW in terms of availability, models of respite care provided, and outcomes of respite. The study also examined providers' views on the factors influencing the use of respite services, their expectations of respite and respite service delivery.	90 members of Interchange Respite Care NSW	There is a strong argument for respite service funding to be flexible, responsive to the needs of carers and to be consumer-driven. Appropriate staff training remains an important issue.	The minimum fees ranged from as little as \$1 (\$1.02 CAD) to \$25 (\$25.38 CAD) per respite service. The maximum fees ranged from \$2 (\$2.03 CAD) to a limit of \$75 (\$76.15 CAD).
Chan, J.B. (2012) Australia	Journal of Policy and Practice in Intellectual Disabilities	Review of the literature and policies	The history of disjointed service provision suggests the need for a rethink of respite policy.	Jeffrey Chan*, Brian Merriman†, Trevor Parmenter‡, and Roger Stancliffe§ (authors discussion)	In order to achieve a balance at each point on the continuum, a shared understanding of respite care and of services in general, is required. The shared understanding is the foundation for the training, communication, funding flexibility, and mutual trust among stakeholders.	The authors discuss the conceptual framework and prevalent thinking on respite policy such as a shared understanding of respite care among stakeholders. In turn, this shared understanding is seen as generating a move toward integrated service development, recasting respite as part of a continuum of family support services in which funding policies

						<p>give families more control.</p> <p>Funding for respite across Australia makes up 8%, \$A196.7 million (~\$199.7 million CAD).</p> <p>In Ireland (2007), the unit cost of a residential place and respite place was €80,000, or €219.18 per night (\$114,456 or \$313.58 per night CAD)</p>
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Chou, Y.C. (2008)  Taiwan	Journal of Intellectual & Developmental Disability	Interview and questionnaire for demographic information  Quantitative	Examine the effects and associated factors of respite care, which was legislated as a community service for adults with an intellectual disability (ID) in Taiwan in 1993.	116 family carers (ages 25-82) who live with an adult (ages 15-65) with ID and have utilized the respite care program	We conclude that in more well-educated, more urban communities, family carers receive more respite care than in less educated and more rural areas. Respite care – often in conjunction with the carer's religion, area of residence, and nature of use of respite care – reduced the carer's overall level of stress. In order to give practical support to family carers of adults with ID, an infrastructure of supportive in-home and community-based services needs to be developed and made more widely accessible for family carers of adults with ID in Taiwan.	The total population with ID in Taiwan in 2002 was around 75,000, of whom 62,000 (83%) were adults over the age of 15 years. Yet only 352 (0.6%) were found to be using respite care.  One full day of respite care costs 1500 New Taiwan Dollars (\$54.48 CAD), and a full month's respite care costs 45,000 New Taiwan Dollars (\$1,634.40 CAD). This compares with the cost

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
						of institutional care (such as at the Yang-Ming Institution for Persons with ID in Taipei City), where a month's stay costs 75,000 New Taiwan Dollars (\$2,724 CAD).
Chou, Y.C. (2008)  Taiwan	Social Science & Medicine	Structured interviews were held in the family homes and standardized questionnaires were administered to the family  Quantitative	Investigate the possible determinants of awareness and utilization of social services by adults with intellectual disabilities and their families living in Hsinchu City.	792 interviews were completed with primary family caregivers of adults with intellectual disabilities, making a response rate of 94.2%.	We found awareness and utilization to be mostly associated with predisposing and enabling variables including caregiver's socioeconomic status, family connection with social networks, and family participation in related groups or associations. Younger caregivers were more likely to access formal assistance, while adults whose families were more connected into social networks were more likely to be aware of in-kind and voucher services.	32 (4.3%) of family caregivers made use of respite services. 10 (1.3%) of family caregivers made use of home care.
Cocks, A. (2000)  UK	Disability & Society	Reflection of literature and services	Examines the proposal that by exploring at a micro level the control exercised over children it is possible to identify the wider societal mechanisms for maintaining power at a macro level.	Focus on the provision of respite care for disabled children in settings away from home.	When focusing on respite care, issues such as separation and the apparent non-participation of children in decision making can be viewed as a reflection of perceived adulthood for disabled people.	NOTE: Article is not necessarily helpful in regards to present respite services
Collins, M. (2014)	British Journal of Social	Interviews (n=17) and a narrative	Examine parental perspectives on short	25 parents whose children accessed	Short breaks provide parents of disabled children with breaks	Five sections reflect the themes generated during

England	Work	tool (n=8)  Qualitative	break provision by exploring how they talk about and use short breaks in the context of caring for their disabled child	short beaks	from caring and that these are crucial to their ability to continue to provide care or more effective care as signaled by current legislation and policy. Understanding how parents make sense of their need for a break from caring is an important element of making sure their needs for a break are met.	the analysis: obtaining a break from caring, providing wider care, reducing social isolation, preparing for not being able to provide care, and the impact of exclusion from short breaks.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Cotterill, L. (1997)  UK	Disability & Society	Literature Review	Discusses themes and argues that a break with the traditional notion of respite as primarily a way to relieve carer burden is long overdue.	Service planning and provision for adults with learning disabilities.	Whilst respite services have traditionally focused on providing relief for carers, the changing conception of respite as a break for service users represents an important shift of emphasis.	
Cowen, P.S. (2002)  USA	Public Health Nursing	Questionnaire: pre-test and post-test  Descriptive Study- Quantitative	The purposes of this study were (a) to describe the socio-demographic, health, and stress characteristics of families parenting a child with developmental disabilities who used respite care interventions, and (b) to determine if utilization of the respite care intervention program impacted	148 self-referred families with developmentally disabled children completed the socio-demographic questionnaire. 87 completed follow-up data collection.	Comparison of matched pretest and post-test parenting stress scores did indicate significant decreases in Total Stress scores, Parent Domain scores, and Child Domain scores after the provision of respite care. Through logistic regression, it was determined that life stress, social support, and service level were significantly related to the occurrence of child maltreatment during enrollment.	A Total Stress Score of 260 or greater indicates that the parents are at risk for development of dysfunctional parenting behaviors. Both the pretest ( $M=289.6$ , $SD=47.5$ ) and the post-test ( $M=275.1$ , $SD=51.1$ ) means were above the high stress range ( $> 260$ ). However, there was a significant decrease in the Total Stress Score ( $t=3.27$ , $df=86$ , $p=0.0016$ )

			parenting stress, foster care placement, and founded child maltreatment.			following the respite care interventions. The Child Domain pretest ( $M=138.6$ , $SD=24.4$ ) and post-test ( $M=133.5$ , $SD=24.5$ ) means were both above the high stress range ( $> 122$ ) and were the source of the high Total Stress score.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Cramer, H. (2008)  UK	British Journal of Social Work	Postal questionnaire  Qualitative and Quantitative	Collect qualitative and quantitative information about short break services from the co-ordinators' perspective	Co-ordinators of all known family-based short break services in the UK $n=120$ (response rate of 64%)	The survey identified a number of key challenges facing short break services in 2005. These included: <ul style="list-style-type: none"> <li>• reducing waiting lists or lists of unmet need;</li> <li>• the continual need to recruit new carers;</li> <li>• the impact of the National Minimum Standards, introduced between 2002 and 2004;</li> <li>• the impact of other policies relating to children's services.</li> </ul>	Payment rates from the current survey showed that payments to short break carers ranged between less than £20 (\$36.00 CAD) to just under £150 (\$270 CAD) for a twenty-four-hour overnight period ( $n = 109$ ). The national average for short break carers in the UK was £44 (\$79.20 CAD) for a twenty-four hour overnight period.
Department of Education (2011)  UK	N/A	Report drafted to provide non-statutory advice to government.	This is non-statutory advice from the Department for Education. It has been produced to help local authorities understand	N/A	The Government has already announced a continued investment in short breaks by providing over £800 million (~\$1.44 billion CAD) over the 2011 to 2015 period as part of the	

			how to fulfil their duties under the Children Act 1989 and the Breaks for Carers of Disabled Children Regulations 2011. In this document, these Regulations are referred to as “the Short Breaks Regulations”.		Early Intervention Grant.  Local authorities are required to ensure their services are accessible to disabled people, to promote equality for disabled people, and to encourage their participation in public life. The scope of the Equality Act 2010 to extend to schools and other public authorities.	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Doig, J.L. (2009)  Canada	Child: care, health and development	Interview  Qualitative	Explore caregivers’ experiences seeking respite care for their children with special needs within Canada.	10 caregivers recruited from two agencies providing respite care for children with fetal alcohol spectrum disorders and other mental health developmental difficulties.	Caregivers discussed their frustrations with the process of finding and obtaining respite care, a course of action described as ‘jumping through hoops’. Also explored subcategories of emphasizing the complexity of ‘navigating the system’, the bidirectional process of ‘meeting the requirements’ and the challenges of ‘getting help’.	The process of acknowledging the need for support can be a difficult process already for parents. This in addition that many applicants were ignored or denied is troubling.  Recently, new legislation was passed in Alberta with the intent of reducing the limited availability and strict eligibility of respite care by providing additional funding.
Dossetor, D.R. (1993)	Journal of Child Psychology and Psychiatry	Interviews at home and questionnaires conducted  Mixed Method-	Seeks to examine the use of hostel respite care by adolescents with developmental retardation and their	92 interviews were conducted with families profound or severe retardation,	Compared with those who do not use hostel-based respite care, the families who do so have less of their own resources for even occasional practical help from	In this study, although the care was well run and was needed by carers as a source of relief it does seem to be

