

## 4.3 Group 2: Training for Augmented Powered Mobility

### 4.3.1 Stephen

#### Introduction

Stephen was 11.5 years old when he was referred to the Smart Wheelchair project in March 1992, and was the younger child in a family of two, his older brother being of working age. He attended the senior section of an Edinburgh special school, which he had attended all his school life, and knew well.

He suffers from athetoid cerebral palsy, with great problems controlling any limb. Stephen was thought to be quite an aware child, but he had problems maintaining eye position thereby making his vision difficult to assess. He was a non-speaker, communicating only through a consistent yes/no response to structured questions.

His parents were supportive of the Smart Wheelchair project, but didn't have very many expectations that Stephen would succeed. Nevertheless they were anxious to provide him with the opportunity of using the Smart Wheelchair.

#### Pre-project Profile

Stephen is a very disabled boy, and his disabilities have profoundly affected many aspects of his education, communication, and home life. Teacher, parents and therapists contributed to the profile, sometimes relying on other data like the Jordanhill assessment results, but mainly inferring his abilities from functional observation.

##### *Personality and cognitive abilities*

Stephen was described as a generally happy boy who quite often was mischievous. He seemed to like rough and tumble and playing with toys, but his tolerance of being handled in rough play did not extend to acceptance of facilitation techniques. He could be impatient. Stephen would show his emotions clearly, frequently getting agitated if unhappy or upset: in this state, he might react by biting, and did not always stop when bidden to do so. He showed a little inquisitive behaviour.

##### *Sociability*

Stephen was described as being quite unsure of unfamiliar situations or people and did not mix well with children outwith the school, becoming withdrawn and quiet.

##### *Vision*

Stephen had spectacles to correct a squint, but used every opportunity to remove them. His gaze was fleeting and this constant eye movement hampered his ability to fix on objects. Nonetheless, he could look for and locate desired objects (his mother reported that he knew and could recognise his toys by name since, during his bedtime routine he would say good night to each of the toys individually looking in their direction as each was named).

##### *Hearing*

No hearing defects were reported.

##### *Expressive communication*

Stephen expressed himself using limited gaze and vocalisation. He used a consistent yes/no response, eye pointing accurately to a thumb up for yes and a thumb down for no and would withdraw from a situation by closing his eyes and turning his head away. Stephen would raise his right arm to indicate turn-taking. Despite the fact that the classroom team used his yes/no response for choice making, neither of his parents felt that they had had any success with his yes/no response and therefore said that he didn't make choices in his home life.

##### *Receptive communication*

Stephen reacted appropriately to conversations in and around him, was aware of voice tone, and tried to organise himself in response to being asked to do something.

### *Educational development*

Stephen had established object permanence: he would attempt to pick up toys if they had dropped from his view. His Jordanhill profile showed him to be aware of body parts and their names.

### *Mobility/physical skills*

Stephen does have some saving reactions, putting a hand before him if falling, but his muscle tone was generally low and movement jerky which made them difficult to control. He tended to use gross swiping movements. With help he could sit and move from a sitting to a standing position. At home he used a Linburn Walker, but this was not functionally effective. Some positions distressed him: Stephen had a great dislike of lying both on his front and on his back.

## **Initial video interpretation**

The pre-intervention school videos showed Stephen as a child who was very much inhibited by his uncontrollable movements. Triggered by any intentionality on his part, random movements would increase, inhibiting him from doing whatever he had set out to do. Despite this, he still persevered: video sequences show him trying to imitate the movements of other children during their therapy, and he will persistently try to handle object placed near his grasp (to the extent that staff felt the need to control his hand movements, and tended to seat Stephen with his hands tucked down by his sides).

The home video showed Stephen being fed on his mothers knee, and being brought toys, mainly for younger children. These sessions placed few demands upon him.

## **School and home settings**

Stephen attends the senior section of a grant-aided school for children with special needs. His was a classroom with areas of wide open space, although the school itself is an old Victorian building with a long narrow corridor and little other space to allow exploration or play. His teacher runs a formal timetabled structure and was keen that Stephen's Smart Wheelchair sessions would not be disruptive to the other children in his class.

At the outset of the project, Stephen and his parents lived in a bungalow. His mother felt that his chair could be used in the living room and up and down the hall without too many problems. In addition, the back garden was paved and so Stephen could be given the opportunity to play outside on good days. The chair went home for the first summer holidays. Unfortunately, the family moved house at the end of the first year, and the chair could not be taken to the new home.

## **Aims and Aspirations**

Stephen's school staff identified the following curricular and therapeutic aims. These were derived from written goals built into his individual learning programme, and were not specifically directed toward, or integrated with, Smart Wheelchair activities.

### *General educational aims*

- to expect consistent cooperation and participation in all areas of the curriculum
- to increase awareness and anticipation of routine events and sequences of events
- to increase enjoyment of various types of music
- through therapy, to encourage Stephen's ability to communicate through music
- to develop picture/object recognition
- recognition of the voice of an adult or familiar peer in a group, finding them with his eyes
- to encourage listening to simple instructions, and attempts to carry them out
- to have Stephen able to operate his own toys and increase his ability to use a switch
- to increase his self, body, and peer and environmental awareness

### *Communication and socialisation*

- to develop pre-linguistic skills, particularly listening skills
- increased peer and familiar adult interactions through eye contact and vocalisation
- to look in response to a familiar person
- to encourage a smile in greeting with eyes open
- choice making by eye pointing
- to develop the use of a consistent yes/no response
- attending to general language stimulation
- to develop language comprehension

### *Physical skills*

- to encourage positioning of head in the midline
- to encourage hand/eye coordination
- to encourage Stephen to initiate interaction through vocalisation and eye contact
- to work on tracking skills
- to encourage sitting balance
- to encourage weight bearing through upper and lower limbs
- to control involuntary movements

### *Functional mobility*

In addition, it was thought that Stephen would benefit from the Smart Wheelchair by

- increasing his motivation
- offering him purposes for movement
- increasing his independence
- increasing his opportunities to interact
- increasing his control over his environment and increase choice
- developing and improving motivation for switch work
- encouraging development of concepts of space, size and the relationship of objects to each other, and lastly
- developing the basic skills of planning and sequencing.

## **Chair, seating and controls design**

Stephen's manual chair seating was not suitable for transfer to the Smart Wheelchair and so an individual seating system was built for him by the Princess Margaret Rose Hospital Bioengineering team. A tray was also built to accommodate any switching that would be required.

Because Stephen had such problems controlling his arm movements, the school staff felt that he would not successfully target a switch, and initially requested joystick control. Stephen also had a tendency to play around with anything placed on his tray, and the fear was that he might displace or damage wires or the switch itself: this pointed to a firmly fixed control system. School staff favoured a joystick with a T-bar, preferably supporting whole arm movement during operation. The suggestion was that his left (control) hand should be strapped into a guttering device which would restrict all unwanted movements in his forearm and wrist, while his right hand was tied down, grasping a small handle secured to the tray.

Given the fears about control, Stephen began with a timed motion tool and the 'Bump and Stop' collision tool. He began work with these systems in June, 1992 with a full month of approximately two sessions per week with his helper.

As with other children, he began his chair work sitting on his helper's knee, but partly because of his size and uncontrolled movement and partly because he seemed to be happy with the chair, he quickly progressed to driving the chair solo. In these early sessions, he had a tendency to repetitive operation of the control, taking no account of the fact that the chair had been activated.

Although the chair went home for the summer holidays, it was used quite infrequently there. There was therefore a considerable gap in the early timetable of intervention.

However, development of a suitable control proved very difficult, and the period between June and the end of October had been dogged with joystick problems. The joystick was just not robust enough for Stephen and it frequently had to be repaired or strengthened. With each strengthening came a reduction in the versatility of that particular joystick design. To achieve the right strength, degrees of freedom were being sacrificed, until it could only be used for moving forwards.

Chair work increased considerably after returning to school in late August. Stephen was beginning to make some functional use of his very limited mobility: during that term, his diaries record him interrupting his travels to view pictures on corridor walls, and stopping to look in other classrooms as he was travelling around the school.

Around this time, Stephen had shoulder straps added to his Smart Wheelchair seating which stabilised his trunk (and also foiled his attempt at operating the switch with his nose, his forehead and his chest.)

By his general increase in awareness of his environment Stephen was showing signs that he was ready for directional control. At the end of October, both CALL and school teams were convinced that, poor limb control or not, alternative strategies were needed. It was decided at the beginning of November that he should try a large target switch. This was velcroed to the tray, and at the same time, Stephen changed from using a timed tool to a momentary motion tool. This way, his tendency to strike repeatedly at the switch would get him little reward - he would have to learn to maintain his hand position on the switch in order to achieve movement.

This combination seemed immediately to be much better and Stephen very quickly learned how to make the chair move using his new switch and new motion tool. He did, however, still find it very difficult to control movements when he became very excited and didn't particularly like to have an audience (i.e. the video camera). Chair work was still isolated from other aspects of the curriculum during this period. Sessions tended to be carried out with him withdrawn from the classroom and was limited to driving down the corridors of the school.

The staff were reluctant to make further changes, although the project team believed that steering was becoming much more important. It was March before the introduction of a further switch was agreed to. The move was made in two stages. Firstly, the team decreased the size of the single switch system, to get Stephen used to smaller targets which would be needed as the numbers of switches increased. Stephen did not take terribly kindly to this at first, and became very agitated. However, by the middle of May, and when left to his own devices, he showed that he could manage to operate the smaller target switch effectively.

In mid May, the second stage took place. Stephen was introduced to a primitive notion of steering, by way of another target switch on his tray. He proved himself physically able to swivel his arm from one to the other, and work began on developing his directional skills, including planning, control, and visual attention. Part of this was achieved through interactive games with his speech therapist, placing particular emphasis on visual location and tracking

Just prior to the summer holidays of 1993, Stephen managed to steer the length of the school corridor non-stop.

