

From

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Submission

Caring for a person with a disability is very much an individual situation for the carer as disabilities vary greatly from mainly physical to mainly behavioural or a mixture of both. In this submission what is expressed is our experience.

Conclusion

Just in case this submission is too long to be read in full the main point for us is the concern at the future accommodation for our daughter as we age (now late 50's). The current alternate accommodation is only granted under crisis situation (death or major health problems of the carer(s)). We would like to see a lot more of this supported accommodation but for this type of accommodation to have a transitional phase that allows a disabled person to move gradually from their family accommodation to supported accommodation. The disabled person spends a few days each week with family accommodation and a few days in supported accommodation. When our daughter is not using the supported accommodation another person, in the transitional phase uses the accommodation.

It should also be well understood by the committee that caring for a person with behavioural problems can be more difficult than caring for a person with purely physical disability.

The role and contribution of carers

This is a vast topic that can only be briefly touched on in this submission.

Carers save the community vast amounts of money by housing and day to day care in a large range of activities such as transport, shopping, managing their medications, their money, their health, the list is too long to detail. Most disabled people can not or do not understand their health issues, such as diet for example. What most of us take for granted as an individual does not apply for a disabled person. Some disabled people do not understand safety and require 24/7 supervision. Perhaps the best understanding is caring for someone who has no concept of the wider world, their safety, their economic situation, even a concept of our mortality. You are as a carer their entire world in every aspect.

It is important to add that most often the caring role is not shared with other members of the wider family such as brothers, sisters of the carer. It is just too hard and the wider family may be sympathetic but that is all.

How to Recognise the role of carers

Recognition of the vast amount of money saved by the community is the most obvious.

Recognition of the saving of resources such as paid carers, transport, housing, hospital – hostel-nursing home beds.

Recognition that the disabled person has usually a better life when cared for by their family and as a result is happier and may even be able to be a productive part of the community as a result.

Barriers to social and economic participation – employment

The barriers are obvious.

Caring for a person 24/7, unless there is family or external caring, results in no opportunity for work or social participation. In order for there to be any external participation from the home by the carer, there must be more than one carer. Just going out shopping is difficult or impossible without support. In short, employment is impossible and day to day living is near impossible without support.

Employment for carers would in most (all) cases require flexibility in the work hours. Employers would have to be encouraged to recognise the role of a carer and their limiting situation.

Employment, if undertaken by a carer for purely financial reasons, would have to be weighed against the cost of external care for the disabled person while the carer is working. Little point in working for little or no money.

The practical measures required to better support carers

There is support for carers. People do come into your home and allow carers time to shop, bank, sleep, fill up the car and so on. Normal life activities that most people take for granted.

Also there is activity support where disabled people go out on visits to the shops, cinemas, bowling alleys etc. This type of support is more beneficial as it gives the disabled person activity and the carer can do many things at home that can be difficult with the disabled person at home.

For example vacuum cleaning. Some disabled people don't like the sound of a vacuum cleaner. Trying to clean the house, and in particular the disabled persons accommodation with them present can be near impossible. A simple normal everyday task for most of us but a difficult task for some carers.

One type of support that is available for some in limited situations is the sleep over by another carer while the prime carer sleeps elsewhere. This has benefits but does require the prime carer to sleep elsewhere away from their home. This can be at a relatives or friend or at a cost at a hotel etc. Not a best case situation, valuable as it is.

What would be better is where the disabled person sleeps over away from their home. This then offers the exhausted carer a chance to catch up with all manner of things and in particular a taste of normal living. For example not having to prepare special or different meals for the disabled person for various reasons, medication, supervision the list is large. Just being able to fall asleep in front of the TV with no responsibilities is a joy for carers.

Important key priority

To make the point in another way in relation to "**practical measures required to better support carers**" part time away from home caring would make a big difference. If the disabled person had another home away from their normal home that they could spend time at, say one, two, three times a week and be safe and well cared for and have

much of what they have at their regular home, such as TV computer etc and be happy this not only greatly helps the carer but widens the World for the disabled person. Many disabled people are bored due to the limitations disability places on them. Many disabled people love to be in a range of environments.