		Comparative cross-sectional study	families	moderate retardation, there were 13 cases and 13 controls, and similarly there were three cases and three controls with mild retardation.	relatives and friends and are the focus of professional concern. Consumer opinion indicates that hostel care is not meeting the carers' perceived needs for relief. A great range of "normalized" and family oriented respite care resources might be more effective for relieving stress and providing support to improve family-based community care.	part of a suboptimal level of family adaptation and used for negative reasons.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Durà-Vilà, G. (2009)  London, UK	Journal of Intellectual Disability Research	Survey in four special schools in London  Quantitative	Whether service utilization among children with intellectual disability (ID) varied by ethnic cultural group.	242 children aged 7 to 17 years with mild and moderate ID. The following six ethnic categories were used: South Asians (Indian, Bangladeshi and Pakistani), Black groups (African Caribbean and Black African), White British, White European, Middle East/Arab, mixed ethnic group/ other ethnic groups. Service utilization categorized as use of: child and adolescent mental	There was particularly low service use for the South Asian group. These differences might arise because of differences in family organization, as more South Asian children lived in two-parent families, which may have been better able to provide care than single-parent families.	Regarding uptake of respite care, statistically significant differences were found among the ethnic groups ( $F = 12.40, P = 0.009$ ): White European 4/22 (18.2%) was the ethnic group that had the highest use of these facilities while South Asian group 0/36 (0%) presented the lowest use.

				health services (CAMHS), social services, physical health and education services.		
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Evans, E. (2012)  NSW, Australia	Journal of Intellectual Disability Research	Literature review	Review the current state of mental health services for people with ID using Australia as a case example, and critically appraise whether such services currently meet the standards set by the Convention on the Rights of Persons with Disabilities.	N/A	Recommendations are made for adopting a human rights-based approach towards the development and provision of mental health services for people with ID; these include improved policy with measureable outcomes, improved service access via clear referral pathways and sharing of resources across disability and mental health services, and improved service delivery through training and education initiatives for both the mental health and disability workforce.	Information regarding the vulnerability of this population is pulled from the United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2006.
Gerstein, E.D. (2009)  USA	Journal of Intellectual Disability Research	Longitudinal study- telephone intake interview, appointments to the families house including assessments of the child, and questionnaires for the parents	(1)examine the trajectories of daily parenting stress for mothers and fathers of children with ID, considering both the absolute and relative stability over time by identifying growth curves for both parents. (2)three specific risk and compensatory	115 parents of children with ID (age 36 – 60 months)	Parenting stress processes are not shared entirely across the preschool period in parents of children with ID. Although individual parent characteristics and high-quality dyadic relationships contribute to emerging resilience in parents of children with ID, parents also affect each other's' more resilient adaptations in ways that have not been previously considered.	NOTE: No mentions of respite.  Should be <u>removed!</u>

			factors may affect these trajectories of daily parenting stress: parental well-being, marital adjustment and a positive parent–child relationship.			
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Geelhoed, E.A. (2011)  Western Australia	Journal of Pediatrics	Population-based data were derived from a cross-sectional questionnaire Children with Down syndrome aged <25 years were identified from the Intellectual Disability Exploring Answers database.  Quantitative	To assess the direct annual health care costs for children and adolescents with Down syndrome in Western Australia and to explore the variation in health care use including respite, according to age and disease profile.	363 families who had a child with Down syndrome as old as 25 years of age (73% response rate)	Direct health care costs for children with Down syndrome decrease with age to approximate population costs, although costs of respite show an increasing trend.	Mean annual cost was \$4,209 Australian dollars (\$4,273 CAD) for direct health care including hospital, medical, pharmaceutical, respite and therapy, with a median cost of \$1701 (\$1,727.03 CAD) and an SD of \$6705 (\$6,807.59 CAD).  Respite care was accessed for only 14% of individuals, although use increased with age and dependency.
Gent, C. (2012)  UK	PowerPoint presentation to 8 <sup>th</sup> International Short Break Association Conference	N/A	Measuring the costs and outcomes of short break services for disabled children and their families in the UK.	N/A	Table depicting costs of short breaks included in slide show (#6).  Examples of child outcomes: - knowledge about risks to safety and how to deal with them. - improvement in emotional wellbeing	

					<ul style="list-style-type: none"> <li>- parents/caregivers capacity to cope with difficulties enhanced</li> <li>- engages safely in leisure activities</li> <li>- views are sought, heard and contribute to decision making</li> <li>- social skills improve</li> <li>- improvement in practical life skills</li> </ul>	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Hartrey, L. (2003)  Ireland	Journal of Psychiatric and Mental Health Nursing	<p>Provide social data by documenting a diary of events over a 24-h period and recording a taped narrative reflection on life with their child. Additionally, a written reflection on their use of respite services.</p> <p>Qualitative: Phenomenological approach</p>	Illuminate the meaning of respite care to parents of children with learning disabilities through description and interpretation.	Convenience sample of 2 primary carers (mothers) of children with learning disabilities who used residential respite care and who were known to one of the researchers	Three categories were identified: the emotional meaning of care; the social meaning; and relief from physical effort. Respite services in Ireland, and those who work in them, not only need to be available to take on the care of a child with a learning disability temporarily so that the family carers may be ‘rested’, but also need to provide supportive preparatory interventions so that family carers can feel that respite is an integral and legitimate part of being a caring carer.	<p>By removing themselves from their children, respite care provided an opportunity for psychological calm. However, strong attachments to their children (rooted in their child’s dependency) made this removal difficult and led to a sense of guilt.</p> <p>Respite care allowed Helen to participate in social activities that she ordinarily is unable to do owing to the demands of caring for her daughter.</p> <p>Mary and Helen physically benefited from respite care. For</p>

						example, when Mary talks about the physical relief of Francis's absence when she refers to him as a 'handful'.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Holmes, L. (2010)  UK	Research report	Focus groups, questionnaires	To calculate the costs incurred by Children's Services Departments of providing short breaks to disabled children and their families; aimed to calculate the costs of individual services and full range of costs associated with the provision of short breaks.	Three local authorities were recruited to participate (anonymously). 5 focus groups were held with the three participating authorities; total of 37 professionals participated in the focus groups. Completed questionnaires returned by 17 people.	Costing short break provision for disabled children and their families is complex. It is evident that the costs of the individual services or social care processes are best analyzed in relation with one another, whereby different components are built up to calculate a more comprehensive cost to social care of the provision of short break services.  The level of social care activity is determined by the needs of the family (this was reflected by the referral routes of each of the authorities).  Some of the services require additional activity before a child could access them (ex. Introducing them to a service).  Further consideration may need to be given to the costs of contracting and commissioning services (setting up, negotiating and maintaining contracts take up	Detailed tables with cost breakdown of referral processes by the three authorities and the costs of services by service type are provided on pages 8 and 9 of the article.

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Jeon, Y.H. (2005)  Australia	Journal of Advanced Nursing	An initial literature search was undertaken using the key words 'respite', 'short-term care', 'shared care' and 'day care' in major electronic databases for nursing, psychiatry, psychology and sociology literature between 1967 and 2002	Reviews research literature over the past 10 years of respite care for people affected by severe mental illness; and identifies key implications for nursing practice in provision of respite care for family caregivers of people with severe mental illness.	Respite care for caregivers and people with severe mental illness	The majority of family caregiving studies identified a need for greater quality, quantity, variety and flexibility in respite provision, and the literature has remained largely silent in relation to those affected by severe mental illness.	Health care workers can help caregivers overcome some of the barriers and problems associated with the provision, access and use of respite care services by: -developing mutual trust, understanding, planning and collaboration; -giving information and advice; -listening clearly to caregivers and care recipients concerns; -clarifying options; -increasing caregivers' understanding of what - respite care will involve, including practical details and responsibilities; -improving access to adequate respite services when most needed; and -providing continuity, re-assurance, emotional support and opportunity for feedback during and after respite care, both

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Kang, T. (2008)  USA	Disability and Health Journal	Secondary databases (3)  Quantitative	Examine the type of service use and expenditure patterns for individuals with DD living at home and in the community in California in 2004-2005.	138,336 individuals with developmental disabilities living at home and in the community in California in 2004-2005 who received services	This study demonstrates that there are wide variations in the types of services received and expenditures for services beyond client need. The major concern is that children (age 3-21) and minorities had less access to a number of services and lower expenditures for some services than adults and whites	<p>for caregivers and care recipients.</p> <p>In 2004, state spent \$15.7 billion (~\$17 billion CAD) on Medicaid home and community-based services for 416,546 individuals with DD.</p> <p>The 138,336 individuals who received regional center services had a total of \$1.8 billion (~\$2 billion CAD) in expenditures in 2004-05.</p> <p>In-home respite (49,600) and day programs (48,883) were the next most frequently received services, whereas only 7,834 used out-of-home respite services.</p> <p>The average expenditure was \$13,323 (\$14,464.78 CAD) per individual. The most expensive service was the out-of-home expenditures, which averaged \$23,539</p>

