

Justification for the Need & Funding of Working Surfaces

for boys with Duchenne muscular dystrophy (DMD) - & for children with other types of muscular dystrophy & allied neuromuscular conditions

The average age at which a boy with DMD becomes unable to walk is 9½ years. However, long-established physiotherapy research at the Hammersmith Hospital has shown that keeping boys on their feet for as long as possible encourages a lordosis (a forward curvature of the spine at the lumbar region), which can delay a scoliosis, a lateral curvature that often involves rotation. Other physiotherapists working in muscular dystrophy clinics and muscle centres around the UK have proved that good physiotherapy management can keep a boy with DMD standing well beyond his teens. The methods used with varying success are long-leg calipers, swivel walkers (which also serve as standing frames) and standing frames.

For years, boys with DMD have been asked to stand in classrooms to do their work, but this was not being carried through at home because of a lack of incentive – or, at best, children were asked to stand to have their meals and watch TV. This was not productive and, for a number of years, staff working for the Muscular Dystrophy Campaign have recommended the installation of height-adjustable working surfaces in bedrooms. These should have a **600mm** square (or **800 x 600mm**) section at standing height with the rest of the surface for use in a wheelchair. Under the standing surface, a drawer unit with drawers on rollers is installed so that these can be opened easily. The top ‘drawer’ is a pull-out surface, to provide a work area to the side of the user sitting at the surface and thereby increasing the area for reference books etc.

Boys with DMD are unable to raise their arms to reach; wheelchair access right under the working surface allows them to slide their arms and maximise their reasonable hand function. In addition, architectural designers are asked to plan for the sitting surface to be L-shaped, so that a computer keyboard can be placed across the right-angle, with the monitor in the corner and the adjacent surfaces used to support the boy’s forearms.

Without this well thought-out provision of working surfaces, boys in wheelchairs were confined to using a wheelchair tray or table, both of which proved too small and limited their independence. Now the boys can come and go from their activities as they wish and the importance of these surfaces to their happiness cannot be stressed strongly enough. Many boys in the past had no purposeful activity in the home, other than watching TV. They are often artistic and creative, making excellent models, which require space and the ability to support their forearms. Now that GCSE examinations include project work, adequate working space is essential. In addition, the importance of computer literacy cannot be ignored, as many children develop an interest in the subject at a young age and are able to follow it through to further education and employment.

Justification for the Funding for Working Surfaces

Following the appreciation of the importance of working surfaces, there have not been any applications for an adaptation where the space required for a minimum-sized unit of **1200 x 1800mm**, has been denied. Although the space is allowed – with the added bonus of increasing the circulation space in the bedroom – the provision of the surface and drawer unit by the housing grants have to be justified.

The surfaces have to be installed on height-adjustable brackets so that the height can be altered as the boy grows or when he changes his wheelchair (or uses a cushion) and the wheelchair armrest height and joystick control are raised. A fixed height for the surfaces has proved to be a disaster for boys undergoing spinal fusion, as their wheelchair armrests had to be raised to support their increased back height and after the trauma involved in the operation, they returned home to find they could no longer gain access to their hobbies.

‘Cheap’ adjustable brackets have in the past proved to be unsatisfactory as the surfaces began to ‘bow’ and then needed vertical supports to take the weight. This restricted accessibility in a wheelchair and did not allow a boy to turn under the surface and thereby limited the wheelchair circulation in his bedroom.

The brackets and drawer units recommended are available from:

*Astor-Bannerman (Medical) Ltd
Huntleigh Renray Ltd*

Most boys’ rooms are in ground-floor extensions with doors swinging through **180°**, so that they have independent and speedy access between their bedroom and the family areas. Others have a lift with electronic doors which enables them to go to their rooms independently. This allows them to use their rooms in the same way as a non-disabled teenager – for homework, interests, to entertain their friends and for privacy. The majority of families would say that the provision of suitable housing and ideal facilities has been the single most important factor in helping them to cope.

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