The reason why this is important for us as carers is for many reasons.

We are both in our late 50's and the future of our 26 years old daughter is a constant worry. Once we are unable to care for her for a variety of reasons what happens? At the moment alternate accommodation is only available in a crisis situation like death of the carer, health issues with the carer or total exhaustion (mental breakdown...?).

What would be a much better for all concerned is a wider gradual change from living with the carer (parent(s)) to living part time away from the carer. A second home for the disabled person that they are happy with and enjoy the variety. This may only be one day a week but as the carers age the time spent at the second home gradually increases. When the time comes that the prime carer is no longer able to care there is not a crisis situation but a normal transition. Good for all, carer and disabled person alike. Good decisions are not made in a crisis situation.

strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

It is difficult to see how carers would ever have the same range of opportunities and choices as the wider community.

The capacity for carers to make choices within their caring roles is difficult because of the high work load of caring. Many carers do not even know all of the existing choices. Just to get to a community carers meeting at the best is difficult and at the worst impossible. It is not always possible to find someone to take over the roll of carer even for a brief period of a couple of hours. Added to this is the exhaustion factor most carers live with 24/7.

What could make a difference is a comprehensive document listing all the existing services. Even professional people who work in the area, such as local area co-ordinators, often mention how they are not fully aware of all the options. For example it is only of recent times that we became aware that a disabled person living at home with their parents is eligible for rent assistance.

Transition into and out of caring, meaning respite, can either be done in the home where the carer leaves the home for respite, or where the disabled person leaves the home. This is a matter of individual choice but in the situation where the disabled person leaves the home offers the carer a wider range of normal activities, like cleaning the house, watching television uninterrupted, going for a walk, having a good nights sleep in your own bed, the list is all the normal activities that most of us take as given.

Effectively plan for the future

As mentioned the future is the great unknown and the most worrying. The future means different things to different carers largely depending on age. When you first start your role as a carer, the future is what schooling, work future, what potential the disabled person you are caring for has. All this is covered with the sadness of the situation and coming to terms with a roll you know nothing about. So the future is the immediate future. Even hope that the disabled person will need a normal life is upmost in your mind.

As the future for the disabled person becomes more obvious with time, the degree of caring becomes more obvious. Some disabled people live near normal almost self supporting lives, but for the ones that will never reach this level and require full time caring for life, our experience is that transitional second home accommodation offers real hope for a better future for the carer and disabled person.

As mentioned before in this submission, accommodation away from the home exists now, called supported accommodation, but it is only available under crisis situations and the waiting list is many years. Some carers have applied a dozen or more times. More of this accommodation is urgently needed. However what is also needed is greater flexibility with this accommodation. Once this accommodation is granted it is for life and does expect that the disabled person will make the transition from their family carer accommodation to away from home accommodation in a very short time. There is not the intention to make the transition gradually over perhaps a year or more. It is seen as a waste of accommodation if the accommodation is not being fully used.

Supported accommodation as it exists now is a house that is staffed full time with carers and may house two, three or four suitable people who each have a bedroom and shared facilities like kitchen etc. If this type of accommodation had the flexibility to allow a greater number of disabled people to share, due to attendance being variable, say 3 times a week, this would achieve the transitional accommodation and allow more people to use the accommodation. The individual bedrooms would require changes when people swap the room but these changes are only personal items and once built into the system the person using the accommodation would never know they share the same bedroom. This change could be seen as "motel" type accommodation with bedding and personal items changed as people move between it and their family accommodation.

Conclusion

As stated this is our experience and solutions vary depending on a wide range of different issues, and in particular the age of the carer and cared for person.

What we want at our age (late 50's) as carers now, is transitional accommodation that allows our daughter to move gradually to shared accommodation over several years and not the current situation that is done in crisis and in a rush.

Many carers who eventually relinquish the life long role of looking after a disabled child through adulthood are physically and physiologically exhausted and they could well be in their 80s by this time.