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Representing Adults & Children with Learning Disabilities & Autism

The Scrutiny Officer,

Morier House,

Halkett Place,

St Helier

JE1 1DD

16<sup>th</sup> March 2016

Dear Madam,

**Scrutiny Review March 2016: Living on Low Income**

Firstly, I would like to acknowledge and second the concerns raised by Deputy Richard Renouf on 8<sup>th</sup> February this year where he stated that 'The way we look after the poorest, most needy and most vulnerable is a measure of our society' and 'the gap between rich and poor is growing'.

SNAP feel that families living and caring for a child or young person with a Learning Disability and or Autism are very likely to struggle financially. A parent will, more than likely, have had to give up their career to care for their child/young person with all the pressures financially and emotionally that this entails. An individual with a disability living in the community will probably not be able to earn a living wage, that's if they are able to find any suitable employment at all.

Aside from the everyday household expenses that these families and individuals have to budget for, they will also have to face many outgoings to support their needs...disability equipment and aides tend to be very expensive. The most obvious would be adaptations to the house, adapted vehicles to less obvious, but just as essential, pieces of sensory

equipment to enable people to access the community by lessening anxiety and pain caused through heightened senses. On top of these costs there will be numerous GP appointments and possibly trips to UK hospitals, specialised feeds and related products.

Unfortunately, families and individuals become reliant, whether they like it or not on the benefit system. Changes within the system can be very unnerving, leaving families and individuals feeling very vulnerable and isolated. These changes should be handled carefully and with understanding and transparency. The people who will be affected should be made aware, in a timely fashion, of what is to happen and when. Coordination and good communication between staff within the department and other related States departments is essential. However, this does not always happen, when there are so many changes even staff within Social Security have trouble keeping up which leads to misunderstandings and ultimately leads to a negative impact on these families and individuals.

For sometime SNAP has been highlighting issues via The Service User Forum and more recently SNAP has been meeting directly with William Lakeman and his colleagues from Social Security. We are very appreciative of these meetings and the chance it gives us to highlight specific issues.

The Social Security Department is aware that SNAP is making this submission.

The following issues have been brought to us by families and individuals.

Home Carers Allowance (Open to those who care for someone on PC Level 3 dependant on specific conditions)

#### The Figures

HCA: £799.96 every 4 weeks = £10,399.48 per annum.

This works out at an hourly rate of £5.71.

Minimum wage is £6.97 per hour.

Income Disregard of £149.54 per week = £7776.08 per annum.

The Income Disregard seems very low taking into consideration today's cost of living...how has this been calculated?

The Home Carers Allowance: is an issue that we appear to be approached about more and more. The new law that removed means testing allows more families to claim the HCA and is good for carers whose partner is the main earner. However, if the carer was the main earner and has had to give up their career, the family will find themselves under increasing pressure with such things as mortgage payments, rent and household bills etc. Some carers will try to balance a career alongside their caring role; however this is not always possible as being a carer is a demanding and exhausting job. Those who do try to continue in employment are finding it increasingly difficult to find work that will keep them within the income disregard.

A carer will only be entitled to the HCA if their child is on a Level 3 (amongst other criteria), at this level of need it would be very difficult if not impossible to find childcare.

It has been suggested by an Officer at Social Security that some of our carers, who are mostly Mums, might consider returning to work full time and pay for a carer to look after their child. Whilst we appreciate that this was probably a well intentioned suggestion, it only goes to show that they really do not understand our families' situations; this would financially cripple most families and would really not make financial sense.

For example: If a person worked a 37 hour week, a carer would be required for at least an hour in the morning and 3 hours after school. In the 14 weeks of school holidays between 37 hours and 50 hours of care a week would be needed dependent on the level of need. Care costs would be about £20 per hour which would amount to between £740.00 and £1000.00 per week, without any household bills and mortgage/rent payments.

We have been advised of parents, many highly skilled, who are lucky enough to have found part-time jobs that they can fit in with caring for their child but are struggling to keep them due to the restriction of only earning £149.54 per week. They quite often have to work nights or weekends when a higher rate of pay is given which will then take them over the disregard. We also have the situation where a mother who is an experienced and well qualified Mental Health Nurse is trying to juggle working day and night shifts as well as being up at night with her son who has complex needs. She is exhausted and it is affecting her health. She does not want to give up her job completely as she would face losing her nursing qualifications.

