

Submission to the Department of Health on the Provision of Respite Services

Family Carers Ireland welcomes the opportunity to submit our views to the Department of Health on issues relating to the provision of respite services. Family Carers Ireland is a national membership charity for carers. For 26 years we have worked to improve supports, services and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, disabled or has mental health difficulties. Through our network of 22 resource centres and 66 support groups we engage with approximately 20,000 family carers throughout Ireland every year. This submission is based on our experience of supporting and advocating for Ireland's 355,000 family carers¹.

1. What are the strengths and weaknesses of the current provision of respite and what improvements could be made?

Strengths

The current respite crisis makes it difficult to identify any significant positives. That said, a strengths-based analysis of current respite provision would undoubtedly highlight:

- The provision contained within the Charges for In-Patient Services (Amendment) Regulations 2011 which allows for **30 days free in-patient services** in HSE public facilities, including respite, and thereafter caps weekly charges at a maximum rate of €175.
- **Host Family Respite Care**, while not appropriate to all children/adults with a disability, has offered an alternative model of respite care, giving clients the opportunity to enjoy care in a family home rather than a residential centre, while giving the family/carer a break from their routine of care.

Weaknesses

- There is **no standard definition** of respite care, with a broad range of definitions proffered depending on the profession, client profile, type of disability, service provider and the nature and regularity of the service. This variation in definition, while understandable, makes it difficult to establish a baseline for respite provision or indeed measure differences across regions or time.
- The **number of respite beds and in-home respite hours available is wholly inadequate**. Ironically, while respite is consistently identified as a key intervention to support the health and wellbeing of carers, in recent years a perfect storm of events has led to respite becoming increasingly difficult to avail of. Funding cuts, staff shortages, bed closures as a result of HIQA inspections and the transfer of respite beds to transitional care beds or long stay beds have combined to reduce respite availability and deny carers this vital support. Figures released in August 2018 show that 1,741 fewer respite care sessions, both overnight and day sessions, were provided in the first three months of 2018 compared to the same period in 2017, despite an ever increasing demand for this vital service. This has resulted in a total loss of 1,588 overnight sessions and 153 day sessions for family carers² (appendix 1).
- There is a **lack of appropriate and flexible respite options** available, particularly for children with life limiting conditions and adults with a disability. In many cases, even when respite is available, families are unwilling to use it due to the risk of injury to their loved one, the lack of specialist care or its age-inappropriateness. Indeed, there is currently no dedicated respite service available for carers caring for a loved one with a mental health difficulty.

¹ National Carers Strategy (2012) defines a Family Carer as 'someone providing an ongoing significant level of care to a person in need of that care in the home due to illness or disability or frailty'.

² Figures obtained by Sinn Fein TD Louise O'Reilly.

2. Any initiatives you would suggest; if funding became available? What are the priority actions should funding come available?

Priority Actions

- Respite care must no longer be regarded as desirable, but rather as an essential component in our health and social care infrastructure, supporting people with care needs and giving carers and families the breaks they need in order to sustain themselves and continue in their caring role. As is the case in Germany and the Netherlands³ any package of home support must include regular, flexible and appropriate respite. To this end Family Carers Ireland believes that **the impending statutory home care scheme must enshrine an annual entitlement to at least 20 days respite** in line with the statutory leave available to paid workers.
- The centrality of the cared for person, means that carers can only really benefit from respite if they are satisfied that the cared for person is happy and is also seen to benefit. Respite is therefore not only about a break for family and carers, nor should it be solely for those under stress. **Any respite service must provide positive opportunities for young people, adults and older people to interact with their peers, to achieve a measure of independence and to enjoy relationships** with people outside their immediate family. Where appropriate, it should also facilitate a transition pathway to independent living in later years.
- Respite delivered by services within child, disability and aged sectors should be **demand rather than resource-led and address the how, where, when, what and who of flexible respite services**:
 - *How*: Service providers should conduct a comprehensive assessment of the goals and needs of both the client and their carer and personalise respite services with regard to:
 - *Where*: The respite setting should be appropriate to the client's needs, age and location.
 - *When*: The time, frequency and duration of respite should be appropriate to the client/carers needs.
 - *What*: The respite service should provide a good range and choice of appropriate activities to meet the person's interests and capacity.
 - *Who*: The respite service should employ quality, well-trained and suitable staff.
- Carers/families must have **access to regular, planned and secure respite**, enabling them to plan for and enjoy holidays, family events etc. It is also important that mechanisms are in place to deal with **emergency situations**, whereby carers can be confident that their loved one will be looked after appropriately should they become unwell, or face a crisis themselves.