						(\$25,556.29 CAD) for the year, and the least expensive was health care services (\$1,477 for the year) (\$1,603.58 CAN).
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
MacDonald, H. (2004)  North-west England	Child: Care, Health & Development	In-depth interviews (1-2 hrs), participant observation and document review  Qualitative	To examine the meaning of respite care to parents of children with complex conditions and providers.	19 mothers and 7 fathers of children between the ages of 8 and 16 years who required complex care and from their respite providers, including 13 nurses, and 4 social workers from 3 counties in North-west England	Although all participants agreed on the need for some form of respite, differences of definition suggest tensions between the expectations of parents (users), health services and social services that ultimately could impact on the acceptability, uptake and benefits of respite services. Only when each of the participants involved in the allocation and uptake of respite share their meaning of respite and collaboratively build a package of care, can hidden agendas be tabled and acceptable and appropriate respite be negotiated.	Parents consistently described three distinct forms of respite: short breaks provided by the extended family or friends, short breaks (3–4 h) provided by an agency (usually in the home), and overnight respite outside of home. Social workers described three forms of respite: short in-home breaks, overnight in-home breaks and respite facility placement. Nurses described two forms of respite: short breaks and play schemes and overnight or longer in respite facility.  Nurses spoke more positively about removal of children from homes. Social workers emphasized the value of

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Mac Donald, E. (2006)  Ireland	British Journal of Learning Disabilities	(1) 21-item Demographic checklist for carers (2) Carers' Assessment of Managing Index (CAMI: Nolan et al. 1996) is a 38-item assessment instrument designed to tap into carers' coping strategies  Qualitative (?)	Learn more about how carers cope and why carers use respite care	46 children with ID and 71 carers	The likelihood of families using respite care was not significantly related to presence of challenging behaviours or level of support required by children. Additionally, likelihood of using respite care was not significantly related to family size and social support. Children who needed a lot of support with personal care or who had difficult behaviours did not use respite care more than children without these needs. Uptake of respite services may be low in the case where carers are unsure of facilities, unfamiliar with support workers, or unaware of other parents' reports that children's personal care needs are addressed with skill and dignity.	keeping children in their homes with their families.  Female carers mostly coped by doing something to solve problems. Male carers mostly coped by trying to understand problems in a different way. Male and female carers sometimes coped in similar ways, for example, seeing the funny side of problems and making sure they had free time for themselves.
Mansell, I. (2009)  UK	Journal of Intellectual Disabilities	Semi-structured questionnaire and two focus groups  Qualitative and Quantitative data - Mixed methodology triangular design	Report family and informal carers' perceptions of respite care services offered to them by their local authority.	151 members of a parent/carer federation, a charity set up and run by parents and informal carers of people with ID (23% response rate)  15 carers	The study found evidence of continued unmet needs, with the majority of carers reporting that they had not been able to access the required respite support. Data from this study showed that carers perceive that there is a mismatch between their own definition of respite and that of the professionals they came into	65 carers (43%, $n = 151$ ) received 'respite' support. Of the 65 carers who reported being in receipt of some form of respite support, over 50 percent had not had a break over two consecutive days or an overnight break.

				<p>participated in one of two focus groups</p> <p>Carers aged 25-64 years old</p>	<p>contact with. Carers suggested that until there is a shared definition of ‘respite’ the current service would not meet their current respite needs.</p>	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
<p>McConkey, R. (2000)</p> <p>Ireland</p>	<p>Child: Care, Health and Development</p>	<p>Study 1 – information from the four Community Health and Social Service Trusts</p> <p>Study 2 – A structured questionnaire. Families were interviewed in their home by the second researcher or a social worker employed by the Health and Social Services Trust.</p>	<p>Assist the Eastern Health and Social Services Board review the short break services that they commission.</p>	<p>Study 1 – 476 families who had children and young people (aged 19 years and under) with disabilities and who had been in receipt of one or more short break services during the period 1 April 1996–31 March 1997.</p> <p>Study 2 – 76 parents or carers of children with a learning disability who were registered as being in receipt of social services with one of the four Health and Social Services Trust in October 1996</p>	<p>First, there are not enough short break services to meet the demand. Second, breaks in what are perceived to be hospital settings are not a favoured option. Third, the preference is for services that benefit the child as well as giving the carers a break. Families were near unanimous in their desire for more leisure activities and holiday breaks. Four, family income appears to influence the type of breaks they receive. Family-based breaks are used by more affluent families (as are leisure activities) whereas those on low incomes or benefits are more likely to use hospital or ‘institutional’ services.</p>	<p>For the financial year studied, the Health and Social Services Board had spent around £1.59 million (~\$2.86 million CAD) on short break services; three quarters on residential homes (41% of the total) and hospital-based breaks (35%). Domiciliary services accounted for 15% of the total; family based schemes for 5% and 4% was spent on leisure activities and residential holidays.</p> <p>215 of the 476 children (45%) took part in some form of leisure break such as summer schemes. 118 (25%) families and children had domiciliary services. 106 (22%) children had breaks in a residential</p>

						<p>home.                  106 (22%) children used hospital-based breaks.                  84 (17.5%) had a residential holiday.                  46 (10%) had a breaks in another family's home.</p>
<p><b>1<sup>st</sup> Author (Year) and geographical location</b></p>	<p><b>Journal Name (or type of document)</b></p>	<p><b>-Type of study (qualitative vs quantitative)                      -Method of data collection (survey, interviews etc.)</b></p>	<p><b>Aim of the Study</b></p>	<p><b>Sample description (e.g. parents, care providers) &amp; #</b></p>	<p><b>Main findings of the literature (short statement 50 words)</b></p>	<p><b>-Any other outcome measures?                      -Cost Analysis (respite)                      -Advantages and/or Disadvantages of respite services</b></p>
<p>McConkey, R. (2000)  Ireland</p>	<p>Evaluation of respite services.</p>	<p>Open-meeting, interviews, questionnaires.</p>	<p>Evaluation of Beechfield Services (overnight breaks and domiciliary support services for families and children with learning disabilities) with two main aims:                      1) Identify ways of making services better.                      2) identify lessons from services that can inform development of similar services elsewhere.</p>	<p>All main stake holders in the service welcome to participate (families, staff and Trust staff).</p>	<p>Conclusions about overnight service:                      - evidence that parents were more satisfied with the overnight service in terms of mix of children, transport to school, activities for children, homey environment.                      - two main issues(identified by parents): staff turn-over and greater availability of the service                      - Main issues identified by staff and professionals: lack of parking, transport to activities outside of the house, better communication with the school.                      - children appeared to enjoy stays, mentioned having larger rooms and more outings; main concerns were missing their families and having a say when they attend.</p> <p>Conclusions about the Domiciliary Service:                      - appreciated with wider diversity of benefits for both caregiver and</p>	<p>Evaluation was successful in meeting two main aims. Lessons identified for future services:                      - ordinary style housing (with certain safety adaptations) can be successfully used as short break facility                      - there is much merit in integrating domiciliary and other forms of short break provision into an overall family support service                      -n essential next steps are to define more clearly the outcomes expected from short-break and support services and find means for assessing/reviewing the need for such services.</p>

					<p>child than with overnight service.                  - main issues mentioned by parents: having more of it and continuing of staffing. Main issues mentioned by staff: better matching of family needs to hours and the lack of say they have in service.</p>	
<p><b>1<sup>st</sup> Author (Year) and geographical location</b></p>	<p><b>Journal Name (or type of document)</b></p>	<p><b>-Type of study (qualitative vs quantitative)                      -Method of data collection (survey, interviews etc.)</b></p>	<p><b>Aim of the Study</b></p>	<p><b>Sample description (e.g. parents, care providers) &amp; #</b></p>	<p><b>Main findings of the literature (short statement 50 words)</b></p>	<p><b>-Any other outcome measures?                      -Cost Analysis (respite)                      -Advantages and/or Disadvantages of respite services</b></p>
<p>McConkey, R. (2004)  Ireland</p>	<p>British Journal of Social Work</p>	<p>Structured interview  Qualitative</p>	<p>Little is known about the characteristics of children who meet British legal definition of “looked after”.</p>	<p>Data was obtained on 108 such “looked after” children living within one geographical area in Northern Ireland and who spent 90 days or more in a 12-month period living away from the family home. Median age of the children were 14 years old; most had challenging behaviours allied with learning disabilities, communication difficulties and some technologically dependent.  Views of family</p>	<p>Results are presented in 3 main sections:                      Characteristics of children and families: severe learning disabilities, profound or multiple disabilities, mild or moderate learning disabilities and physical disabilities were all present issues. These issues resulted in challenging behaviour, severe communication difficulties; and technology dependency (requires tube feedings, blood transfusions, etc.).                       Family’s present use of services: majority of families (34%) utilized one respite services, while smaller groups used more, and 14% did not use any.                       Likely need for services in the future: greatest need was for more respite and shared care either through residential facilities or</p>	<p>Future service needs included increased respite breaks for families and the provision of more residential placements and more appropriate accommodations.</p>