After the period of the evaluation had finished, Stephen's chair was fitted with a Line Follower, with the aim of giving him more functional ability. It was hoped that it would increase his opportunities for play and exploration.

## Post-study profile

We report only changes in the profile, which was made up by the same team members who had provided the pre-study assessment.

### *Personality and cognitive abilities*

Stephen's Smart Wheelchair work revealed his liking of being outdoors, where his freedom is greatest. Indoors, he showed inquisitiveness and exploratory behaviour when using the Smart Wheelchair, stopping at doors to look into classrooms. Stephen proved himself to be assertive: he would push someone out of the way when he was in his Smart Wheelchair in order to pass him, and seemed to like to drive ahead of the member of staff he was with. The class team in general felt that Stephen's confidence had increased over the last year although it had a tendency to regress if he was absent from school.

### *Sociability*

Stephen reacted differently in and out of his Smart Wheelchair. Out of it, he likes to be part of a group. In it, he dislikes crowds (and has pushed people out of the way in protest).

### *Vision*

The class team felt that Stephen's visual skills had improved. When securely seated, he has developed a better ability to observe, and also keeps his eyes open for longer periods of time. Stephen's eye contact is much better. He tracks people or objects effectively, both at close and long range. The class team also reported that a large step forward in the Smart Chair was that Stephen kept his head up more; his eyes were open; and he was looking much better.

### *Expressive communication*

Stephen's eye contact was reported to be much better and his eye pointing has continued to improve. This in turn has led to easier and more powerful choice strategies, reducing reliance on 'thumbs up' or 'thumbs down' signals. However, his mother still feels that he doesn't have consistent yes/no responses at home.

The class team also reported improvements in Stephen's appropriate use of vocalisation. Although more assertive, he is tolerant of turn taking needs of others in the class. Moreover he will attend to the person as they take their turn, looking at them directly. Stephen's improved eye pointing has not yet transferred to any other form of functional communication, i.e. an eye pointing board.

### *Receptive communication*

Although still very difficult to assess because of the poverty of functional acts which are open to him, there were signs that Stephen now anticipated conversational events better and could relate them to what was taking place around him. Much of the chair work relied on some level of verbal instruction, and Stephen seemed to respond appropriately to these. He was less reliant on prompting.

### *Education*

Despite Stephen's success with the switch system on the Smart Wheelchair, he has not yet shown any interest in using switches with anything else in his classroom or home setting. It may be that it is too early for such transfer to take place. Or it may be a side effect of the lack of integration of chair work with other activities: Stephen may not have made the link between his achievements in one situation and possibilities in another.

### *Physical and mobility skills*

Stephen appears to have increased limb control, and an awareness of his own ability to influence unintended movements. For instance, after being reminded that he will drive better if he is calm, there is a definite change in the control of his arm movements.

Reports both from home and school suggest that Stephen's head control has improved in general. This improvement has also influenced his eye-pointing and visual abilities, and through them, his communication.

Stephen is mobile in the Smart Wheelchair. He can maintain continuous movement from the top of the school corridor to the bottom and has definitely grasped the function of the steering switch. These efforts have taken time, and we consider him still to be in the motivational phase of Smart Wheelchair work. The task now is to shape his enjoyment of mobility into functional skills.

## **Long term process measures**

Stephen benefited from a stable environment during the project. The staff and the school setting remained constant throughout the work. As a result, the project team were able to be of maximum use to the school team as they developed their own skills.

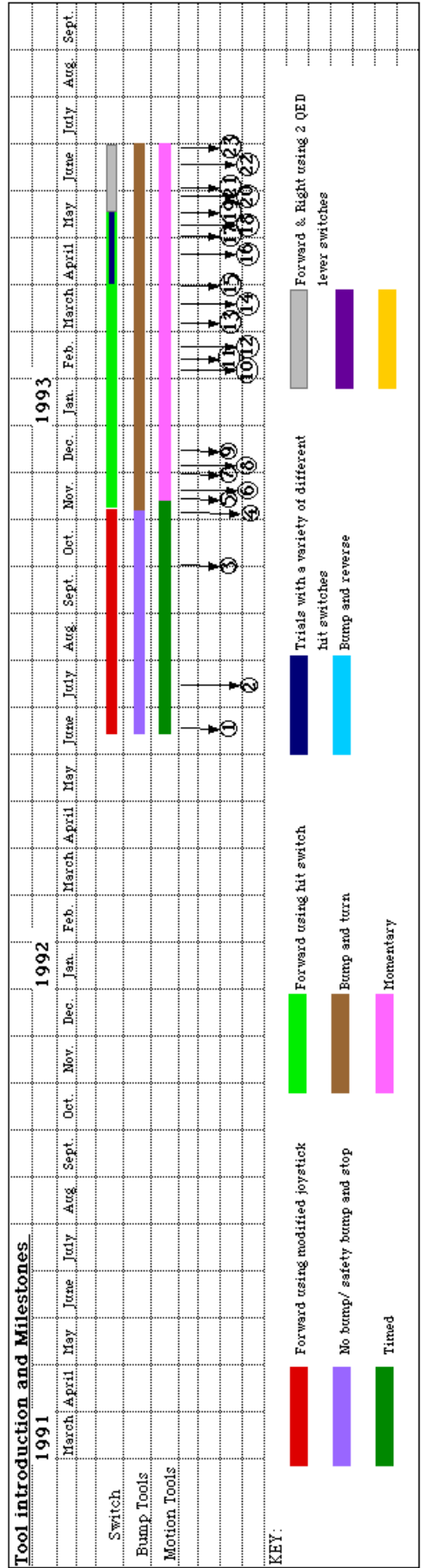
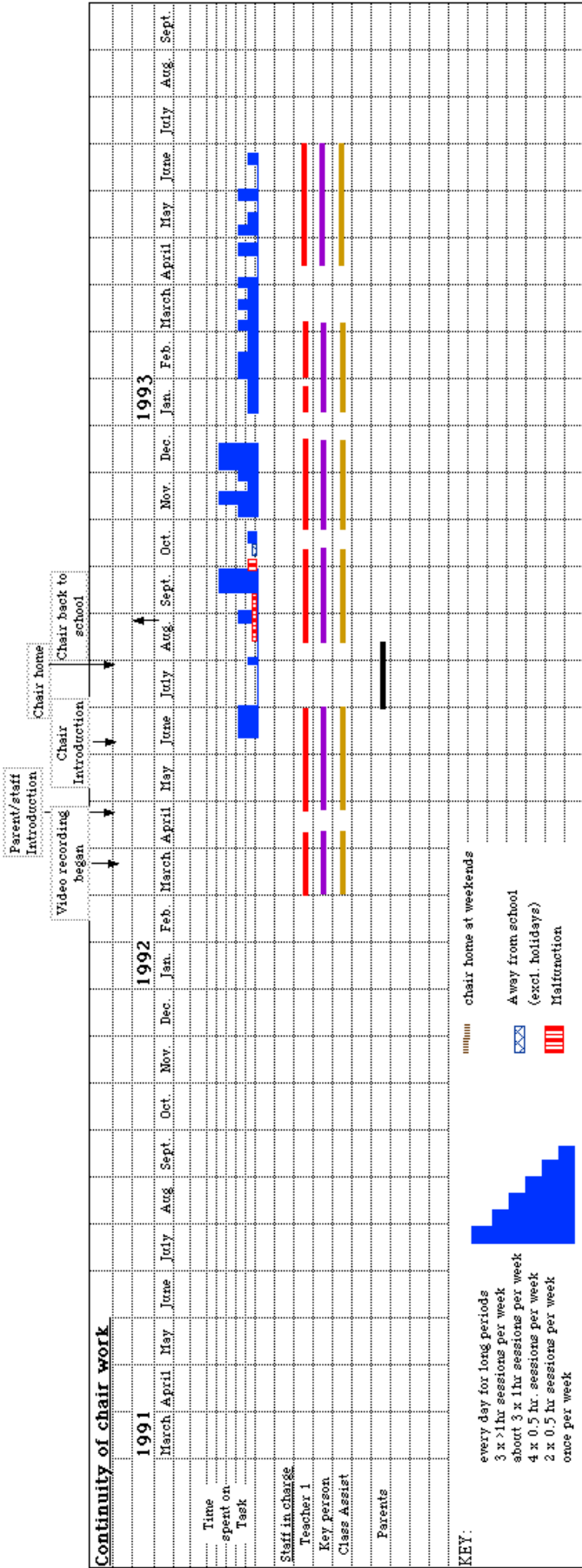
A long term goal for Stephen is independent functional mobility, and he is far from that goal yet. Nonetheless, he has made some solid progress towards that goal, and there is no reason to suppose that his improvements will not continue. Related to the staff's functional mobility aims for him, his achievements include

- increased motivation
- emerging understanding of the potential and usefulness to him of independent movement
- some early steps toward his independence, through his autonomous control of the Smart Wheelchair
- increases in his opportunities to interact, which he is exploiting
- increases in his environmental choices and control
- improved motivation for switch work, and effective uses made of such controls.

The next steps should build on these foundations to

- encourage development of concepts of space, size and the relationship of objects to each other
- developing the basic skills of planning and sequencing.

To do this, the team feel that closer integration with day to day classroom activities are needed. As the process chart shows, Stephen's achievements have been made through one or two sessions per week of about a half hour per session, away from the classroom setting. Functional improvements will happen when the opportunities for practice increase, and when these are related to other curricular and therapeutic goals. At that point, transfer of skills (such as his switching abilities to other computer-based-learning or augmentative communication tools) can also be better encouraged.