3. What views do you have on appropriate criteria for allocating and prioritising respite resources

All **fulltime carers**, caring for a loved one **medically assessed as requiring fulltime** care should have access to regular, planned respite – a minimum 20 days per year. As noted above, respite arrangements should be **embedded within the statutory home care scheme**, and designed around the outcomes of a **comprehensive needs assessment** which takes account of the preferences of both the carer and the cared for person, and is clinically appropriate. No fulltime carer should be denied respite due to their financial circumstances or their geographical location.

4. Any views on current booking arrangements? Would an electronic booking system be useful?

Current arrangements for booking respite are ad hoc, inconsistent and happenstance, particularly where families are attempting to secure respite within the public system in order to avail of the 30 free in-patient days provided for under the Charges for In-patient Services 2011. Families who cannot secure respite under the public health system and rely on private provision can pay in excess of €1,000 weekly. Not only do families face significant challenges securing respite, but on occasion some families have found themselves in the unfortunate situation of having had booked respite but

³ HRB (2017) Approaches to the Regulation and Financing of Home Care Services in Four European Countries (p.63/69).

then being let down by the respite provider at short notice due to staffing issues, bed shortages, HIQA inspections etc. and have had to cancel holidays or miss family events. The introduction of a reliable and secure booking system for respite would be enormously helpful to families, allowing them to plan for and look forward to future events. It would also be of assistance to the HSE who will be better able to forward plan staffing and respite budgets.

5. What would be the balance between families / individuals who get no support at present, and those who need additional support?

Not all families or cared for persons want to avail of respite, and these wishes should be respected. For those who are assessed as needing respite and wish to avail of it, then a minimum annual level of respite should be available i.e. at least 20 day in line with the statutory entitlement for annual leave for paid employees. Families who provide high level complex care should be offered more regular respite.

6. Any recommendations on important literature or research on the issue of respite care.

Family Carers Ireland wish to highlight three specific themes emerging from literature on respite:

(i). Respite is not desirable but essential:

Respite care is regarded as one of the key formal support interventions to alleviate the stress of caring and is consistently identified in literature as critical to caregiving efforts.

(ii). Respite should be based on 8 principles and provided as a 'Right'.

In their review of international best practice, Merriman and Canavan (2007)⁴ argue that respite care should be a critical component of a comprehensive and integrated range of services in the community for people with disabilities and should reflect the specific needs of the person and family involved and be provided as a right. Furthermore, the authors argue that respite services should have clear systematic goals which should be regularly reviewed and evaluated. In the course of their research, Merriman and Canavan identified 8 principles of best practice in the provision of respite care:

Principle 1: Respite services be person and family-centred;

Principle 2: Respite services be provided on a rights basis;

Principle 3: Respite be defined as a support service and regarded among a system of support services;

Principle 4: That there be a single point of access to respite care services in a given administrative area.

Principle 5: That respite services be designed in consultation with families in acknowledgement of their expertise in providing care;

Principle 6: That respite be designed to facilitate the service user in building relationships in their community;

Principle 7: That respite services be age-appropriate and develop as the service-user develops;

Principle 8: That respite care services have clear goals and that systematic and regular review ensure achievement of those goals.

(iii). Despite its importance statistics show that respite provision in Ireland is decreasing

As discussed above, figures obtained by Sinn Féin for the first quarter of 2018 show that respite provision is declining. This is despite a 36% increase in the older population and a 63% increase in the number of people with a number between 2006 and 2016 (Census 2006/Census 2016).