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
McConkey, R. (2004)  Ireland	Journal of Learning Disabilities	Semi-structured individual interviews  Qualitative	Better understanding of the benefits of family placement schemes that involved adult persons and elderly caregivers.	25 caregivers aged 55 and older, of people with intellectual disabilities using placement schemes in northern Ireland, along with an additional 20 caregivers recommended for these schemes were interviewed.	Placement schemes were very favourably received. Elderly caregivers welcomed respite breaks and valued relationships with placement provider. Placement providers were very satisfied with the way the schemes operated.  Seems to be a feasible means of meeting the needs of older caregivers and their relatives with intellectual disabilities.	Main complaint: low level of payments.  Key factors affecting the further development of services include recruitment of male providers; registration issues and training of providers and the difficulty in meeting the demands of multiply disabled persons.
McConkey, R. (2004)  Northern Ireland	Journal of Social Work	Parents in the Belfast area were interviewed individually at home.  Those in rural areas were send a postal questionnaire for self-completion.  qualitative and quantitative	Identify the features of short-break residential services that families value.  Phase Two: determine if the identified features of a “good short-break” service discriminated among different services which provided short residential breaks to families who had children with severe learning disabilities.	Phase One: 108 parents in urban and rural areas described the short-break services they had received and perceived benefits to them and their child in the past year.  Phase Two: 59 families used them to rate one of three short-break services they had used	Twelve distinguishing items were found across the three services. They were grouped into three distinct factors: characteristics of the services, benefits to the child and benefits to the carer. Short breaks are primarily about creating beneficial experiences for families in the present and not with any other long-term intent, such as enabling parents to continue caring for their children rather than seeking an out-of-home placement.	At least there is agreement as to the goal: namely, ‘the development of imaginative, person-centered and flexible respite or short term breaks’  Benefits to the carer: to meet other parents; and to get information about other services.  Benefits to child: Children are shown love and affection; simulation and other activities for

						<p>the children</p> <p>Short-break service features: Small numbers of children at a time; homely environment; located in pleasant surroundings; low risk of abuse; child looks forward to going; child-oriented service; standard of care provided; and gives me someone to talk to.</p>
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
McConkey, R. (2005)  Ireland	British Journal of Learning Disabilities	Interview  Qualitative	Study the characteristics of the suitable people who are recruited to provide respite care for adult persons with intellectual disabilities, in the client's own home (aka family placement), and the reasons why the individuals are chosen.	Thirty providers of family based placements to adults with intellectual disabilities were individually interviewed. All but one was female and two-thirds were aged 50 or over.	Majority of placement providers were recruited from the care sector and many had experience of working with adults with an intellectual disability.	<p>AD: All providers felt they gained a great deal of satisfaction and enjoyment from involvement; stressed the amount of commitment required for this position. Were also overall very satisfied with the way the schemes operated.</p> <p>DIS: - often long waiting list for family placement schemes; resulting in an ongoing need to recruit</p>

						providers.  Large number of providers recruited from those already working in health and social services.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
McConkey, R. (2005)  Ireland	Journal of Intellectual Disability Research	Two sided pro forma divided into 4 sections: 1) Respondents were asked to rate the individual receiving care according to the level of care they required along with their specific needs and level of independency. 2) Information about family careers (who they lived with, employment, income, etc.). 3) The family's use of listed support services in the past 12 months (day care, respite breaks, etc.). 4) Future service	Learn more about the characteristics of careers, use of support services and unmet needs of the family members who are caregivers for an adult person with an intellectual disability.	1,500 pro-formas were returned from the service staff who knew the family and the person (aged 20 years and above) with the disability best. These service staff members were located all across Northern Ireland.	Nearly half of the people were being cared for by both parents, approximately one third lived with one caregiver and 20% lived with another relative. The subgroups of caregivers varied in characteristics. Regression analysis identified the relative's higher dependency for care was the only common variable that was predictive of the caregivers' access to support services. Overall, a possible measure of caregivers' unmet need for various support services was derived.	Indicates that greater priority is to be given to monitoring the characteristics of family caregivers, their service usage and possible unmet needs. (Would ensure greater transparency across Trust areas in the provision of family support services that should make it easier to identify areas in which under-provision is evident and the reasons for it.  It appears all caregivers do not have equal access to the supports services when they need them. Characteristics of the person with the disability were sometimes significantly

		needs.  Qualitative				associated with the provision of services, which could reflect a disposition by Trust staff to judge the need for services on the basis of the person with the disability, rather than the needs of the family or caregivers.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
McConkey, R. (2006)  Ireland	Journal of Social Work	Individual and group interviews, and /or questionnaires.  Qualitative	Investigate the benefits of holiday breaks for adults with intellectual disabilities and their older-aged care givers.	100 volunteers; people with intellectual disabilities provided feedback through group or individual interviews. Information was also collected from their caregivers in the form of questionnaires.	Overall the breaks were thoroughly enjoyed; provided participants with a range of activities; family caregivers reported more benefits to their relatives in later years.	AD: holiday programs (Opening Doors) have vital role to play in providing opportunities for people with intellectual disabilities to experience new forms of leisure to develop necessary skills for relating to other people and offer some support to older caregivers.  One disadvantage of study was that those intellectually disabled adults who attended these breaks/outings were more competent, so implementing this program for those with more specific needs could be a challenge.

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McConkey, R. (2010)  Ireland	Journal of Applied Research in Intellectual Disabilities	Using data from a national database in Ireland (National Intellectual Disability Database)  Quantitative	(1)To monitor changes in the usage of out-of-home, overnight respite services over an 8-year period of increased resourcing of intellectual disability services within the Republic of Ireland. (2)To identify the characteristics of families using overnight respite services and those who are recorded as needing them. (3)To assess equity of provision across the country.	around 16 000 persons living at home with parental or other carers were selected	The increase in respite provision over the 8 years was accompanied by an even greater increase in the proportions of people recorded as needing it. This was expressed more in terms of children requiring a service they had never received, but over the years the rise in need was even more marked for those requiring enhanced provision to the services they were already receiving. In all eight areas of the country, the proportion of respite users had increased but this happened in some areas more so than in others. This suggests that equity of provision across a country can take a long period of time to achieve especially when reliance is placed on differential increases in provision over time rather than transferring resources out of advantaged areas to those with less provision.	1999 – people who received respite breaks (n=2396) -1130 persons were recorded as needing respite (14% in 2003 and 16% in 2007 were now receiving respite who explained the “need” for it  2003 – an additional 1899 persons were now receiving respite breaks who did NOT receive them in 1999  2007 – an additional 2537 persons were now receiving respite breaks who did NOT receive them in 2003
McConkey, R. (2011)  Ireland	Journal of Advanced Nursing	Survey design was used on the data recorded on the National Intellectual Disability Database for 2008	This paper reports the findings of a national study of the variations in the provision and correlates of respite breaks to families.	4000 families’ use of respite breaks in a full calendar year (2008) with moderate, severe and profound disabilities.	Striking differences across health service areas were found on both indicators of usage. These were not solely attributable to the availability of provision but also reflected variations in the criteria local services used to allocate	One in four persons living with family carers (N = 4241; 25.4%) were recorded on the Database as having received a respite break. The median number of

		Quantitative		The proportion of carers who had any access to breaks and the median number of days they had received.	places. Those persons with more severe disabilities were given priority, whereas carer characteristics were not a major influence. Contact with social workers and community nurses also increased the likelihood of carers receiving respite breaks.	nights per person was 20 (range: 1–313 nights)  Twice as many families received respite breaks in one area of Ireland than in other areas. Similar variations were also present in the number of nights; 3.5 times more nights in one area than in another.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
McConkey, R. (2011)  Ireland	Journal of Intellectual Disabilities	The model was documented and validated through individual and group interviews with a range of stakeholders.  Review of services	The rationale for complex service models is discussed and the key lessons for replicating this model are reviewed.	30 stakeholders involved. The services are embedded within multi-agency partnerships and four particular features are highlighted: the values and ethos underpinning the service; the service procedures; the organization of short breaks; and the role of an intensive support/outreach service.	The amount of service provided to families is carefully matched to their needs and can be increased and decreased. The services strive to assist the children to become more competent and to reduce their challenging behaviours. The staff have particular expertise and experience around behaviour management, which means they are well suited to advise and train others, such as parents or staff in other services. The service aims to forge trusted relationships with parents, and through personal contacts offers them emotional as well informational and tangible supports.	In total 123 families had accessed the services in the period 2008–2010.  The families predominantly have low incomes (65%) and high proportions were lone parents (40%).  Overall more boys (74%) than girls used the services  Short breaks: The services have homelike accommodation in which four or five children stay overnight in their own bedroom and share domestic-style