## KEY TO MILESTONES

1. Stephen goes solo.
2. Stephen looks around when moving backwards.
3. He is very interested in the pictures on the wall, but not the photographs. He also likes to look in the other classrooms.
4. Stephen quite obviously does not want to play hide and seek with a furry white rabbit and chooses instead to hide a train.
5. Stephen is given the hit switch and plays about with its position on the tray. R. shows him how momentary works and he starts flailing about a bit although he appears to be much better if no-one talks him through what he is to do.
6. He manages to drive down the corridor in one movement.  
"When asked if he is leaning on the switch, he immediately sits up straight."
7. "He stops at every door to look in and giggles when he realises he can do this."
8. He becomes conscious of the video camera and "giggles when the operator tries to hide further up the corridor. He finds out he can use his nose to work his switch and thinks this is very funny."
9. Stephen is initially agitated during rehearsal for class play. At one point during the performance, he is so excited, he cannot operate the switch.
10. He enjoys a chair session, driving the chair to choose toys for his classmates.
11. "Coming back up the corridor, he has to get past the trolley and D. He just lifts his hand and pushes her and finds this quite amusing."
12. "He does very well although he is still [repetitively] banging the switch now and again."
13. "He tries his new switch, but there is so much going on, he is not able to concentrate." "He does very well on the way down, but not so well coming back; his arm is down and he seems very angry when asked to bring it up."
14. "His head control is not as good as it can be. He does not vocalise at all today, but seems interested in his surroundings."  
"His head control is very good today. There is no vocalisation, but he gives very nice looks when meeting people."
15. "Another switch is tried today, but Stephen is not really in a terribly good mood. He uses his chest, head, nose, or anything but his hand in order to operate the switch. There is a lot of moving switches about. He is generally quite angry, but is better when his own switch is put back on the tray. This could imply that it is the change of switches which is upsetting him. He is then given R.'s switch set-up and another switch."
16. "Stephen bumps into M. knocking her into Mrs. T's office; he finds this very amusing."  
"He goes in search of an apple and pictures in the corridor, but finds it quite difficult. He manages to find one, but is too excitable today."
17. "He walks with me to the top of the corridor. I walk on ahead, allowing him to follow on. He stops at every open door to look in."
18. "The shoulder straps from JL's chair are tried today and this looks much better. Previously, he had to make an effort to sit up and keep his head up. His head is often down on the tray and the switch operated thus or by his chest."
19. "Stephen plays around with both switches, and enjoys turning. He looks for me when I am hiding behind him and laughs when he turns and sees me. The shoulder straps remain in a good position and I think help Stephen maintain a more functional position, with his head up more often and his eyes opened wide. He has a short spell of being close and looking well at me. This is the best session I have had with Stephen; he is showing interest in his surroundings and is prepared to go off on his own."
20. "He is much more confident with better posture, enabling him to look around. He is using B.'s switches at the moment, but they are not very secure as he is able to pull at them. Stephen's head is up most of the time and he seems a lot happier."  
"He is encouraged to look in the different directions available, e.g. passage to right or doorway ahead to indicate where he wants to go. He does seem to want to go outside and this is a favourite activity. As before, he has periods of [random switch] hitting and agitation, and then periods of activating the switch much more calmly when he appears to relax and take in more of his environment. He makes a definite attempt at searching when I hide at end of corridor: head up, eyes open for 4/5 seconds."

21. I hide in various doorways and call to him, jumping out and saying 'boo' which he enjoys immensely. Only the forwards switch is used initially. Once in the hall, I show him the other switch and he does several circles. He is encouraged to use his eyes to look for me each time he comes round. He seems to understand about 'big eyes' and enjoys the game of making big eyes to encourage me to come nearer and see them close up. He has periods of excitement and accidentally hitting the switch still. I explain to him that holding his switch on calmly makes the chair go better. He decides to go outside to look for T.'s dog. He laughs a lot at me whistling and shouting for the dog. There is better, smoother switch action by the end of the session.
22. "He starts at the top of the corridor, puts his hand on the switch and sets off. He doesn't stop until he reaches the office. I then point him in the right direction and off he goes. He is very calm and confident today."
23. "He looks at the pictures on the wall, and is very relaxed and confident. He is still not sure about his right turn switch."

## 4.3.2 Jack

### Introduction

Jack was referred to the Smart Wheelchair project in May 1991. At six years old he was the youngest child in a large family who were keen to participate in the project, but were not so keen to have the chair at home. He frequently stayed with a 'Share the Care' family who were also enthusiastic about his participation in the project. Jack attended a local special school run by a national charity. He is spastic diplegic with dystonia, has good head control and gross motor movement but little fine hand control. He was described as a sociable child who talks continually.

### Pre-project Profile

#### *Personality, cognitive state and sociability*

Jack was described as a highly sociable little boy. He was very responsive to his surroundings, talking about what he saw and about anything and anyone new although he was also cautious in unknown situations. He could be easily distracted and seemed to have a short attention span. He occasionally used opting out behaviour, frequently requesting to go to the toilet. Jack demonstrated good memory, remembering the words of songs and anticipating the events during the daily routines. He was quite assertive and often wanted to take charge of the group, saying "I want to be in charge"; "I want to do it myself".

#### *Vision*

Jack had a slight visual defect and wore glasses in the classroom.

#### *Hearing*

Jack's hearing was unimpaired.

#### *Expressive communication*

Jack was able to initiate and sustain conversations. He was described as "chatting incessantly" and would shout your name to gain your attention. He knew several songs, was able to give relevant instructions when in charge of a group song, and could imitate several different accents. He indicated choice by eye pointing or naming the object of his choice.

#### *Receptive communication*

Jack followed conversation at his own level, but his understanding of adult conversation was inconsistent. He was described as too distractible to listen and respond appropriately to stories. He could follow two stage commands. He responded to an angry tone of voice but relied on the situation as a guide to appropriate behaviour.

#### *Education*

Jack had grasped the basic concepts such as size, position and object permanence. He was also able to discriminate and name primary colours. He had understanding of cause and effect and demonstrated some problem solving abilities. He was reported to have difficulty transferring knowledge from one task to another and was very easily distracted.

#### *Mobility and physical skills*

Jack had good head control and could sit with minimal support for a short period of time. When excited, he tended to go into a mass extensor pattern and his muscle tone increased more distally with lower trunk tone. He had limited voluntary movement, mainly over his upper limbs, with scrabbling action in both hands. He was able to 'commando crawl' over a very short distance only.

### Initial video interpretation

The pre-intervention videos taken in school show Jack to be a child who is extremely aware of his surroundings. He was able to capture his audience before delivering his request for his message. He did, however, tend to get quite fixed on certain ideas and would ask the same questions time and time again, never seeming to comprehend the answer. He loved rough and tumble games and was frequently heard asking if he could do something himself. The initial videos taken of him with his Share the Care worker show similar behaviour.

## School and home settings

Jack attends the Junior Department of a grant-aided school run by the Scottish Council for Spastics. The team that put together his initial profile changed before Jack began the Smart Wheelchair work. His classroom was large and cluttered and his new teacher was concerned that Jack would be a danger to the other pupils if he worked in the classroom. Most Smart Wheelchair sessions therefore took place in the hall area of the Junior School, an access area to all the other classrooms in the school and therefore open to interruption. The class itself operated a structured timetable and initially Jack was only allowed chair sessions once a week for a short period of time. As time went on, Jack did have extra play sessions in his chair at lunchtimes.

The school team anticipated that Jack would only use the chair in a limited way and so it was decided that he would share his Smart Wheelchair with another child in the Junior School (William). This child later became a member of his class. The chair was not expected to go home with Jack and the staff intended that it would be primarily for the use of the other child in the classroom.

## Aims and aspirations

### *General education aims*

- to increase his attention span
- to improve colour recognition

### *Communication and socialisation*

- to improve concentration in music
- to improve his listening skills
- to encourage turn taking in conversations
- to extend Jack's spoken language
- to try to interest him in pictures and photographs
- extend his awareness of when it is appropriate to communicate
- to develop anticipation of group activities and follow the correct sequence of events
- to increase the complexity of the instructions given to him
- to improve peer group awareness

### *Functional mobility*

- to have more control of his own environment and increased independence
- to provide him with the opportunity to visit rooms, other people and to go messages
- to improve sitting balance and encourage rolling and independent mobility on the floor

### *Physical and life skills*

- to encourage Jack to wear his glasses and increase his tolerance of them
- to improve feeding patterns
- to improve attainment of independent skills, appreciating his limitations
- to encourage weight bearing
- to encourage bilateral activities.

## Chair, seating and controls design

Jack did not have an existing seating system for a manual wheelchair and therefore the Bioengineering Centre at Princess Margaret Rose Hospital built a seating system with tray, based on a modified Britax car seat.

Jack's poor hand function and tendency to scrabble meant that he had difficulty targeting and releasing conventional lever switches. A joystick was chosen so that he could grasp and lock his hand on, then use gross arm movement to activate the switch. A suitably sized analogue joystick was used, modified with a forwards-only gate and electronics to provide a switching action (on the basis that a switched control system is easier to understand initially). A T-bar was fitted to give him a more secure grip by separating his thumb from his palm, providing a reflex-inhibited position for his hand. The joystick was located on a tray slightly right of midline to be accessible to his right hand (although no dominant hand had been identified). Jack's first sessions used timed motion and either no bump tools, or 'Bump and Stop' for safety.

## Using the Smart Wheelchair

### *Introduction*

The team had intended to introduce Jack to the chair gradually, but this was quickly abandoned in the face of his enthusiasm: he wanted a 'go' before his Smart Wheelchair was prepared, asking to drive it himself before he had even seen it working. Jack set the agenda during his early, single-switch experiences, asking to be turned in a different direction after hitting obstacles. At first he thought the spoken feedback from the speech synthesiser was funny and each time the chair synthesiser reported to him, he would burst into a fit of giggles.

