The Scottish Huntington's Association welcomes the Carers' Bill and supports the greater recognition of the needs of carers.

We recognise that carers of people living with Huntington's disease are particularly impacted by the condition. They are likely to be unable to work within four years of diagnosis, experience high levels of anxiety, depression and poor wellbeing, are frequently economically disadvantaged. At the same time they have a significant need for information, advice, emotional support and access to support services to help manage the pressure of caring responsibilities.

We see carers from around Scotland and already note that there are significant differences in local policy (Self Directed Support is a good example). We do not think the Bill addresses this issue.

We do no think the Bill addresses the issues arising from a difference of opinion between the care and cared for person or makes provision for mediating these situations.

We are concerned that in many areas of Scotland support services cannot meet the needs of HD carers and the Bill may give rise to increased expectations that cannot be met. in particular we believe that general services are poorly equipped to accurately understand the needs of people living with rare conditions and more needs to be done to 'capacity build' within general services while at the same time improving pathways and inter agency relationships.

We agree with SCVO that the Bill is likely to increase the demand for services from the Third Sector at a time when funding is being significantly reduced.

Anticipative planning and preventing hospital admission are key issues for people living with HD and we would have liked to have seen these better addressed in the legislation. Successful anticipative planning can significantly reduce harm resulting from hospital admission and should be a higher priority within health and social care.

Scottish Huntington's Association