⁴ Merriman, B. & Canavan, J. (2007) Towards Best Practice in the Provision of Respite Services for People with Intellectual Disabilities and Autism Galway: Child and Family Research Centre, U.C.G.

Appendix 1: Figures on Respite Care Sessions Quarter 1 2018

No. of overnights (with or without day respite) accessed by people with a disability

CHO	LHO	Q1 2017	Q1 2018
National Total		40,597	39,009
CHO 1	Total	2,307	2,403
CHO 1	Cavan Monaghan	742	727
CHO 1	Donegal	1,024	1,047
CHO 1	Sligo Leitrim	541	629
CHO 2	Total	9,573	9,147
CHO 2	Galway	6,284	6,127
CHO 2	Mayo	2,083	1,969
CHO 2	Roscommon	1,206	1,051
CHO 3	Total	3,556	3,368
CHO 3	Clare	865	854
CHO 3	Limerick	1,155	552
CHO 3	North Tipperary East Limerick	1,536	1,962
CHO 4	Total	5,828	5,380
CHO 4	Kerry	1,204	817
CHO 4	North Cork	1,018	956
CHO 4	North Lee	1,904	2,089
CHO 4	South Lee	649	448
CHO 4	West Cork	1,053	1,070
CHO 5	Total	2,193	2,510
CHO 5	Carlow Kilkenny	694	234
CHO 5	South Tipperary	707	762
CHO 5	Waterford	792	943
CHO 5	Wexford		571
CHO 6	Total	2,841	2,308
CHO 6	Dublin South East	0	0
CHO 6	Dun Laoghaire	962	668
CHO 6	Wicklow	1,879	1,640
CHO 7	Total	6,746	5,357
CHO 7	Dublin South City	559	811
CHO 7	Dublin South West	1,659	437
CHO 7	Dublin West	2,731	2,352
CHO 7	Kildare West Wicklow	1,797	1,757
CHO 8	Total	4,917	4,250
CHO 8	Laois Offaly	957	830
CHO 8	Longford Westmeath	1,056	976

No of day only respite sessions accessed by people with a disability

CHO	LHO	Q1 2017	Q1 2018
National Total		7,717	7,564
CHO 1	Total	964	1,048
CHO 1	Cavan Monaghan	10	7
CHO 1	Donegal	210	212
CHO 1	Sligo Leitrim	744	829
CHO 2	Total	1,441	1,496
CHO 2	Galway	622	981
CHO 2	Mayo	483	373
CHO 2	Roscommon	336	142
CHO 3	Total	1,772	1,340
CHO 3	Clare *	1,088	775
CHO 3	Limerick	287	304
CHO 3	North Tipperary East Limerick	397	261
CHO 4	Total	427	497
CHO 4	Kerry	192	179
CHO 4	North Cork	2	0
CHO 4	North Lee	49	94
CHO 4	South Lee	123	134
CHO 4	West Cork	61	90
CHO 5	Total	389	341
CHO 5	Carlow Kilkenny	160	62
CHO 5	South Tipperary	170	150
CHO 5	Waterford	59	67
CHO 5	Wexford		62
CHO 6	Total	351	337
CHO 6	Dublin South East	0	0
CHO 6	Dun Laoghaire	210	199
CHO 6	Wicklow	141	138
CHO 7	Total	1,252	1,379
CHO 7	Dublin South City	0	0
CHO 7	Dublin South West	99	124
CHO 7	Dublin West	1,053	1,076
CHO 7	Kildare West Wicklow	100	179
CHO 8	Total	407	299
CHO 8	Laois Offaly	65	51
CHO 8	Longford Westmeath	205	193

CHO 8	Louth	1,219	1,129
CHO 8	Meath	1,685	1,315
CHO 9	Total	2,636	4,286
CHO 9	Dublin North	922	1,996
CHO 9	Dublin North Central	483	1,367
CHO 9	Dublin North West	1,231	923

CHO 8	Louth	4	17
CHO 8	Meath	133	38
CHO 9	Total	714	827
CHO 9	Dublin North	477	76
CHO 9	Dublin North Central	36	601
CHO 9	Dublin North West	201	150

* The reduction of activity in this metric reflects retrospective data received from Clare.