### *Veering*

As shown by the Continuity Chart, Jack's chair started behaving erratically a few weeks after it was introduced. In particular, the chair veered away from the straightline which caused obvious problems for Jack as a single switch user. The Smart Wheelchair Database shows that higher tolerance components were fitted to the Smart Wheelchair interfaces and a software offset added to compensate for the veer. Bugs were found in the bump tools software, and the collision sensors had some mechanical damage. Lastly, the DCL wheelchair motor controller exhibited a fault and was replaced. These malfunctions were disruptive: the only positive benefits were communicative. Jack would reprimand his 'bad' chair and discuss the faults. He showed his motivation to use the system by his efforts during the session; by his objections to ending it; and by his conversations about his chair which 'speaks'.

### *Bump and Turn*

In March 1992, Jack had 'Bump and Turn' added to his chair. He soon anticipated that, following a collision, the chair would reverse and turn and he would talk along with his speech synthesiser, reporting what the chair was about to do. At the same point momentary control was introduced. A few weeks later, the staff allowed Jack access to the chair during unsupervised lunch and break times. This mixture of supervised, structured sessions and unsupervised free play was thought to be important in developing Jack's confidence.

### *Steering in one direction*

The school staff required persuasion from the research team to introduce a turn switch (chosen in preference to gating the joystick because of more obvious cause and effect), and when steering was finally offered in June 1992, it was adult controlled. His helper would offer him the switch only when she thought it was necessary, and would decide whether the turn was to left or right. The rationale offered for this restriction was that the staff wanted Jack to prove he could control turning before they would allow him to use it. The research team could not persuade the staff that the most effective way for him to learn and demonstrate his skills was through practice, nor convince them that his steering was almost certainly better than the chair's 'Bump and Turn' tool. After some time the turn switch was fixed permanently to his tray to provide right turn, with 'Bump and Turn' giving a turn to the left. The diary records that his driving was improving (Milestone No. 8) despite this limited practice.

### *Steering in both directions*

At the end of April, Jack was finally given another hit switch to turn left. During the first session he began by playing with the new control, but soon demonstrated his abilities with it by driving himself to the boys' toilet without help. His functional use and accuracy continued to improve and he became skilled at driving in quite cluttered environments.

### *Staff attitude and assessment*

The Formative Evaluator reported a considerable increase in staff enthusiasm for Jack to use the chair after the second switch was introduced, and it seemed that this was because they perceived him to be driving appropriately and independently (even although it is likely that he *did* possess these skills at an earlier stage, but was not allowed to demonstrate them). A diary entry in May 1993 (Milestone 12) notes that Jack was ready to use the chair in a classroom situation. Jack began to take charge of his mobility as a result. If a problem occurred, he would shout to the staff that his bumpers were not working or he was stuck in the toilet and so on.

### *Home use*

In July 1993, the chair went to his 'Share the Care' volunteer during the first two weeks of his school holidays. Video taken prior to the holidays showed Jack to be a proficient driver who was able to drive competently and make fine adjustments using his three switches. The Continuity Chart records that his weekly use jumped from two half-hour sessions per week while at school, to three sessions lasting more than an hour. Later in the holidays the diary records that he was driving on most days (and was frustrated with the chair's limitations on pavements and outdoors).

### *Jack's attitude*

Although Jack's control was now very good, he did not use the chair as a full and complete functional mobility aid. He perceived the chair as a special activity with a beginning and an end to each session so that although he could make good independent use of the chair while in it, he would ask to be taken out of it after some time. His understanding of the capabilities of the chair was still dubious: on one occasion he asked his helper if he could go up stairs in the chair.

### *Epilogue*

In January 1994 approximately six months after the period of formal recording ceased, a new speech therapist started work with Jack. In February she asked if a switched joystick could be provided as she thought his physical control was now sufficiently good to attempt joystick control. A stick was supplied based on a standard 'V3 microswitch' type, but it was not sufficiently robust and the shaft with T-bar rotated in the socket. This meant that Jack had difficulty grasping it. Nevertheless, on the basis of only a few sessions the staff felt that he had the ability to use a suitable joystick and the Bioengineering Centre are manufacturing a more robust device from scratch.

## **Post-study Profile**

### *Personality and cognitive state*

The Class team report that Jack is more confident in unfamiliar environments although it also depends on his mood. His attention to some tasks, particularly driving, is thought to be better, but he is still very distractible. Pre-intervention his long term memory was good, and the post-profile describes it as excellent. He remains assertive and seems more persistent particularly when driving, although he shows frustration if the Smart Chair gets stuck or is faulty. He shows a desire to have more independence and tackle tasks by himself, although is sometimes unrealistic about his (and his chair's) abilities.

### *Expressive communication*

The class team report that Jack's language has improved. He uses more complex sentences and verbs appropriately. He also uses directional terms (left and right) freely and appropriately. He is persistent when communicating. His speech is usually appropriate although if he has something on his mind he won't listen to what you have to say to him and can still offer quite bizarre answers. One staff member noted that he is a difficult child to start a dialogue with because he does not listen well.

### *Receptive communication*

The team report that it is difficult to separate his seeming lack of comprehension from his lack of auditory attention. Jack seems to have more understanding of prepositional concepts. It is thought he can understand and follow up to three information carrying words. He has some difficulty recognising or perceiving pictures of objects, although he has no difficulty in identifying the object itself.

### *Education*

Jack's understanding of different forms of cause and effect is judged to be better through his use of switches to control the chair. The staff report that there are indications of improvement in problem solving but only when driving the chair (although whether this is a new development or simply an empowerment of existing ability is hard to tell): it does not appear to transfer to other situations.

### *Physical and mobility skills*

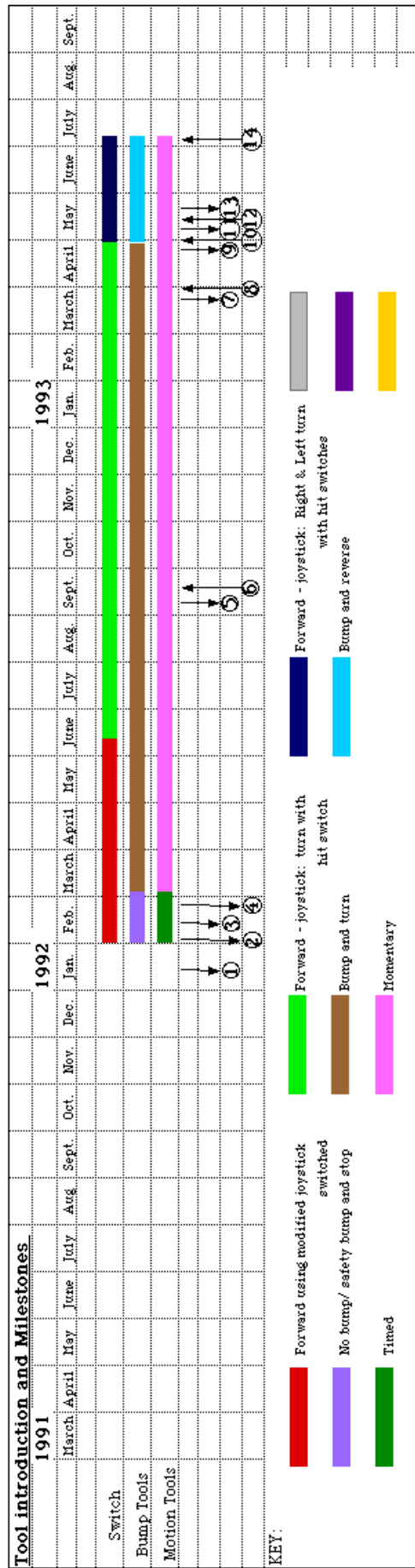
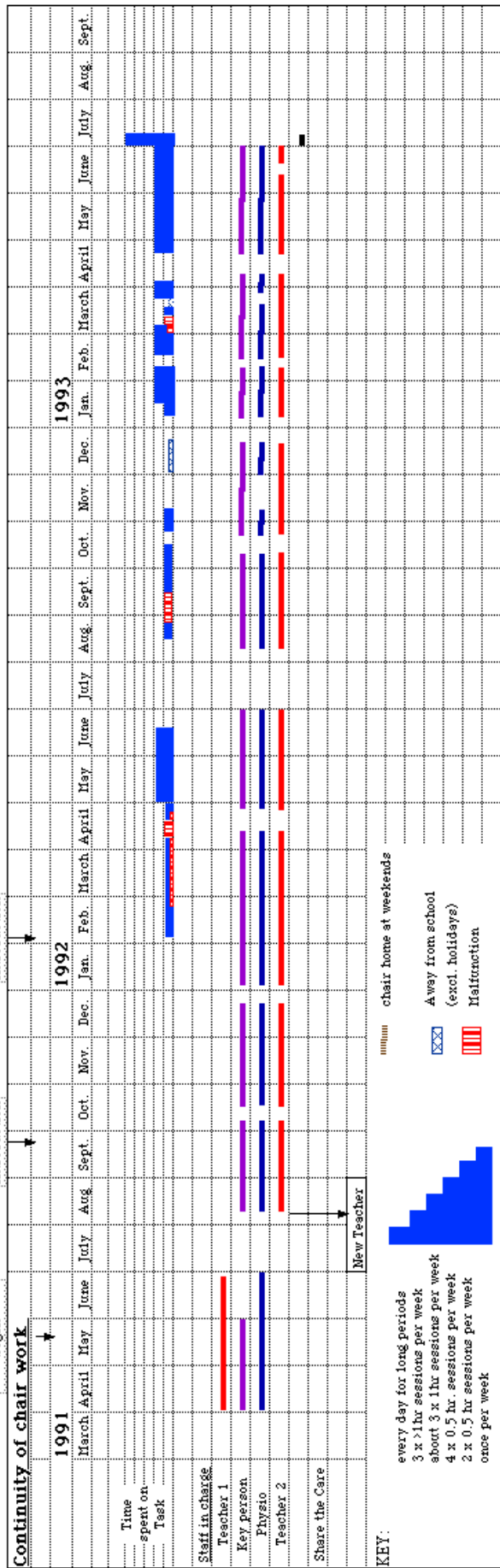
The class team report a general improvement in his fine motor skills (although they are still poor), illustrated by the use of more switches. With the hit switches, he still 'swipes' but is more controlled and can maintain switch closure. His sitting balance and head control are thought to have improved. His upper limb function has improved and this has enabled crawling on the floor. The staff report that Jack likes the Smart Chair and would be in it all day if he had the opportunity, although this is contradicted by diary entries from his 'Share the Care' worker which report him asking to be taken out of the chair after 30 to 40 minutes. Nevertheless, the class team now consider him a candidate for a powered chair whereas previously he was never considered. They felt that Jack had been more successful in the Smart Wheelchair than had ever been anticipated.