Carer's feel discriminated against and penalised for being in this position as the threshold dictates they can only work in low paid jobs although they have the qualifications and experience to do higher paid employment. None of our carers want to be in a situation where they have to give up their jobs, become unemployed and then dependant on benefits.

Part-time jobs are becoming increasingly hard to find. There is very little part-time/term - time only work on the island. The majority of employers are looking for staff to work at least 18 hours; a night shift is at least 12 hours. It is also becoming more common for employers to request that their staff attend training and meetings which are paid in addition to their regular hours.

SNAP is not asking that these carers are given more money by way of benefit. Instead we are suggesting that the Income Disregard is raised to allow our families to keep on working for a realistic wage; this will not only be good for the families at this moment in time but it will also benefit them later in life. They will be able to remain in the workforce developing new skills. In the long-term this will benefit the island with less people dependant on the States for financial support.

We would also like to suggest that:

- 1) Payment for mandatory training /meetings is treated as separate to a Carer's assessed earnings?
- 2) HCA be assessed in hours rather than how much a person earns?

### Long Term Care Benefit v Income Support ( Impairment Component)

SNAP would like to acknowledge that this is a new scheme which should in the long-term benefit many people. However, SNAP also feels that it has been produced with the older person in mind who has savings and a property. Individuals with LD and or Autism are very unlikely to be in this situation.

### Community Homes

Firstly, taking in to consideration a person in a community home; they are given a personal allowance of approximately £35.00 per week and will no longer receive Income Support. With no other income or ability to earn; this payment will be nowhere near enough to support their day to day needs and activities. SNAP is concerned that this will lead to people becoming isolated.

SNAP is aware that there are other issues around community homes, however these are very specific and we are not in a position to comment further.

### Family Homes and Independent Living

Children are entitled to claim Income Support at the end of the school year in which they reach 16 years old. Historically, the payment could go into the household budget, whether at home or living independently in the community. Income Support includes the Impairment Component which in turn is made up of the care, clinical costs and mobility costs; these can be at varying levels dependent on the level of need of the applicant.

The person would then receive support/respite paid by Health in addition to their benefit. As far as SNAP is aware, no one has ever been asked to pay for their support or respite; these funds were then available to help with other costs as already detailed for example GP's fees, or specialised equipment etc.

The move from Income Support to LTCB is dependent on the person's level of need and the choice is then based on which benefit would serve the person best.

If the LTCB is chosen the person will have their care paid in a process involving both Social Security, and Health who pay the bills. Unfortunately, during the early days of this change mistakes have been made leaving the individual and/or their family owing vast amounts of money to Social Security. We have been advised of one family who were put in such a financial position that that had to ask for food coupons. We are hopeful that with better systems and communication that these instances will become fewer.

The person will still receive their adult income support payment plus other elements dependent on their situation. The impairment component will be paid less the care element; this element has in many cases been as much as £145.00 per week.

While SNAP appreciates that Social Security cannot pay twice for care; this is a huge amount for people to lose from their household budget when having to manage the costs of living with a lifelong disability.

SNAP believes that if people choose to remain within Income Support and not change to the LTCB that they will have to pay for their support/respite from the care element of Impairment.

SNAP has also been advised that people accessing Day Services will soon be asked to pay for this service in addition to those services already mentioned.

### **Clinical Costs within Impairment Component of Income Support**

A figure of £6.30 per week is paid to an individual on the highest level of clinical need within Impairment. In 2007 this figure was set at £5.32 per week. On looking at the Comparison of Consumer Prices 2015, Personal Services which includes GP visits rose by approximately 42% since 2007.

SNAP understands that benefits rise, but not linked directly to RPI. If it was, then this benefit should now be paid at approximately £7.55 per week.

In Jersey we are very lucky to be able to access GP's easily, however they are very expensive. It seems to be down to the individual GP within a practice whether or not they discount visits for their patient. With fees being around £38.00 per visit before adding on the cost of blood tests etc and out of hours being around £90.00 during surgery hours, £6.30 per week does not go far to support these costs.

SNAP is aware of the HMA Scheme, which is a saving scheme for people who have to make frequent visits to their GP, but even this cannot keep up with the rising costs of visiting the doctor.

Finally, SNAP would like to reiterate our concern that the most vulnerable, including carers, families and individuals living alone, will end up with less disposable income, little or no employment opportunities and less ability to socialise leading to isolation and possible health issues. SNAP would like to thank you for your interest and looks forward to reading your findings.