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McConkey, Roy (2013) UK	Journal of Applied Research in Intellectual Disabilities	Interviews conducted with a parent, the child's key worker within the service and the professional who had referred families to the services  Qualitative	Identify how these three services were perceived to meet the needs of families whose children are severely challenging. Uniquely, this would be done from the perspective of parents, of the key workers within the service and of professionals who had referred families to the services.	17 randomly selected children (out of 123) who were currently receiving services or had done so in the past 2 years from three specialist short break and community support services	Short break services can make a vital contribution to retaining children who are challenging within their families but under some important conditions which this study has identified: notably, the management of complexity, the formation of trusted relationships and creation of tangible benefits for the child and for the family.	AD: -consensus among families was that the amount of services they received was appropriate to their needs -it is the children and young people who are reported to benefit most DIS: (improvements) - parents being given short notice of changes to the notified arrangements, earlier notification of allocated dates for breaks, the use of agency staff, the amount of record keeping and having more clarity around the goals for the community support service
McGill, P. (2006) UK	Child: Care, Health and Development	postal questionnaires  Quantitative	Perceptions of family carers of children and young people with developmental disabilities and challenging behaviour of the help, support and treatment received from services and	66 family carers on the nature of, and their satisfaction with, services, professional help and advice received in respect of their family member's challenging	Most carers were dissatisfied with support and services received. Almost half reported receiving no professional input or none that was helpful. Over two-thirds reported receiving respite care but, in a third of these, the child had been excluded because of challenging behaviour.	A total of 68% of respondents had received respite care, beginning at an average age of 6.2 years. Respondents identified 72 separate respite packages, 49% being rated as helpful. 39% of

			professionals.	behaviour.		parents reported at least one package helpful. Sixteen parents (36% of those in receipt) reported their son or daughter's exclusion from respite, 13 of them (81%) for reasons of, or including, challenging behaviour.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Merriman, B. (2007)  Ireland	Child and Family Research Centre (publisher)	Combination of a focused literature review and consultation with stakeholders (service providers, academics in policy field, and parents of people with intellectual disabilities and autism).	Primary: investigate best practice in respite care for people with intellectual disabilities and autism.  Secondary: provide a resource for raising the policy profile of respite care, and for leveraging support for further research.	N/A	First step is understanding context in which services are provided (policy/legislation changes): - Rights of Persons with Disabilities (2006) -Madrid Declaration (2002) (offers framework for progress and a set of ideals.  Next must define service: - Defines respite and provides rationales - Introduces different forms of respite care (informal help, formal respite care in the home, out-of-home respite care and recreation/holiday breaks).  Most important step is determining the outcomes intended: - Benefits include social development and independence; benefits clustered around health	From understanding limitations from current practice and looking at examples of best practice, can move towards ideal level of provision by defining 8 provisional principles.

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Miller, S. (2002)  England, UK	Paediatric Nursing	Review of respite services	Provision of respite care, including types of respite care that might meet the needs of the child and his or her family, and also identify the advantages and disadvantages of various types of respite care.	Children with complex health care needs and their family	Having briefly reviewed the diversity of provision that might be available it is clear that parents need information about the types of services provided in their area. While not all parents will take advantage of the services on offer, for some, just knowing that they can take a break will enable them to continue caring	Generally there are three types of respite care available: institutional, in the child's own home or in another family's home (shared care/link family). Since each family is unique, different types of respite care might meet different families' needs.
Mullins, L.L. (2002)  USA	Children's Services: Social Policy, Research and Practice	Quasi-experimental, 6-month pre-post design 3 questionnaire measures  Longitudinal Study	(a) to examine the psychological benefit of respite services on parents of children admitted to an inpatient developmental disability center, (b) to examine whether the beneficial effects of respite care are maintained over a 6-month time period, and (c) to examine the effects of respite services on child functional abilities.	Primary caregivers of children admitted to an inpatient facility for children with developmental disabilities (n=80)	Parenting stress was significantly lower at discharge, but at 6-month follow-up had returned to admission levels. Notably, both groups demonstrated improved functional ability from admission to discharge despite the respite care group receiving little formal therapy over a much shorter stay in the center. Respite care appears to result in reductions in psychological distress in parents of children with developmental disabilities; such reductions are comparable to that of a longer term stay.	

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Nageswaran, Savithri (2009)  US	The Archives of Pediatrics & Adolescent Medicine	Cross-sectional study using 2001 National Survey of Children with Special Health Care Needs (NSCSHCN)  Quantitative	To describe (1) the subpopulation of children with special health care needs (CSHCN) in need of respite care and (2) the factors associated with unmet respite care needs	Caregivers of CSHCN (n=38,831)  Children younger than 18	Respite care needs of CSHCN are frequently unmet. Strategies are needed to improve access to respite care for families of CSHCN.	Determined the association of socio-demographic factors and health status of CSHCN with need for respite care and unmet needs for respite care.  DIS: N=767 described reasons for unmet respite care needs: 26% - lack of availability or transportation problems 22% - too much cost 13% - health plan problem 7% - time not convenient 18% - other  9% need respite care; of those, 25% do not receive such care
Nankervis, K. (2011)  Australia	Journal of Intellectual Disability Research	Review of client files for information around their relinquishment into out-of-home respite care facilities for an	investigate the relinquishment of individuals with ID into out-of-home respite care, with a focus on what factors lead to relinquishment, what were the potential	32 individuals for whom families have relinquished their care in a defined 12-month period  17 staff members involved with these	Factors that can lead to families and carers deciding to relinquish care can be categorized into characteristics inherent to the client (high support needs, high medical needs, limited communication and young adult age), characteristics inherent to	Several positive strategies to prevent relinquishment of care that were suggested by staff included: (1) teaching parents strategies while the individual is young in

		<p>extended stay.</p> <p>Qualitative</p>	<p>risk factors for relinquishment, the potential strategies that could be implemented to improve supports for families and the outcomes experienced by families after relinquishment had occurred</p>	<p>families were also involved</p>	<p>the family (psychological distress, single parent family, parental expectations, marital breakdown, desire to have 'normal' life) and characteristics associated with the support context (availability of respite care services, availability of appropriate supports, relinquishment being used as a strategy to gain out-of-home permanent accommodation).</p>	<p>order to prevent the development of challenging behaviours; (2) arranging marriage/relationship counselling before the relationship is in crisis; and (3) treatment for carer depression.</p> <p>After time, staff reported a dramatic improvement in the family's quality of life. Staff indicated that many families reported experiencing uninterrupted sleep for the first time in years, and feeling more relaxed and in control of their lives.</p>
<p><b>1<sup>st</sup> Author (Year) and geographical location</b></p>	<p><b>Journal Name (or type of document)</b></p>	<p><b>-Type of study (qualitative vs quantitative)</b>  <b>-Method of data collection (survey, interviews etc.)</b></p>	<p><b>Aim of the Study</b></p>	<p><b>Sample description (e.g. parents, care providers) &amp; #</b></p>	<p><b>Main findings of the literature (short statement 50 words)</b></p>	<p><b>-Any other outcome measures?</b>  <b>-Cost Analysis (respite)</b>  <b>-Advantages and/or Disadvantages of respite services</b></p>
<p>Nankervis, K. (2011)  Australia</p>	<p>Journal of Policy and Practice in Intellectual Disabilities</p>	<p>Review of the literature</p>	<p>Examine to what extent the literature has discussed the issues associated with the need for urgent respite and how this need may link to relinquishment of care.</p>	<p>Family having to relinquish the care of their family member with a disability</p>	<p>Firstly, the research points toward a trend of increased demand for respite services as many families feel that their respite care needs are not being met. Secondly, there also appears to be certain individual and family characteristics that are associated with need for respite care such as developmental stage and severity of disability, poor support, poor health, financial issues, and high</p>	

					levels of carer stress. Thirdly, poor service allocation and coordination may mean that families will find the caring role even more challenging that may lead some families to relinquish care. Fourthly, poor coping and high stress levels—because of challenging behavior by the individual with the disability—can also be considered factors that could lead to relinquishment.	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
nef consulting (2009)  UK	N/A  Report commissioned by the Action for Children and Every Disabled Child Matters campaigns	N/A; report	Examine the social and economic value created by the short breaks component of the Aiming High for Disabled Children (AHDC) programme, for disabled children with complex needs; whose largest component is providing families with “short breaks”.	N/A	There are substantial financial savings to be made with the effective delivery of short breaks; therefore it is imperative that short breaks services are provided as part of a holistic range of services that support families with disabled children.	AHDC identified short breaks as the highest priority service for families with disabled children, and of the £430 million (~\$774 million CAD) allocated to new investment in disabled children’s services during 2008–2011, £370 million (~\$674 million CAD) is devoted to short breaks. <ul style="list-style-type: none"> <li>- Childcare – £35 million (~\$63 million CAD)</li> <li>- Transition Support Programme – £19 million (~\$34.2 million</li> </ul>