### **Long term process measures**

Jack's Continuity Chart shows that although his access was regular, it was limited. This lack of opportunity for practice was compounded by periods of chair malfunction, by the chair being shared, and by initial lack of access during the school holidays. The increase in use at the start of the school holidays in July 1993 is due to efforts by his 'Share the Care' worker.

Despite the lack of practice, Jack made steady albeit slow progress in his acquisition of new skills and control of the chair for functional mobility. The long periods between presentation of new tools prevented Jack from tackling new challenges and consequently from developing new skills. This is illustrated by the clusters of progress Milestones around the times when new opportunities were offered, at the introduction of the chair in January 1992, and in May 1993 when the second turn switch was added.

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## KEY TO MILESTONES

1. At the seat fitting, Jack asks, "Can I have a shot? Can I drive? Who'll push me?"
2. Before helper has even sat on the chair, Jack asks, "Can I have a turn?". Jack puts his hand out to have a turn, and he goes solo. "I want to turn."
3. "The chair's talking!"
4. His final comment on leaving the chair in the hallway is, "I've parked".
5. During the time the chair is away to be repaired, he asks why the chair is not speaking to him. He tells A. that she is going backwards on the school bus: she was sitting in a rear-facing seat.
6. He asks to drive to the Snoezelen and it is explained that it will take a long time. His response is "Can I try?".
7. "He is encouraged to come towards me while I keep changing my position in the room. He uses the chair and switches appropriately to turn."
8. "He turns the chair 180°, requiring only a little guidance from me."  
"He uses both Right switch and Forward alternatively to correct his direction, and needs very little help or guidance."
9. "He wants to go into the hall and manages independently most of the way. Once in the hall, he wants to go to the girls' toilet and manages to get there with no help. Twice the chair switches itself off without my realising it and Jack has to shout over to me that the chair is not working. Left to 'experiment' on his own, he manages to disappear into the cupboard where he shouts 'A., help me, I'm stuck ... I'm in the cupboard!'. "
10. "Introduce Left switch and explain its use. He is able to use it appropriately, but is more inclined to play with it initially. It is better at lunchtime: he makes his way into the class next door and to the boys' toilet with no help."  
"Jack is desperate to go outside in the Smart chair. He copes really well with new Left hit switch but is unable to go completely independent due to the uneven sloping surface and small chips in the tarmac which prevent the wheels turning. Jack does not like being helped and tells me 'not to help' on several occasions. Unfortunately I have to help for safety reasons."
11. "He wants to go into the hall and is allowed to do so. He is left on his own and uses Left and Right switches appropriately. Jack reports 'chair is not working well'. As it turns out, the bumper needs fixing. Also, each time the chair switches itself off, Jack shouts to tell me 'it's not working'."
12. "He manages to negotiate the physiotherapy door independently. Getting out of the physiotherapy room is quite difficult as it involves going through a narrow opening. I think Jack is ready to use the chair in a classroom situation rather than on a 1: 1 basis. He is using the left and right switches appropriately."
13. "He is told to go to the toilet himself when he needs to go. Due to lack of time, he is given a little help to get there, but is able to go from the class to the toilet independently. He shows this during informal lunchtime sessions with Smart chair."
14. Jack helps to set the table. "He goes from the lounge through the door into the hall, collecting items (one each trip), turning in a fairly confined space, through the lounge into dining room. He has to manoeuvre round several corners (making both right and left turns) and this encourages him to travel short distances without bumping into anything. He is also careful not to drop the item on his tray. He uses his Smart chair each day to move around downstairs in the house. He helps to carry various items, and goes to the television to turn it on/off when requested. He goes into the hall to collect letters, newspapers etc."  
"He chases the dog!"  
"Jack chooses when to come out of his chair; it varies each day but he is in it for approximately 30 - 40 minutes. He is most frustrated that the chair does not work in the street."

### 4.3.3 Adam

#### Introduction

Adam was first selected for the Smart Wheelchair project in April 1991, when he was 12 years old (although it was May 1992 before he began his Smart Wheelchair work). Adam was described as suffering from a right hemiplegia and being prone to frequent seizures. Throughout the project, he was living in a home for children with multiple disabilities run by the local Health Board. Despite his being away from home, his family were keen that he should be involved in the project. They took an active part in putting together his pre-study profile and attended the introductory courses. However, they made no input into the post-study profile.

#### Pre-project Profile

Adam is a very disabled child. The clues needed to judge his cognitive, social, and other skills are quite subtle, and were mainly drawn from observation of Adam in functional settings.

##### *Attention*

Adam was described as having a variable attention span although it was felt that this was largely dependent on his moods and his seizure pattern. The class team felt that he could often be coaxed back to participate after his attention was lost.

##### *Behaviour*

He was also prone to challenging behaviour at home, but less frequently at school: for example, he would nip or hit anyone in the vicinity.

##### *Sociability*

Despite his challenging behaviour, Adam was described as a quite sociable boy, interested in his surroundings, and preferring situations where he could see what was going on. For example, his dislike of being in the ball pool was attributed to his not being able to see anyone over the edge of it. He also likes being handled or touched and especially being cuddled.

##### *Memory, motivation and social interaction*

Adam's challenging behaviour gave helpful insights into his skills and abilities. The staff were confident that Adam could estimate distance well (which would be needed for wheelchair control) since he knew, for instance, when he was near enough to someone to nip them. He was able to attract attention to himself by hitting the table and on the odd occasion hitting himself in order to gain attention. Adam also understood and remembered people and situations, reacting appropriately (if disruptively). Adam attached meaningfully to familiar people or situations when expecting to be disturbed, and brightening for people that he hasn't seen or heard for a while.

Adam could anticipate well during a turn-taking game. He would watch his classmates, lifting his head up ready for his turn. He responded better to extrinsic, adult encouragement than to the intrinsic reward of achievement: solitary computer based learning was not a good way to learn, say, switch control.

##### *Sight*

Adam had little or no sight in his right eye, and tracked objects only in the left field of vision.

##### *Hearing and understanding*

There seemed to be no evidence of a hearing problem. Adam would search for the origin of a sound, could recognise familiar voices, and responded to whispers.

##### *Expressive communication*

Adam's expressive communication was limited to non-verbal demonstrations of upset, pleasure or annoyance, with some (unconfirmed) eye pointing and reaching. Adam initiated communication by hitting the table in order to attract attention, or by using a scream or a non-verbal vocalisation. His teacher felt that he made good attempts to turn take in a group situation and even better when in a one to one situation with his teacher. Efforts were being made to teach signing, with very limited success.

##### *Receptive communication*

Adam seemed to recognise his own name and the names of his family and familiar people. He would make eye contact if someone spoke to him.

### *Education*

Adam had already shown an understanding of direct cause and effect using switches in computer based learning tasks. However, his demonstrated problem-solving abilities were restricted to rolling over or kicking in order to move himself into range to be able to nip or kick someone. His abilities to plan using chains of reasoning or to deal with time-deferred problems were unproven.

### *Physical/mobility skills*

Adam sat up well and was also able to pull to sit. He was also able voluntarily to turn his head although this was mostly to his left. He was walking with one person supporting him. He could cross leg sit using his right hand to help his balance.

For manipulation, Adam tended to use his left hand although there was some evidence that he was beginning to try to use his right (he would occasionally use it to bang on the table for attention). In general, Adam's right hand was held in a tightly flexed position at both elbow and wrist joints, and was not used. He showed evidence of some fine motor skills in his left hand: he would use a pincer grip to nip people and yet would use a gross hand movement in order to pick up crisps.

## **Initial video interpretation**

The pre-intervention videos confirm the staff profile, showing Adam as having a complex mix of developed and undeveloped skills. He was a child with some obvious physical ability (for example, his fine hand control when feeding), and yet an inability or unwillingness to extend or transfer his physical skills into other functional areas. He tended to be an observer in a group situation unless prompted by an adult.

## **School and home settings**

Adam began his Smart Wheelchair project in a mixed ability class at a Regional Education Department special school for severe multiply disabled children. His classroom environment consisted of a small, rather cluttered classroom and a larger, also space-constrained, eating area (with obvious implications for the Smart Wheelchair work). He later moved into another classroom which, whilst also constrained, had a large open shared area outside the classroom door. Also available to the classroom teacher from time to time was the school gymnasium: another large open space.

Adam does not live with his family. Home is a large Victorian building with a spacious, infrequently used playroom, a lounge area (with little free space), and bedrooms. There was also a large tarred area outside which his nursing staff intended to use for Smart Wheelchair work during good weather. Towards the end of the project, the nurses from Adam's home requested that the chair might come home with him. They were trained by the project team, and the chair went home for the occasional weekend.

