

## IPWSO SUMMIT MEETING

### **Preventing obesity and other risks, and promoting a good life: global experiences of restrictions<sup>1</sup> and supporting independence**

Led by organisations such as the United Nations (e.g. UN Convention on the Rights of Persons with Disabilities, UN CRPD) Governments are expected to ensure support is available to enable people with disabilities to lead fulfilling and independent lives. Few would disagree with this vision, and it is in itself an indication of how far attitudes have changed for the better in many countries. However, whilst such Conventions can set the objectives they do not address how such objectives can be achieved nor can they address specific and perhaps rather unique challenges that may be associated with rare neurodevelopmental conditions, such as Prader-Willi syndrome (PWS).

Being able to obtain an accurate diagnosis, the availability of information on PWS, informed healthcare and access to skilled support all vary substantially within and between countries. Children and adults with PWS and their families living in different countries and in rural and urban settings may have very different experiences, but all will be faced with how to manage the risk of life-threatening obesity associated with their child's hyperphagia and what to do to reduce and manage emotional outbursts or self-harming behaviours if they occur. Whilst the ideal would be to reduce the risk or intensity of hyperphagia and of other behaviours through early intervention and psychological support, the reality is that there is still limited research on what can be done, and for most people with PWS limited expertise is available. Limiting access to food remains one of the main recommendations suggested to parents in order to reduce food related anxieties and other behaviours and prevent severe obesity and its complications.

In adult life the consequences of hyperphagia, emotional outbursts, and severe skin picking are likely to be more serious, particularly with greater independence that comes with transition from childhood. This is a time of considerable change and also the age when the possibility of developing mental ill-health increases. The risk of severe obesity and concerns about the person with PWS or others coming to harm because of emotional outbursts and/or social misunderstandings, is ever present. If they occur, behaviours such as running away from home or behaviours that results in police involvement can be very difficult to manage and may lead to increasing limitations and restrictions in that person's life. The response of health professionals may be limited to offering increasing amounts of psychiatric medication and families or social care providers may decide that the only intervention possible to prevent harm is to increase restrictions on the person's freedom or for them to move, often to a more restrictive environment. For many people with PWS such circumstances may never occur but if they do, they can give rise to difficult clinical, moral, and ethical dilemmas.

In this second IPWSO Summit families and health and social care professionals will share their experiences and reflect on how such issues and crises are managed in their country. Our aim is to identify possible options when seeking to resolve these complex challenges and to consider whether limitations on choice and other restrictions are necessary and justifiable in order to prevent harm and their legality. Parents and professionals working with people with PWS will address the following questions so that ideas and experiences are shared and provide the basis for discussion. In preparation for this Summit you may wish to view the [presentation made by Dr Elizabeth Fistein](#) for the Leadership ECHO programme.

## Questions

1. Are families of children with PWS in your country informed early in the child's life about hyperphagia and other behaviours that can result in harm and how to manage them?
2. To what extent is it accepted that restrictions on access to food are necessary and likely to be required over a person's lifetime? How restrictive can they be and what happens if an adult with PWS refuses to accept food security and has become severely obese and their health and possibly their life is at risk?
3. A child or adult with PWS is engaging in behaviours that are distressing and dangerous to them and others. Would restrictions on freedom be justified? How would such restrictions be implemented and monitored and how can the quality of life be maintained?
4. There is much debate about the use of psychiatric medications to 'treat' difficult behaviour, such as emotional outbursts, and limited evidence to indicate benefit. Whilst it may be appropriate for medication to be used to treat serious mental illness there are concerns about the excessive use of such medication at times of crisis because of problem behaviours and their on-going use without medication reviews and without clear evidence of benefit. Such medications, when used to treat these behaviours, are seen as restrictive because of their effects on a person's function. Is this a common experience and how might restrictions that are chemical in nature be addressed?

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<sup>1</sup> The English word 'restriction' is used in this paper to refer to situations where a person's choice is limited (e.g. access to food) or, for example, it is expected that when the person goes out they always go with a family member or support worker and not by themselves. Such restrictions or limitations on choice may be empowering for the person with PWS as they feel safe and supported or they may object to the restrictions being present. In circumstances where an adult objects to the restrictions that are imposed on them this is likely to have legal implications.