						<p>CAD)</p> <ul style="list-style-type: none"> <li>- Parent Forums – £5 million. (~\$9 million CAD)</li> </ul> <p>Financial savings from short break support: England. £174 million (~\$316.9 million CAD) savings if short breaks were effectively delivered to all those eligible to receive them, based on following:</p> <ul style="list-style-type: none"> <li>- decreased cost of long-term residential care from reductions in children placed outside of family home: £135 million (~\$243 million CAD).</li> <li>- decreased cost to health services from reduction in parent/family/career stress: £18 million (~\$32.4 million CAD)</li> <li>- decrease cost to schools of educating siblings with behavioural/emotional difficulties: £21 million (~\$37.8 million CAD)</li> </ul>
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Ng, G.T. (2009) Singapore	Health and Social Care in the Community	questionnaire, comprising both closed and open-ended questions  Quantitative	Provide feedback to service planners and programme staff on the delivery of services to caregivers and opportunities for improvement	Providers of caregiver support services, n=36	The need to offer more caregiver support services has become pressing and will continue to increase. There is scope to expand support services for caregivers, particularly those who care for persons with disabilities: some service providers had given feedback that family caregivers of persons with disabilities tended to become overly dependent on professional aids in the care of their dependent family members.	AD: Respite - # of service providers: Home Support (n=19) Day care service (n=11) Short-stay in institution (n=8) Emergency/Overnight stay (n=3)
O'Brien, J. (2001) Australia	Australian Journal of Social Issues (Australian Council of Social Service)	Literature review on past qualitative studies.	Using respite care breaks for families to prevent abuse of the child with a disability, and family breakdown	No sample, literature review.	Planned respite services play an important element of an integrated family support system by reducing stress on people's capacity to raise their children effectively, and lessen the likelihood of child maltreatment and the possibility of children's removal to long-term care.	Vulnerable families also face additional sources of stress from adverse social and economic conditions.
Preece, D. (2007) UK	Journal of Autism and Developmental Disorders	Postal Survey  Quantitative	Sought to obtain as close to a whole (geographically defined) population of families with children with ASD as possible, identifying why some families accessed short breaks services and others did not.	155 families with a child with an autistic spectrum disorder (ASD) (response rate of 60.5%)	Results confirmed high degrees of stress and low levels of informal support for all families, but no significant difference in the informal support available to non-users as compared to users of short break services. This research suggests that parents who feel they need short breaks are more likely to receive this support if they have a social	Forty-nine of the 114 families that did not access short breaks (43%) expressed a current need for them.  Children of users of short breaks were reported as being, on average, dependent in 8.2 of the areas

					worker, if their child is in a special educational setting, over 11 years of age and has a diagnosis of ASD (possibly with SLD).	measured on the Ten Point Dependence Scale, compared to 6.9 areas for the children of non-users.
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Preece, D. (2009)  UK	Practice: Social Work in Action	Review of services	Identifies the importance of short breaks (respite care) services to many families with children with autism spectrum disorder (ASD), as well as the obstacles that may prevent families accessing such services	Short break services for families with children with Autism Spectrum Disorders	Generic short breaks services often prove inadequate, and that extra consideration must be given to a range of key factors when providing or commissioning short breaks services for this group. These are: (1) the physical environment (2) consistency between home, school and short breaks (3) use of ASD-appropriate approaches (4) staff attributes, including their understanding of ASD (5) individualization (6) successfully accessing the community, and, (7) grouping of children By effectively addressing these points, cost-effective autism-specific short breaks services for families with children with ASD in Northampton shire (both family-based and residential) have been developed that have produced high levels of satisfaction among families.	DIS: Short breaks providers may seek to provide an environment where children can be with their friends: children with ASD may prefer being solitary, and may have no concept of ‘friends’. Providers may seek to give children opportunities to do different and exciting activities: children with ASD may cling to predictability and routine. Problems can occur for a number of reasons, including the lack of staff understanding and expertise regarding ASD; ecological issues, such as noise, light, space, security and staffing levels; and as a result of attempting to meet the needs of a wide

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Radcliffe, J.L. (2008)  UK	British Journal of Learning Disabilities	Questionnaire  Qualitative	Examine the effects of respite care children with learning disabilities, to determine the need for greater awareness of the possible distress to children attending respite.	Questionnaires sent to the parents, teachers and respite staff of 48 children with learning disabilities who had received respite in the previous 12 months.	Many adults are unaware that 37% of children were described as showing a strong negative reaction to respite at home or school which lasted for several days. This suggests that a sizeable minority of children suffer significantly, yet continue to attend.	DIS: - evaluating the differing perspectives of parents, teachers, respite staff and children is a challenge to the due to differences of views (ex: may view negative reactions to separation as “normal”). - unclear when negative reactions reflect a serious problem, as opposed to transient distress
Ridley, G. (2003)  Australia	(Report) to the Department of Ageing, Disability and Home Care (DADHC)	Literature Review	Identify and summarize Australian and international research and program material for appropriate models of respite care for children with a disability under 7 years, and for children with a disability and challenging behavior.	N/A	It is evident from the literature reviewed that the success of respite care model and programs is dependent on the utilization of information that is provided by the users and non-users of respite care, in the development of such models.	Majority of families favor a combination of short break respite care options and in-home respite care. In conjunction, families believed the following factors further improved their situation: - In-home assistance on a regular basis by a case manager/respite service coordinator who becomes familiar to

						<p>family/child for emotional support, advocacy and information about other community services.</p> <ul style="list-style-type: none"> <li>- Power to choose through flexible funding packages to help pay for respite carer in home and other family supports.</li> <li>- To be included in the decision making process.</li> <li>- Provision of training and support to parents.</li> <li>- Central service or telephone advice line.</li> </ul>
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<p><b>-Any other outcome measures?</b></p> <p><b>-Cost Analysis (respite)</b></p> <p><b>-Advantages and/or Disadvantages of respite services</b></p>
Rizzolo, M.C. (2009)  USA	Intellectual and Developmental Disabilities	Data from the State of the States in Developmental Disabilities	Summarize trends in family support services and spending nationally and in the individual states	Family support for children and adults with ID and DD	The growing cohort of aging family members caring for persons with ID and DD nationally only heightens the importance of enhancing family support services. Improving understanding of the nature and quality of family support though improved data collection is a necessary part of this process.	<p>In fiscal year 2006 annual nationwide family support spending per family averaged \$5,376 (\$5,837.26 CAD), ranging from \$232 (\$251.91 CAD) per year per family in Alabama to over \$10,000 (\$10, 858 CAD) in 11 states.</p> <p>Between fiscal year 2000 and 2006, the number of individuals</p>

						receiving family support services increased by over 108,000 (34%). Total adjusted expenditures for family support increased from \$1.3 billion to \$2.3 billion (~\$1.4 billion – \$2.5 billion CAD) during that same period. In two years between fiscal years 2004 and 2006, there was an increase of 43,000 families supported nationwide from 385,579 to 428,803 families.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Robertson, J. (2011)  UK	Health and Social Care in the Community	Electronic literature searches.	Evaluate the existing international research evidence concerning the impacts of short breaks on families with a disabled child.	Families with a disabled child using short break services – 60 articles or reports were included in the review	Short breaks appear to have the potential to positively impact on not only the well-being of carers, but also the children receiving short breaks and their families as a whole. However, short breaks are not a panacea and policymakers should be cautious of placing undue emphasis on the provision of short breaks in the absence of other forms of support for disabled children and their families.	AD: Benefits of short breaks may be limited to specific areas of carer, child and sibling well-being -short breaks reduce stress in carers and given them time to rest and relax -helping the child to separate from their parents as a step towards greater independence -children making new

						<p>friends</p> <ul style="list-style-type: none"> <li>-parents being able to spend more time with their other children</li> <li>-siblings get to take place in activities that may otherwise be impossible</li> </ul> <p>DIS:</p> <ul style="list-style-type: none"> <li>-negative comments were mostly about missing their family rather than the services provided</li> </ul>
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<ul style="list-style-type: none"> <li>-Any other outcome measures?</li> <li>-Cost Analysis (respite)</li> <li>-Advantages and/or Disadvantages of respite services</li> </ul>
Robinson, C. (2001)  England, UK	Child and Family Social Work	<p>Data from 2 research studies: Study 1 – data from hospice records to discover how many children had stayed in each hospice during a 12-month period</p> <p>Study 2 – semi-structured interview in the family home</p> <p>Qualitative (?)</p>	Which services are families using and the difficulties of obtaining a coherent and consistent package of support.	<p>Study 1 - 38 families; 38 children between two-and-a-half years and 20 years and all were severely disabled (16 had cerebral palsy)</p> <p>Study 2 - 39 families; 40 children with learning disabilities who were tube fed aged one year to 19 years</p> <p>Total: 77 families were interviewed.</p>	<p>Many families in both studies said they valued practical advice and help and someone who always ‘looked out’ for them. Given the ‘round the clock’ care that many parents were providing for their children over many years, it should be a priority to meet such a modest request. Indeed, it is high time that children with additional complex health needs received more attention.</p>	<p>In both groups, parents were generally positive about the care provided through family link schemes and about the benefits to them and their child. However, often they were unable to obtain frequent or long enough breaks to manage with this type of provision alone.</p> <p>Even amongst families who had never used a hospital bed for short-term care, there was an almost unanimous</p>

				Additional interviews were conducted with professionals who worked with families.		dislike of the idea of the child going into hospital, especially as many of the children have been subject to a lot of unpleasant hospital treatments during their short lives.
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Sandy, P.T. (2013)  Limpopo, South Africa	International Nursing Review	Case study design – semi-structured interview at home and then follow up interviews in a community clinic  Qualitative- Interpretative Phenomenological Analysis	To investigate the support needs of caregivers caring for children with learning disabilities	3 families with of children with learning disabilities who attended a community clinic on a monthly basis for the last 10 years	The study findings have implications for practice and policy. Regular training and support should be offered to caregivers in order to broaden their understanding of learning disabilities and enhance their caring ability. Nurses are the main source of training and support and offer these during clinic-based engagement and home visits.	The study identified a range of support needs for caregivers. Examples of these include financial, emotional, practical support, training, respite care, affiliate stigma and partnership working.  Although the South African government offers grant to children with learning disabilities, some caregivers clearly stated that the money they were offered was not sufficient to meet the daily economic needs of this group of children.
SHARED CARE NETWORK (2008)	Shared Care Network (Publisher)	Survey  Qualitative	This report is based on a survey of families of children with autism. It shows the extent to	Surveyed families of children with autism nationwide across UK (no number	“Do short breaks help children with autism to make friends?” – Over half of parents said yes, vast majority (92%) said breaks helped	Children with autism are amongst those disabled children who wait longest for short break