## **Aims and Aspirations**

The school set out the following aims for Adam.

### *General educational aims*

- extending understanding of cause and effect
- encouraging self-motivated exploration, and through this, build up awareness, understanding and independence
- engaging Adam in activities which would promote attention to his surroundings, and allow better assessment of his sensory skills
- developing self help and cooperation in hygiene

### *Communication and socialisation*

- to encourage self-assertiveness
- understanding (and responding appropriately to) simple instructions based around classroom tasks focusing on mobility
- to encourage one on one interaction in class
- to encourage and develop responsiveness in class group work
- to extend Adam's ability to make and communicate choices, and to transfer these to basic signing skills
- to improve attention to other people's communication, focussing on his understanding of simple verbal direction and gesture

### *Functional mobility*

- to develop autonomous mobility used appropriately: e.g. in directed classroom tasks, independent explorations, and social acts

### *Physical skills*

- to ensure that Smart Wheelchair activities did not prejudice development of existing physical skills (independence in swimming and in walking)
- to improve sitting and standing balance
- to develop strength, confidence and coordination in fine and gross motor skills.

## **Assessment and adaptation - chair, seating and control design**

Adam had adapted seating for his manual wheelchair but as this was not transferable to the Smart Wheelchair, the PMR Bioengineering Centre designed and built an individualised seat for him. This proved to be rather difficult because Adam is a very tall young man and he had large feet which interfered with the bumpers. The final seat design was quite high off the chassis (which had the advantage of putting him into a commanding position, near to the height that he would have been had he been standing up). In addition, a tray was added to his seating.

Because Adam had previous experience of using a hand-operated contact switch, it was decided that this switch would be the control device in the initial stages of Smart Wheelchair work. The switch was placed centrally, allowing Adam to use either his left or his right hand. The switch was velcroed to the tray in order to prevent Adam from accidentally sweeping from the tray; in the event velcro was not strong enough and the switch (and its successors) were bolted to the tray.

The chair was initially set up in Timed control mode and with a 'Bump and Stop' tool.

## **Using the Smart Wheelchair**

Adam began using the chair in May 1992, with the early sessions sitting on the knee of his helper (to build his confidence). Because of his size, this was an extremely difficult process. Fortunately, Adam was not disturbed or upset by the experience, and went solo after two sessions. Going solo was also not frightening for him.

Adam's early use of the Smart Wheelchair coincided with his Physiotherapist's programme aimed at preventing further deformity to his right hand using a hand splint. Whenever he was wearing the splint, he preferred to hit the switch with that hand, and, by the end of June 1992, he was using his right hand nearly all the time when he was driving his chair.

Despite the fact that Adam attends a 52 week school, the disappearance of his regular class teacher at the end of June meant that there was no chair work done between then and her reappearance after the school holidays - in fact until the middle of September. Adam was introduced to 'Bump and Turn' (which gives some directional freedom) in September. To prepare for two switch control (allowing more directional control still), the size of the current switch was reduced. Adam would need the time to practice on a smaller target. (Using a smaller switch would also force Adam to locate the switch rather than randomly bang at the tray. It was noted in his diary about this time that he was not actually looking at the switch: he was hitting it and, when the switch was taken away, he continued to hit the tray.) After the new switch was given to him, he often missed it in this situation.

Adam's chair work now decreased in frequency and seemed to be dependent on a member of the CALL staff actually being present during a chair session. Despite these reduced opportunities to practice, his preference for using his right hand continued to be obvious and he began to show an interest in improving his chair control, making efforts to stop his chair to pull or touch things that were on the walls.

In mid-November, it was decided to try to decrease Adam's unproductive banging at his switch by changing his motion tool to momentary. The idea behind this change is that frequent short strikes on the switch would get Adam nowhere; he would have to maintain contact with the switch in order to get the reward of movement. His initial reaction was to lose interest in movement for a few minutes, but he soon became involved in what was going on and showed that he understood that he had to maintain switch contact to make the chair move.

By the beginning of 1993, the CALL team were trying to encourage the classroom staff to give Adam the opportunity for directional control by giving him another switch, but the class team were reluctant to take the step. Frequencies of practice sessions remained low.

During February and March of 1993, Adam was unwell and therefore was not using the chair in school. It was May before he returned to a more regular routine. Again, the CALL team tried to persuade the classroom team to give Adam a change of direction: in June 1993 he was given another switch to enable him to turn right. Up until the summer holidays he spent much time spinning in circles on the spot, to his obvious enjoyment, and the faint frustration of others.

## **Post-project Profiles**

Adam's post-project profile was prepared by pretty well the same team who constructed his initial profile, with the exception of his parents. We concentrate on the changes in the profile. Not surprisingly, given the limited time on task revealed by the diary record, areas of perceived improvement are limited.

### *Personality and cognitive abilities*

Staff reported a distinct decrease in Adam's attention seeking and challenging behaviours: he screams and spits less, and is less vicious in attacking other people.

### *Exploration*

On a larger scale, Adam's exploration of the world is showing signs of purpose. Arriving at a non-human obstacle, he will now examine it. If he causes a corridor jam, he expects some social interaction with those he is inconveniencing.

### *Communication*

Staff report a slightly better communication in other settings, with more tolerance and occasional interaction when in a group.

### *Physical skills and mobility*

His therapists report a decrease in Adam's gross motor skills possibly due to his increasing seizures and the effects of the drugs used to control those. As a result, Adam's walking has deteriorated, as has his standing ability.

One major, positive change in Adam since the initial profile is the use of his right hand. He chooses to use his right hand where he never did before and transfers this skill to other, non-chair settings: he will, for example, now use two hands together in the sand pit. He will also attempt to reach out and hit people with his right hand and is generally showing a marked preference to it, for example, using it with the tambourine. This can be with or without the splint.

## **Long term process measures**

The Smart Wheelchair long term process observations both reveal patterns of learning (and the opportunities for doing so), and indicate specific gains at the points where mastery of chair control leads to new tools being added, or chair control being reduced. These processes are summarised in the table overleaf.

The table shows Adam to have had very little opportunity to practice - the reader should compare the long term profile with those of other children. Despite that, Adam made some significant steps:

His ability to learn new skills (and remember them even over the long gaps in training) are shown both by his mastery of switch control, and his adaptability to the changes in tools and controls imposed during the study.

He will now put more effort into exploring his own abilities. For example, his attempts at switch control using his previously less preferred hand and his adaptability of hand control are both new.

Adam shows an ability to concentrate on (to him) rewarding tasks: his enjoyment of the new turn manoeuvre using a second switch resulted in useful lengths of control practice. No adult extrinsic reward was needed.

To be effective even in these very limited examples of play and exploration, Adam has demonstrated a much finer grip of causality than previously. His awareness of the inconvenience of others due to him is a first step to planning for more taxing driving situations in busy environments, and shows his ability to de-centre.

Any child with enough random movements can appear to operate a Smart Wheelchair, operating the controls by chance. Adam has shown his control to be well beyond that, using features of the chair effectively in play and exploration. This embryonic functional use is still primitive, though, and is being slowed in development by several factors. The major ones are: physical illness; limited integration of Smart Wheelchair work into the curriculum; and, as a result of both of these and timetabling problems, a lack of opportunity to practice.





## KEY TO MILESTONES

1. Adam solo, problems mainly to do with his size: he was eager to go alone.
2. Adam seemed to be motivated - hitting the switch and laughing.
3. Adam's right hand in 'cock-up' wrist splint - now using right hand to hit the switch.
4. Adam using right hand practically all the time when in the chair - as we left the gym, he accidentally knocked the door with his hand, then deliberately hit it a second time to show he had control?
5. Asked Adam if he was having fun in his chair - laughed. Chair on the move practically all the time.
6. Adam now not looking at the switch when hitting it - if switch taken away continues to try to hit where it was: because new switch is smaller, often misses it.
7. "...reluctant to start moving today. However, after a while, he was hitting the controller with both his left and his right hands. Adam seemed to be showing off to a couple of women who encouraged him to keep moving, which he obligingly did without much hesitation...in the beauty therapy room, Adam was having his face cleaned, obviously to his displeasure, judging by his facial expression...he decided (still being in his Smart chair) that he wanted to move so he frantically banged away to try to get some peace, *fortunately for S. (who would have been hit) the power was off*" (report by staff - our emphasis).
8. "...seems as if he was keen on using the chair this afternoon as he rarely stopped for a long break...used right hand - 3 in a row on the way up and down the gym to join us".
9. "Sat up well in the chair, couldn't wait to start, right hand on the go immediately - 3 times in a row. Then bump and turn round the room with giggles all the way. Responded well to the "admiration" of his audience. Out to the area to move round, again in control and enjoying his audience. Even when we finished he was ready to go with his right hand again. Right hand seemed to be dominant for switching (splint on again- now back to using main splint). Only tried once to move the switch - more keen to be on the move".
10. "Adam was all set to go, used right hand by chance to set off - chair did not move - right hand again - no go - right hand x 2 - no go, 1a good hit with the left hand. Quite obviously having chosen to use his right hand with no result, Adam resorted to his left hand. Then waited for the chair to be ready and just time to move off - used right hand too."
11. "Adam was relaxed and happy to be in his chair hitting the switch constantly. Stopping on occasions to touch/pull things on the walls. Enjoys banging his left hand on doors as he passes them."
12. "...initial reaction was one of disinterest with the movement for 5 mins. However, with a little encouragement, Adam soon became involved. When Adam reached the gym area where Group 4 were involved in an activity, he stopped and showed great interest in what was going on before continuing on our way."
13. "Adam was bright and alert as they set out, looking round (thinking no one behind?) - and using right hand with the splint to access switch. Smiles for R. and people met in corridor."
14. "Adam started off at a great rate - right and accessing again and again - quite determined taps. In the gym Adam turned to see D. - used left and right hands."  
"Came under parachute and pulled it with left hand, but accessed switch to move the chair with right hand."
15. "rather than being left out of an activity, he would make an attempt to turn his chair round and re-enter the circle. Once in the circle, he became involved in a game of trying to run over staff...made great use of his right hand, also his left hand for banging on windows and doors"
16. "...jam-ups cause most fun - good interaction here. Outside, Adam was content to look round...fun again causing a hold-up - just looked round and giggled"
17. "Adam started with left hand -and moved through area 2-3 slowly - taking time to look round, then another touch of switch. left hand helped bring up right hand to switch - in red carpet area A enjoyed a bump/turn time - stopping to watch anyone passing through and enjoying a 'chat' when possible. Again switching with right hand, using left hand to knock doors, pull parachute. NB use of right hand to switch allows freedom for left hand to be used independently"
18. After some help to put his right hand on the right turn switch, he hit it a few times. Played interactive games with him, standing out of his field of vision trying to encourage him to turn round and make eye contact. He didn't use the forward switch at all, but kept going back to the right turn, laughing as he was doing so.
19. "first moves were short sharp turns using his right hand (in splint) to control the chair. After 5 or 6 attempts he had turned the chair 180 degrees and was facing the opposite direction from where he had started. At this point, he headed in a straight direction from where he had started. At this point, he headed in a straight direction this time controlling the chair with his left hand. He ran into a table after travelling approximately 12 feet without stopping...continued this circling motion on several occasions"

