Introduction

Like everyone else, there is no reason why older people with PWS may not get bored with things they used to find interesting to do, and so may need encouragement to try out new things, or to find voluntary or paid work.

Day centres

Usually run by local authorities, but sometimes by voluntary organisations, day centres (also known as social education centres or adult training centres) offer a variety of activities for people with learning disabilities. Some people with PWS may feel that these centres cater for people who have far more intellectual impairment than they have, and will therefore be unwilling to go to them.

The activities on offer vary considerably, and some centres are better at managing the dietary and behavioural needs of people with PWS than others. You may therefore need to visit the centre beforehand to check that it meets your son or daughter’s requirements.

Some day services help people into work or voluntary work, and can be a good option to explore for this reason. A good day service should offer the following:

- job training and work experience, or opportunity to do voluntary work
- basic education
- art and craft work
- home management, shopping skills, independent living skills (and a willingness to adapt these to the needs of someone with PWS).
- leisure and recreation
- part-time attendance at local colleges

In most areas you will have to pay a charge for attendance at day centres or extra-curricular activities.

Some local authorities are now phasing out day centres in favour of other alternatives, such as smaller group activities within a community setting.
Training, work experience and employment

Some of the types of work which people with PWS do, which we know about, are:

- Helping with playgroups
- Gardening
- Assisting the elderly in residential care
- Basic office work
- Packing or light assembly work
- Craftwork
- Working with animals
- Kitchen work and cooking (to be carefully considered first)

They may do this as a paid job (usually part-time) or as a volunteer, or as part of a work experience scheme. The Disability Employment Advisor at your local Jobcentre may be able to suggest some work experience or training schemes which would be suitable for your son or daughter.

If any kind of paid work is being considered, consider how this will affect the person’s benefits. This can be very complex, depending on how many hours are worked, and it might be helpful to seek advice from a Welfare Rights Advisor.

In practice, very few people with PWS are currently able to maintain a full-time paid job. Reasons why full time work is impractical for people with PWS are usually tiredness during the day, general slowness in completing tasks, behavioural difficulties or problems with food. However, with the appropriate support, they can make a very valuable contribution to the community, and their individual talents can be given constructive outlets.

Points to consider when looking at paid or voluntary work for people with PWS

There are several issues surrounding people with PWS and work, even if the work is on a voluntary or work experience basis. Each person should have their own person-centred plan drawn up, as individuals' needs and abilities will differ. Issues which may affect the person-centred plan or need to be considered include:

- Tiring easily, and needing time during the day for a nap. Some people are more able to work in the mornings than later in the day.

- Poor muscle tone. Strenuous work is likely to be difficult for many.

- Different needs for stimulation. Some people with PWS are very happy to do repetitive jobs which require them to focus completely on the job in hand. Others need more stimulating work, with a variety of tasks to keep them motivated.

- If things go wrong or do not go according to plan, or if items are lost or mislaid, the person can have a disproportionately intense reaction to this. Employers need to be aware of this, and the best ways of managing it (eg time out)

- Environments which are very hot or very cold are not suitable for people with PWS. They have adverse body reactions to extreme temperatures and some are unlikely to realise that they have become over-heated or too cold, and will dress inappropriately.

Continued ...
Points to consider when looking at paid or voluntary work for people with PWS (continued)

- Communication problems. Some people are very articulate but have difficulty understanding complex instructions. Others have speech problems which make it difficult for them to be understood. Employers should be aware of how any of these problems affect the person with PWS and what is the best way of dealing with them.

- Issues around food. Some cope better than others with the potential to access food, but most find it difficult. Other employees or volunteers should be warned to keep their own food supplies out of sight and it could be that food cupboards in staff kitchens etc need to be locked. Working in a food environment such as a cafe is a possibility for a few, but with suitable provisos in place (eg regular weighing to ensure that the person isn't taking food; or a strict rule about staff generally not being allowed to help themselves to food).

- Human resource/personality tests and answers to interview questions can be misleading. More able people with PWS may be looking for jobs, especially in large organisations, which include personality tests or interviews. They are more likely to score highly on “theoretical” questions such as, “What do you know about the Disability Discrimination Act?”, but less highly on questions on managing situations, such as, “What would you do if a colleague complained about your work?” High scores in one area may produce an average which would obtain the person the job. However, it is important to look at the type of job they are applying for and ensure that, if it does include elements on which the person has scored low, they receive training and support to manage these issues.