<p>UK</p>			<p>which short breaks help overcome many of the difficulties faced by children with autism. The report highlights the need to recruit carers for children with autism who currently make up a third of disabled children waiting.</p>	<p>given).</p>	<p>their child develop social skills.</p> <p>“Do short breaks help children with autism take part in social activities?” – 4/5 of parents said yes.</p> <p>“Do short breaks help children with autism to be independent?” – 2/3 said these helped their child learn independence skills.</p> <p>“Do short breaks make children with autism happier?” – ¾ of parents said yes.</p> <p>“Do short breaks help parents of children with autism cope with the demands of caring?” – 100% of parents said yes, it helped entire families cope; many stressed the importance of knowing their child was safe and their condition was well understood by caregivers.</p> <p>“Do short breaks help families of children with autism live more ordinary lives?” – 100% said yes it helped the entire family, nearly ¾ said it helped their child specifically.</p> <p>Short breaks were also beneficial for non-disabled siblings for it allowed more one-to-one attention from their parents; both parents and siblings get a break from the stress and demands of caring for a child with autism.</p>	<p>services.</p>
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Stalker, K. (1994)  UK	Mental Handicap Research	Semi-structured interviews  Mixed Method	Explore the perceptions and experiences of people using services, examine how far existing provision met parents' perceived needs and allow scope for comparison between the experiences of different service users, a dimension noticeably lacking from earlier research.	160 parents using different types of respite care - 64 parents using family based schemes, 64 using local authority residential homes and 32 using health authority provision including hospital beds, hostels and special respite units.	Uneven access to services was identified, with black and low income families apparently having limited choice. Important features of family based schemes were the child-centered nature of the service, the good relationships generally enjoyed by parents and carers and the informality of arrangements. Some benefits were reported for children receiving respite care in residential homes but widespread difficulty in obtaining bookings and instances of poor physical care were significant drawbacks. Parents using health authority provision reported a range of dissatisfactions, mostly associated with the institutional nature of the service.	<p>The reason most often identified by parents for using respite care was the need to have a break from the caring role and an opportunity to relax. The chance to spend some time with their other children and/or each other was an additional factor. These reasons, which might all be seen as enhancing family well-being, accounted for 40% of responses.</p> <p>The majority of families using residential homes thought they had no choice of respite facility and knew of no other (76%). This was also true of 42% of the health authority group.</p> <p>In all, 10 parents stated that their children did not like having respite care. Several described the children's distressed reactions, such as crying, screaming or an</p>

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Staley, K. (2008)  UK	Resource guide written for commissioners and service providers responsible for services for children with complex health care needs and their families.	Interviews	Collection and collation of innovative practice examples regarding short breaks for families with children who have complex health needs and disabilities.	Commissioners and service providers.	<p>“What kind of short breaks are provided for families?”</p> <ul style="list-style-type: none"> <li>- under five groups</li> <li>- Saturday play schemes</li> <li>- summer holiday play schemes</li> <li>- school holiday play schemes for children with complex health needs</li> <li>- youth clubs</li> <li>- ‘transitions’ summer holiday club</li> <li>- home-based care</li> <li>- home-based palliative care</li> <li>- home-based support worker</li> <li>- residential units</li> </ul> <p>“What are the positive characteristics of the new models of short break services?”</p> <ul style="list-style-type: none"> <li>- Breaks described as “flexible” and “responsive” who the whole family’s needs.</li> <li>- Based at home or in community</li> <li>- Ensure continuity of care</li> <li>- Offer stimulating and educational activities</li> <li>- family-centered</li> <li>- they support parents</li> <li>- They are distinct from healthcare services</li> </ul>	

					<p>“Why develop innovative models of short breaks?”</p> <ul style="list-style-type: none"> <li>- Parents’ expectations have changed</li> <li>- The new service models are requested by parents and better meet their needs</li> <li>- new commissioning arrangements encourage innovation</li> </ul> <p>“What are the financial costs and benefits?”</p> <ul style="list-style-type: none"> <li>- currently little evidence available as to the financial costs and benefits of developing new types of short break; further research required.</li> </ul> <p>Suggestions:</p> <ul style="list-style-type: none"> <li>- provide nursing care to accompany families on holiday to let whole family have a break together</li> <li>- increase flexibility of funding arrangements; help families receive free care earlier on and not at crisis point</li> <li>- homework clubs for siblings</li> <li>-Under-fives groups with one-on-one supports</li> </ul>	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
St.Amant (2012)	Service Policy and Procedure	N/A	Introduce scope of service and philosophy	N/A	Statement of purpose, scope of service and philosophy of	Scope of Service (key points):

	Manual		of St. Amant's short term admissions for individuals with developmental disabilities in order to provide relief to families or caregivers.		St. Amant.	<ul style="list-style-type: none"> <li>- 5 regular respite beds and one additional bed reserved for complex respiratory care needs</li> <li>- Service available to families living in Manitoba at no cost, and serves both children or adults with intellectual disabilities.</li> <li>- referrals for 5 regular respite beds can be made by anyone.</li> <li>- all respite inquiries and referrals are directed to Social Work Services</li> <li>- applications are made at the request of the legal decision maker and in conjunction with the case manager.</li> <li>- families can book respite as needed (within guidelines) and according to availability up to 6 months in advance. Can schedule one admission per month of up to 7 consecutive days; when request cannot be met, it will be put on a waiting list.</li> <li>- during respite admission, individual receives case appropriate to his/her needs and may access limited recreation activities.</li> </ul>
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						Philosophy: Quality care and family centered service delivery.
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St.Amant (2013)	Respite Expansion Summary Report	N/A	Provides a summary of the need and cost of the expansion of respite services at Red River Place of St.Amant.	N/A	<p>- Currently scheduled on 'first come first serve' basis</p> <p>Respite Expansion Summary Report:  - during 2012/13 year, River Road Place (RRP) provided respite care to 29 adults and 10 children, resulting in 2051 days requested and 1878 days provide  - 173 days not accommodated  Current wait list of 25 individuals (16 children and 9 adults) → approx. 2 years wait list  Recommendations:  - Restructuring and expansion of the current respite service delivery model provided by St.Amant (shared-care family-based respite, residential homes and 10 bed amalgamated respite unit).</p> <p>Respite benefits the child/adult (trying new things, meeting people and developing practical life skills), families (reduced stress, increase in time spent</p>	

					together), society as a whole (reduced strain on families thus reducing changes of family break up, stress related illness) and financial savings (decreased cost of long-term residential care, decreased cost to health services and decreased cost of schools).	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Tarleton, B. (2003)  England, Wales and Northern Ireland	Adoption & Fostering	Semi-structured interviews  Qualitative	Investigate the recruitment, motivation, and support of short break carers who were providing short breaks for 93 children and young people with severe or multiple impairments, and/or complex healthcare needs, and/or behaviour that is regarded as challenging.	7 scheme coordinators and 53 short break carers	Short break carers provided short breaks because they enjoyed it and developed real relationships with children, but that way in which they were recruited, assessed, trained, paid and supported was often influenced by a lack of staff time and a lack of clarity regarding their role.	Why do some short break links end? The main reason for no longer providing short breaks is a change in personal circumstances on the part of the carer, the child or their family. In addition to these “natural” endings the short break carers would find that the role is not for them.
Thurgate, C. (2005)  UK	Paediatric Nursing	Review of literature (Databases used: PubMed, CINAHL, British Nursing Index) Includes an audit of respite service for children with complex health	Review research literature related to respite care for children with complex health needs.	Respite care for children with complex health needs.	What was evident was the difficulty parents have in accessing appropriate facilities which could respond to the individual child's needs, rather than the child fitting the service. It is also apparent that more provision is needed, which must be flexible and respond to individual family needs.	

		needs in the East Kent Hospitals NHS Trust.			However, perceptions of need vary: respite providers and funders must work with individual families to ensure fair expectations and equality in provision for all.	
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Truesdale-Kennedy, M. (2006)  Ireland	Child Care in Practice	Interview  Mix of qualitative and quantitative	An evaluation of a newly developed Families Project in one Health and Social Service Trust area in Northern Ireland aimed to identify the impact on parents and ways in which it could become more effective.	19 families who participated in the project were contrasted with two other groups of parents recruited from the same Health and Social Services Trust (n=25), and from an area served by a different Health and Social Services Trust (n=25). Parents were interviewed in their homes on two occasions 12 months apart.	Participating parents spoke highly of project, reported benefits to child (new socializing and communicating skills) and rest of family. In comparison with other two parent groups, they had significantly higher scores on a measure of family functioning and reported greater levels of support.	No evidence of improvements on measures of parental health.  Use of volunteer helpers allied with community resources opened up new forms of activities for the young people, while offering respite breaks to families.  Some parents noted this “person-centered care” would be strengthened with involvement of schools and career guidance (reach beyond remit of the program).  Lack of impact on parental health calls for additional supportive resources.  Study did not get the