### 4.3.4 William

#### Introduction

William was 6.5 years old when the project started. He is the youngest of a family of three children. His parents were supportive of the project, keen that William should have the chair home during the holiday periods and saw it as a means of giving William some independence. William had recently transferred from the Nursery Section of a grant-aided school run by the Scottish Council for Spastics, to the Junior Department full-time. He has dystonic quadriplegia and a bulbar palsy. He was described as a bright child and with no visual or hearing impairment. His communication skills were limited to eye pointing and some vocalisation.

#### Pre-project Profile

##### *Personality, cognitive state and sociability*

William was described as sociable and liked one to one situations. He could also be moody, petulant and manipulative and when disinterested would refuse to respond or participate. He had a good attention span and showed assertiveness within his physical capabilities. He has good memory of people, objects and situations, anticipating situations during the morning programme or during stories. He had good eye contact when communicating but was not particularly motivated to eye-point to his communication board, preferring vocalisation. William was quite frail and he was frequently off sick at home and for longer periods in hospital. He liked to be part of the family group, to play with other children outside, and in particular, enjoyed activities involving cars.

##### *Vision*

William's vision appeared normal.

##### *Hearing*

There was no evidence of any hearing defect and William commonly eavesdropped and interrupted adult conversation.

##### *Expressive communication*

William primarily used eye pointing as his means of communication and to indicate a "yes" response. He had a communication board with 16 choices and 4 colour codes. Although he could use it to express himself, he lacked the motivation to use it as a means of communication on a regular basis. Vocalisation was quite difficult for him. The desire to vocalise could be seen in his body language but it usually took some time for an utterance to be produced. William was good at initiating conversation and he would turn take appropriately during conversations.

##### *Receptive communication*

William had good language comprehension according to observations by staff and parents as well as psychological assessments. He would respond appropriately to humorous or sad events in conversation and on TV and became animated if deliberate errors or changes were put into stories. He could identify everyday objects when asked.

##### *Education*

William had an understanding of cause and effect and used two switches to access computer games and a slide projector toy. He would often put his foot on the wheel of his buggy and stop it from being pushed. The staff thought that he could solve simple problems but assessing this area was difficult because of his limited function and because he tended to opt out of difficult situations. William was able to discriminate between a few colours and showed an understanding of object permanence.

##### *Physical, life and mobility skills*

William displayed an ATNR to both sides, affecting his hand function. He had poor trunk control and sitting balance and was unable to hold his head up for more than a few seconds. William could grasp and release when positioned well but his gross upper limb movement was inaccurate. He had no independent finger movement. He operated his switches either by swinging his arms, or by resting his fist on his tray and using elbow movement to slide on and off the switches. This latter technique gave him better control and accuracy but he could not always achieve a sufficiently relaxed tone to manage the movement. William could roll with minimal assistance. He was toilet trained. He was sometimes difficult to feed.

## **Initial video interpretation**

The pre-intervention school videos show that William was alert and aware of his surroundings but so physically limited that he was unable to effect much control on his environment. His only means of assertion was negative, by opting out of situations and refusing to respond. When interested, he would actively participate in a group although he frequently wanted to be the choice maker in the classroom, volunteering himself regularly.

The initial videos taken at home show William being treated protectively by all his family. William was content to be handled in this way. He nevertheless asserted control over the family and by refusal or by becoming distressed, he usually got his way.

## **School and home settings**

When initially referred to the project, William had recently begun to attend school on a full time basis. He was in a class of children of approximately the same age although possibly less cognitively able. By the time William received his Smart Wheelchair, he had moved into a class of higher functioning children, one of whom he was to share the Smart Wheelchair with (Jack). It was a cluttered environment and the class timetable was heavily structured so chair sessions generally took place outside the classroom in a common hall area used to access all the Junior School classrooms.

William's house was at the top of a steep flight of stairs with consequent access difficulties. Within the house, the living room was large enough for chair practice. The back garden had an easily accessible paved patio area for play.

## **Aims and aspirations**

### *General education aims*

- to assess and expand his knowledge of colours
- to develop the use of a computer for choice making and practice of simple scanning

### *Communication and socialisation*

- to improve social interactions
- to develop eye pointing
- to develop expressive communication through the use of gaze, facial expression and augmentative communication
- to improve functional use of his communication board and extend it by introducing topic or themes
- to encourage vocalisation
- to encourage consistent use of the yes/no response and eye or fist point when choosing
- to assess and develop understanding of simple commands and language comprehension

### *Physical and life skills*

- to improve head control, sitting balance and balance reactions, and to encourage more movement across the midline.

## **Chair, seating and controls design**

William did not have a manual wheelchair or seating system and therefore the Bioengineering Centre at Princess Margaret Rose Hospital in Edinburgh designed and manufactured seating based upon a Britax car seat. A frame was added to accommodate his existing tray containing two light-action, flush-mounted hit switches. William found it easier to access the left tray switch and so it was decided that he would use this to begin chair work with 'Timed' motion tool, no 'Bump' and a forwards only direction.

William's was a shared Smart Wheelchair, the other user being Jack.

## Using the Smart Wheelchair

### *Introduction*

The chair was introduced in February 1992. Initially, William was timetabled only for one half hour session in the chair per week. In his first session he sat on his helper's knee, first watching her with the switch and then operating it himself. It was two weeks before he was confident enough to go solo. He immediately had difficulties accessing his switch because his seating position was more upright than he was used to, and he had to stretch to reach the switch. This particular Smart Wheelchair also veered severely and so when William tried to make the chair go forward to move to a particular target, he would veer off to one side and never reach it. The veer was reduced by using higher tolerance components in the Smart Controller, and adding a velocity offset in software to compensate.

### *Motivation*

Following the Easter holiday break there was a gap in use until the beginning of May before he had another opportunity to use his Smart Wheelchair. At this point he did not want to use the chair and seemed to be doing everything possible **not** to operate his switch. It was not clear why he had suddenly lost all enthusiasm: comfort; fatigue; difficulty of switch access; fear; and simple lack of enjoyment were all possible reasons. His seating appeared to be comfortable. Although he did tire quickly, partly because of his general ill-health, he had shown ability to use switches for other purposes for far longer periods than his chair sessions. Confidence and fun were therefore identified as being of most importance. It was not clear whether he was unhappy because he was physically scared, because he disliked the sensation of movement, or he felt pressured by the directive approach taken by some staff. The CALL team suggested that control over steering might give him more enjoyment, but his helper was reluctant to give him the chance (even though he already had good use of both switches to control computer games). Lack of opportunity compounded these problems. William's sessions were timetabled for Mondays and during May several holidays deprived him of access to his Smart Wheelchair. It was June before he had two consecutive Smart Wheelchair sessions.

### *Steering and Bump and Turn*

William's other switch was plugged into the 'turn right' direction control socket in mid-June, but at the same time the 'Bump and Turn Left' tool was selected. The confusion and uncertainty of coping with two interacting system changes occurring simultaneously may have actually reduced William's enjoyment rather than increasing it. 'Bump and Turn' was turned off in favour of 'Bump and Back Off'.

### *Home use*

When William took the chair home for the summer, his parents were encouraged to let him direct the mobility and use chair sessions for fun rather than as learning tasks. If William felt pressured by having two switches, his parents unplugged the turn switch and negotiated steering with him directly. His diary records 20 minute game-playing sessions where he drove the chair and was also pushed around in it.

### *Small successes*

On returning to school in the August, William's interest in using the chair was no better. His Britax seat was removed from the chair and he sat amongst his class in the seat only, to test whether the seating was making him uncomfortable. However, he sat quite happily in this situation. To reduce his anxiety he went back to sitting on his helper's knee while driving and from this progressed back to driving solo. At the same time his helper altered the chair's response from timed to momentary and increased the speed. Thereafter William showed his first signs of actually enjoying a Smart Wheelchair session.

### *Classroom use*

Shortly after this, his teacher agreed that he could bring the chair into the classroom for a tuckshop library session. William used his mobility to approach staff and then used eye pointing to choose books.

### *Continuity*

There had possibly been some deterioration in William's physical skills since the summer holidays and he had difficulty accessing both switches. He went back to using one switch only with 'Bump and Turn' to provide some steering. In October 1992 William's helper left, was not replaced and frequency of chair sessions decreased. William was off school with illness from February 1993 until the end of April and there was a marked deterioration in his physical skills on his return to school.

### *New staff*

A new key person who was enthusiastic about the Smart Wheelchair was appointed while he was absent. When he returned, he was very motivated to use the chair more frequently within the classroom and around the school building. He was still using a single switch and 'Bump and Turn', and seemed happy to negotiate with helpers when he wanted them to turn him. His illness had reduced his stamina for long chair sessions and reintroducing a means of steering was delayed until he became stronger.

## **Post-study Profile**

### *Personality and cognitive state*

The class team report that William definitely seems to have matured in the last year and has developed into quite a patient yet persistent boy. If something on his chair is not working, he keeps trying with it while somebody fixes it. The class team also feel he is more tolerant and motivated to participate in classroom activities and activities at home. He likes taking part in group sessions, whereas pre-intervention he was more comfortable in one-to-one situations. He seems to enjoy using his Smart Wheelchair around the classroom and combines his mobility with use of an ORAC voice output communication aid.

### *Vision*

William makes good use of eye pointing when choosing drinks or children from a circle. The class team also feel that he knows his colours well.

### *Hearing*

There seems to be no change in William's hearing.

### *Expressive communication*

William still lacks motivation to use his communication board. It is restrictive when communicating with the other children in the class and he prefers eye pointing in these situations. He is keen to use an ORAC communication aid, accessed by hand, and the classroom team are hoping this will be a method of communication for the future.

### *Receptive communication*

There seems to be no changes to William's receptive communication.

### *Education*

William uses the computer more in classroom activities. He is limited by his accessing. The class team report that he can identify sets and shows basic number skills. The class team think that he can count. Both school staff and his mother think that he can count but because of his lack of physical ability, this is hard to judge.

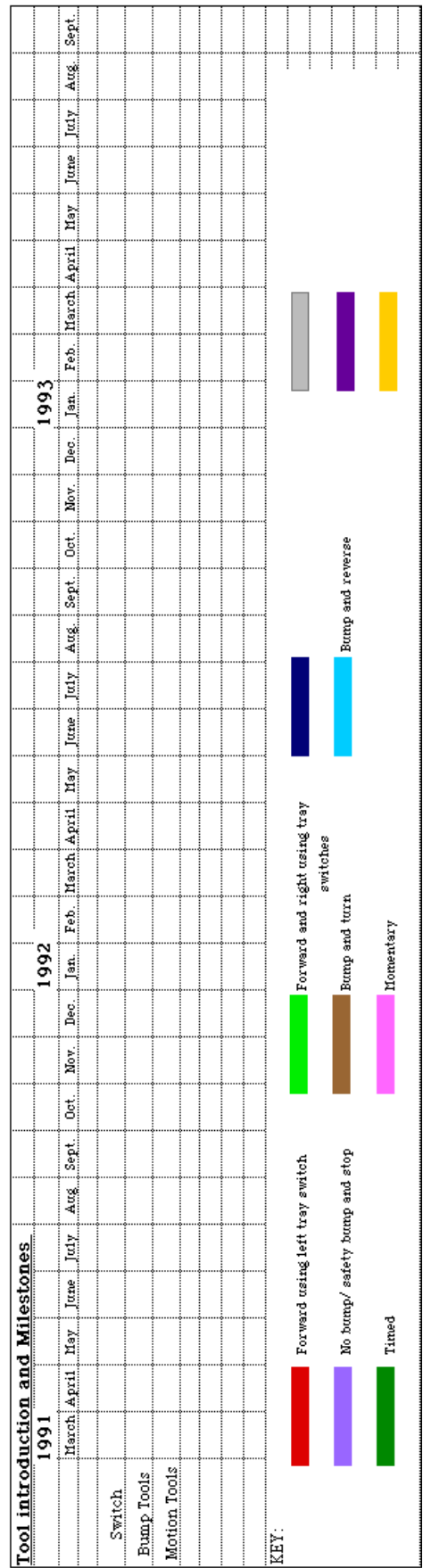
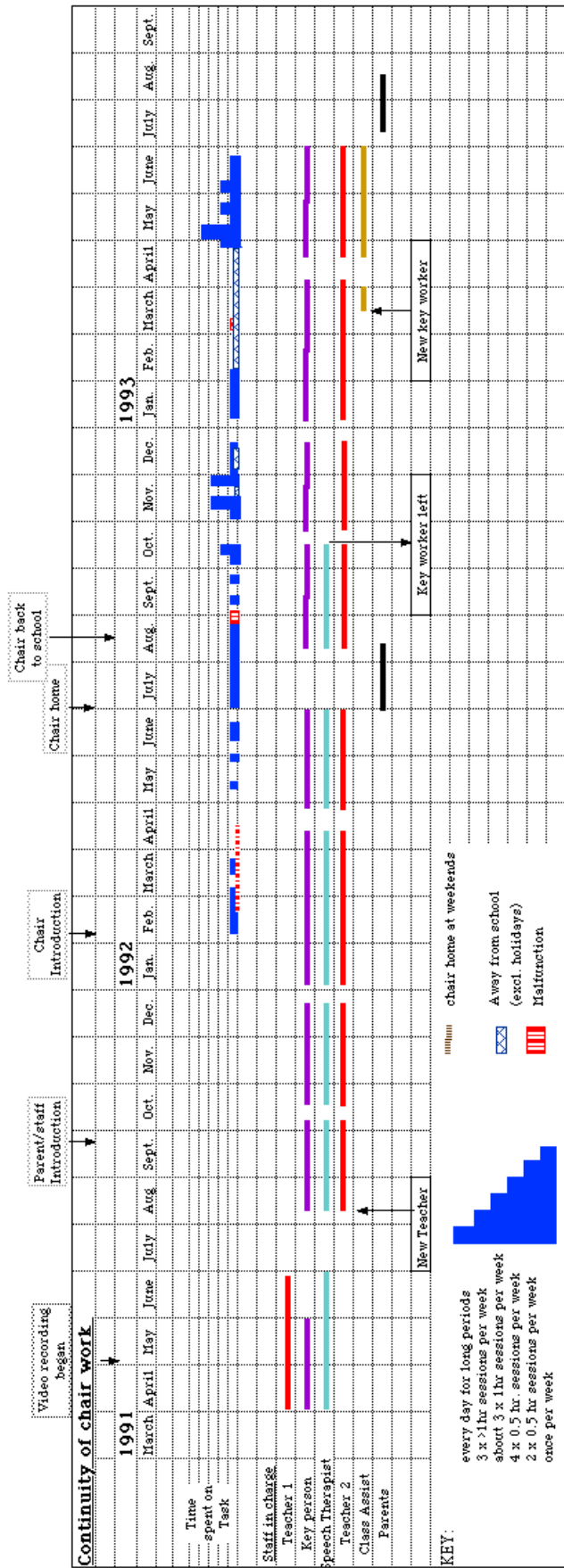
### *Physical/mobility skills*

His motor skills seem to have improved but this is hard to assess given his weakness due to illness. His mother thinks that his head and upper limb control is stronger and has improved, but the class team do not agree. The class team feel that he has limited independent mobility using the Smart Wheelchair but can not be regarded as functionally mobile.

## **Long term process measurements**

William's Continuity Chart shows that he had minimal amounts of practice which were further interrupted by periods of illness. The Tools and Milestones Chart show the consequences of this lack of time on task, by the very small number of milestones, the small changes in tools, and the regression from two switches back to one. Despite these problems, it is evident from the Post-profile observations that some aspects of his abilities have improved, although it is very possible that these improvements have been caused by maturation more than through use of the Smart Wheelchair.

William's attainment of functional mobility skills has been disappointing since he has the physical and cognitive skills to achieve more. However, he was disadvantaged by illness and consequent lack of practice and, health permitting, he will continue to use the chair and hopefully develop greater control over it using a larger number of switches, or a scanner.





## KEY TO MILESTONES

1. William sits on his helper's knee using his own switch. He eye points to go into another classroom, then outside.
2. He has switch accessing problems when solo, but is trying very hard.
3. He is doing everything possible not to operate the switch.
4. "A decision is taken to remove the seat from the Smart chair and to have William sitting in a seat among the class to help him become used to it in a 'low profile' manner."  
He is happy just sitting in the chair
5. "The speed is increased and the system altered to momentary as a previous session that day seems to justify this. This is very successful. William smiles when he discovers that if he keeps his right hand on the switch, he keeps turning in circles."
6. "William moves his chair and begins to eye point to the tape on the table. M., pretending not to understand, shows him various books nearby and gets a 'no' response. Eventually she picks up the tape and they have a chat. He then begins to move his chair forward and to eye point to the working surface at the back of the class (where the tape recorder is usually kept) and to the tape lying on his tray. M. asks him if he is looking for the tape recorder and he indicates that he is. It is explained that J. is using it and it can't be taken away from him. When asked if he wants to be turned round to have a look at another book, he again gives a 'yes' response and moves himself forward to eye point to another book on the table."
7. "William is looking around all the while at the table when he is going to the library. C. asks him if he would like to look at his book. He then, with some steering help from R., drives round to the tuck shop. William is participative and intent on what is happening at the tuck shop and keen to drive off and put his sweets in his bag to go home."  
"He attends assembly in the front hall and, when congratulated for doing so well, he does a circuit of the hall to let everyone see how well he can manage. He waits in the hall until everyone has returned to classes, then he comes back to the classroom on his own."
8. "William is left in the front hall and comes into the classroom for shop and library. He then has to leave the classroom to find me. I had gone to collect some bibs. He finds me in double quick time."
9. "William is determined to get a new symbol for his symbol board from A. He doesn't trust her to come back with it so goes up to the Senior School to look for her and pick it up from her himself."