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>opinions of the young people themselves about the program.  -Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
United Nations (2006)  Geneva, Switzerland	N/A	Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol	The Convention on the Rights of Persons with Disabilities is the response of the international community to the long history of discrimination, exclusion and dehumanization of persons with disabilities. It is historic and groundbreaking in many ways, being the fastest negotiated human rights treaty ever and the first of the twenty-first century.	N/A	Over 650 million persons around the world live with disabilities. Add to that their extended families, and a staggering two billion people daily live with disabilities. In every region in the world, in every country in the world, persons with disabilities often live on the margins of society, deprived of some of life's fundamental experiences.  Persons with disabilities make up the world's largest and most disadvantaged minority	The fact that persons with disabilities are more likely to live in poverty is often the result of ignorance and neglect that is reinforced in Government and development policies and programmes that ignore, exclude, are not accessible to or do not support the rights of persons with disabilities to be included in the socio-economic life of the country.  Approximately 10 per cent of the world's population lives with a disability —the world's largest minority. This number is increasing because of population growth, medical advances and the ageing process.
van Exel, J. (2006)	Health Policy	Survey  Quantitative	Investigate the demand for and use of the four most common types of	273 family caregivers participated, all	Results indicate that respite care meets the needs and desires of many caregivers, it appears to be	Two main changes for policy: 1) Identify and direct

<p>UK</p>			<p>respite care (in-home respite, day-care, short-stay and special holiday arrangements).</p>	<p>were relatively aware of out-of-home existing services; majority were female, older aged and unemployed.</p>	<p>effective in reducing caregiver burden, and users are fairly satisfied with the respite they receive. Current programs could still improve in reaching the caregivers most in need.</p>	<p>funds at efficient respite care programs 2) To develop an information strategy that helps caregivers to overcome the obstacles they perceive for using respite care (particularly recipient resistance).  Informal care increasingly recognized as an integral part of health care in Western Societies as a substitute for and complement to scarce and expensive in-patient care.</p>
<p><b>1<sup>st</sup> Author (Year) and geographical location</b></p>	<p><b>Journal Name (or type of document)</b></p>	<p><b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b></p>	<p><b>Aim of the Study</b></p>	<p><b>Sample description (e.g. parents, care providers) &amp; #</b></p>	<p><b>Main findings of the literature (short statement 50 words)</b></p>	<p><b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b></p>
<p>Welch, V. (2012)  UK</p>	<p>Child: Care, Health and Development</p>	<p>Surveys including open ended responses which highlight families experience of using DPs  Mixed method (?)</p>	<p>We investigate associations between the use of direct payments (DPs) and a range of demographic, socio-economic, well-being, service use and satisfaction indicators.</p>	<p>348 parents and carers in families with disabled children using short breaks.</p>	<p>Direct payments can have a number of benefits for families using short breaks, but access to them is currently problematic and socially patterned. If the uptake of DPs is to be increased and made more equitable, more attention must be paid to promoting and supporting their use in ways which meet the needs of individual families.</p>	<p>Of the families taking part in the surveys, 89% (n= 309) were currently using short break services, with 30% (n= 93) using DPs to fund their short breaks.  Characteristics significantly associated with increased use of DPs include the presence of main carers who are female, more</p>

						highly educated and from White British backgrounds, younger children, lower levels of area deprivation, greater access to service and social networks and use of more hours of short breaks.
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Whitlach, C.J. (2006)  USA	Journal of Aging & Social Policy	Questionnaire  Quantitative	Compare the in-home respite experiences of caregivers using the CRC direct-pay mode (pay family and friends) with caregivers using the agency-based option	168 eligible responded: (1) the person primarily responsible for the day-to-day care of a cognitively impaired adult living in the community, and (2) receiving in-home respite from a CRC (Caregiver Resource Centre) during the one-month study period	Caregivers who hire family and friends may experience both cost savings and the receipt of significantly more hours of relief from the stress of constant care.	Caregiver comments to questionnaire.  Caregivers who hired family and friends received respite at a significantly lower unit cost; \$8.48 per hour vs. \$12.67 per hour in 2005 U.S. dollars (\$9.21 – \$13.76 CAD)  AD: when caregivers hire family they were slightly more satisfied with the respite assistance and received more hours of respite at a lower unit cost. DIS: caregivers who hired family or friends reported poorer physical health

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Wilkie, B. (2008)  Ireland	Learning Disability Practice	interviews with three mothers and one father and a further interview in which both parents chose to be interviewed together  Data analysis was conducted within a five stage IPA framework as outlined by Smith and Osborn (2003)  Qualitative	explore the real life experiences of parents of children with ID who used an established respite care service in the Republic of Ireland.	Six parents of five children with ID who had used the respite care facility for more than one year	The most valuable service to these parents is a respite care facility that provides support based on the unique needs of each family. Given the geographical difficulties encountered by parents in accessing services, it is recommended that such a service be developed locally.	AD: The main benefits to the child include opportunities to interact with others, improvement in their social skills and increased opportunities to participate in leisure-based activities in the community. The main impact for parents and other family members was renewed energy and an increase in available time to undertake other activities not directly related to the care of the child with an intellectual disability  DIS: Most parents indicated that weekend respite was preferable, but rarely offered. The main issue for parents, however, was the lack of respite care during summer periods when their stress levels were most acute.

<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
Withers, P. (2003)  UK	British Journal of Learning Disabilities	Visits made to Amy's parents separately and together, to the entire family together, and to Amy's school. Interviews also took place with respite care staff and the respite family and two meetings with the community nurse.  Qualitative	Outlines a psychological intervention undertaken with the parents that was designed to reduce the parents' levels of guilt and self-blame regarding their daughter, and thereby, reduce marital strain. Additionally, the intervention aimed to increase the level of understanding amongst the child's family and services involved in her care with regard to the extent and nature of her intellectual disabilities.	Amy a 5-year-old child with profound physical and intellectual disabilities. She lived at home with her parents and sisters (one older and one younger)	Two principal issues were identified which required addressing: (1) respite care; and (2) marital discord. At 12 months post-intervention Amy's parents reported that they continued to have a much improved marital relationship, and that they felt more secure and relaxed in caring for their daughter, although they still became depressed at her lack of responsiveness. It was accepted that careful assessment of such individuals would be required to inform decisions about their care, rather than basing decisions upon generalized theories of care.	AD: There was no evidence that Amy was suffering as a result of the level of respite care that she was receiving and that she may have benefited from the increased opportunities for sensory stimulation provided in the three settings.  The Uzgiris and Hunt Scales of Infant Psychological Development were administered. The results suggested that Amy's average estimated developmental age was one month.
Wodehouse, G. (2009)	Journal of Intellectual Disability Research	Interviews (between 31 and 68 minutes)  Qualitative	Identify carer perceptions of the ways in which support is unhelpful and how it could be more helpful.	13 mothers caring for a child with ID and challenging behaviour (children between the ages of 7 and 17)	Participants identified three main issues: First, they reported many problems with generic service provision, services such as schools and GPs and 'generic' children's or disability services. Second, they struggled to obtain adequate access to more specialist provision (i.e. help focused on their child's challenging	Most (11/13) reported issues related to respite provision. Problems with respite/short break provision: insufficient amount, restricted availability, provision unsuitable or unreliable.

					behaviour). Third, when such provision was accessed it was not very specialist, often leaving them no better off.	
<b>1<sup>st</sup> Author (Year) and geographical location</b>	<b>Journal Name (or type of document)</b>	<b>-Type of study (qualitative vs quantitative) -Method of data collection (survey, interviews etc.)</b>	<b>Aim of the Study</b>	<b>Sample description (e.g. parents, care providers) &amp; #</b>	<b>Main findings of the literature (short statement 50 words)</b>	<b>-Any other outcome measures? -Cost Analysis (respite) -Advantages and/or Disadvantages of respite services</b>
World Health Organization (2012)  Geneva, Switzerland	N/A	Report/'tool kit'/ comprehensive assessment	Assessing and improving quality and human rights in mental health and social care facilities	N/A	All over the world, people with mental disabilities, intellectual disabilities and substance abuse problems are subject to poor-quality care and violations of their human rights. Mental health services fail to integrate evidence-based treatment and practices, resulting in poor recovery outcomes. The stigma associated with these conditions means that people experience exclusion, rejection and marginalization by society.	In many countries, the quality of care in both inpatient and outpatient facilities are poor or even harmful and can actively hinder recovery. The treatment provided is often intended to keep people and their conditions 'under control' rather than to enhance their autonomy and improve their quality of life.
Yoong, A. (2012)  Australia	Journal of Intellectual Disability Research	Interviewed about the effect of caring on their quality of life (QOL). Interviews were analyzed thematically.  Qualitative	Explore the impact of caring for an adult with ID on the QOL of parents.	12 parents who were the full-time carers of an adult with ID.	Caring had a positive impact on QOL by enabling participants to develop relationships and receive support, participate in leisure activities, achieve a sense of personal satisfaction and enable a more positive appraisal of their lives. Caring had a negative impact on participants' QOL by restricting their relationships, leisure activities and employment opportunities. Caring was also associated with financial insecurity, frustrations at the	All participants wanted flexible and reliable services, to be able to access emergency and overnight respite when needed, a transitional programme to facilitate adjustment into permanent accommodation, and to have more choices in services.

					service system and fear of what the future held for their offspring.	
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*\*Canadian currency value found using "10 year currency converter" on the Bank of Canada website on Aug. 29, 2014.*

<http://www.bankofcanada.ca/rates/exchange/10-year-converter/>