Spinal Cord Injury Rehabilitation: A wasted resource without appropriate mobility, posture, skin integrity and life role enhancing provision

Emma Linley
Clinical Specialist Occupational Therapist
London Spinal Cord Injury Centre

Claire Kelly
Highly Specialist Occupational Therapist
London Spinal Cord Injury Centre

July 2019

Supported by

Aspire
Supporting people with spinal injury

back up
transforming lives after spinal cord injury

sia spinal injuries association
FOR LIFE AFTER SPINAL CORD INJURY

Introduction

With expert consensus from the Spinal Cord Injury Therapy Leads (SCITL) for the United Kingdom and Ireland, and with support from the three main Spinal Cord Injury Charities (Aspire, Back Up and the Spinal Injuries Association) the following document has been written to be presented to the NHS England Clinical Reference Group (CRG) for Spinal Service Services to formally raise the issue of the accelerated decline of wheelchair and seating provision from Wheelchair Services (WCSs) in England, specifically to those with a spinal cord injury (SCI).

This document seeks to provide a background to Wheelchair Service (WCS) provision highlighting the national deterioration of services that no longer meet the needs of SCI individuals. In addition, it seeks to provide a preferred solution to this situation that maximises the value of spinal cord injury rehabilitation and respects the lives of those living with a spinal cord injury through cost efficient and timely solutions for initial provision.

Throughout this document, staff and patient experiences (represented in italics) will be used to highlight the examples of inadequate and damaging service provision; permission has been gained from all individuals to use their experiences. The experiences highlighted are from data collected across all the SCICs in England.

Executive Summary

1 The NHS England CRG for Spinal Services are being asked to approve the clinical commissioning of the initial wheelchair for SCI individuals, receiving their first episode of care in a designated SCIC, so that an appropriate wheelchair is available for discharge.

2 The above request is made by therapy representation from the twelve Spinal Cord Injury Centres in the UK and Ireland who provide specific and specialist SCI rehabilitation and represents a quorum of expertise in understanding both the initial and life-long needs of individuals with a SCI.

3 Rehabilitation can be defined as "an active and dynamic process by which a disabled person is helped to acquire knowledge and skills to maximise physical, psychological and social function." (1) A core service provision from SCIC expertise is the identification of optimal wheelchair configuration and seating systems in consideration of level and completeness of injury to:

- provide postural stability
- prevent deformity
- maintain tissue viability
- optimise function
- allow engagement in family, social and vocational roles

4 Despite expert assessment and equipment identification within SCICs this information is not acknowledged by the individuals' local Wheelchair Service (providers). Common practice is for Wheelchair Services to provide an 'interim' wheelchair that does not fully meet clinical need but does facilitate discharge, with a planned date for soonest review. Recently provision has deteriorated with some Wheelchair Services now saying that they do not provide wheelchairs for discharge and that it is acceptable that patients, who have just received specialist SCI rehabilitation and achieved maximal independence, be discharged on bedrest while awaiting Wheelchair Service provision with no provided timeframe for same.

5 The provision of an appropriate wheelchair to meet individual requirement can be either manual (self-propelling) or powered (driven by the user [and as required attendant]). In addition, provision must also include a pressure relieving cushion that offers pelvic stability and a backrest system that offers spinal alignment (and where needed lateral stability). For those with higher level injuries the provision of a headrest, ergonomic armrests and elevating leg rests may also be needed.

6 This document is supported by the three main SCI Charities incorporating the views of service users, carers and support groups.

7 There is a financial implication to adopting this proposal but this is negligible when compared to ongoing costs to the NHS from delayed discharges and readmission costs, see appendix 1 for full details, and the human cost to these individuals. For the purposes of this proposal we have used an average figure of £1,500.00 to meet low paraplegia provision; £2,500.00 for high paraplegia/low tetraplegia; £4,000.00 for mid tetraplegia and £7,000.00 for high tetraplegia provision. When compared to the average cost of a SCIC bed day at £600.00 the highest cost would be covered in 12 days and less than 4 days for a delayed discharge from a Major Trauma Centre (approximate £2,000.00 a day). On a 90 day rehabilitation admission this represents a little over 13% of the cost of the highest needs individuals and a little under 3% of the lowest needs.

8 Following initial provision through the English SCICs all equipment would be adopted by the SCI individuals' Wheelchair Service for ongoing maintenance and review.

9 The CRG are being asked to consider initial wheelchair, posture and skin integrity equipment provision within the cost of the first episode of care of specialist SCI rehabilitation to optimise SCI service provision and support individual health and social wellbeing.

Background

The acknowledgement that Wheelchair Services need to improve their provision to clients has been the subject of numerous government led initiatives for over two decades. Inputs span through the Department of Health's Care Services Improvement Partnerships (2006) Out and about; Wheelchairs as part of a whole-systems approach to independence (2); RIGHT CHAIR RIGHT TIME RIGHT NOW (2014) (3); formation of the Wheelchair Alliance (2015) (4); National Wheelchair Managers Forum published Healthcare Standards for NHS-Commissioned Wheelchair Services (2015) (5) to NHS England's Model of Service specification for wheelchair and posture services 2017 (6).

The ongoing themes within all these documents support that 'wheelchairs provide a significant gateway to independence, well-being and quality of life for thousands of adults and children. That they play a substantial role in facilitating social inclusion and improving life chances through work, education and activities that many people … take for granted' (3). Despite this, 'too often wheelchair users find that their social, professional and leisure activities are not enhanced, but instead limited by the sub-optimal chairs' and that 'people often find themselves waiting a long time for wheelchairs and sometimes develop secondary health complications resulting from an unsuitable wheelchair'(3).

Research carried out to inform these documents identified 'some people were found to be waiting more than 12 months for their wheelchair and that half of the people who use wheelchairs go on to develop a pressure ulcer that was felt to be "caused, in part, by ill-fitting or ill equipped chairs" '(4).

With over 3 months' notice of expected discharge, a 24 year old tetraplegic gentleman with significant postural issues (who could self-propel a lightweight wheelchair with appropriate postural support and wheelchair configuration) was provided with a heavy Uni8 wheelchair with a sling canvas backrest and no cushion from his WCS. This offered no postural support, no skin protection and a total loss of independent mobility. In short, a total absence of any clinical needs being met with foreseeable costly secondary complications.

The Wheelchair Service of a young woman with C5 tetraplegia, who is independently mobile in a power wheelchair, state they cannot provide a power wheelchair for discharge. When asked for an alternative manual wheelchair, that meets her high injury needs for posture and pressure relief, they advise she then needs to keep this wheelchair for 2 years before she will be considered for a power wheelchair. In challenging this decision the Wheelchair Service then stated that she does not meet the criteria for a power wheelchair because, despite it being her only method of independent mobility, once she arrives at a destination she does not have the hand function to do anything else.

Data collected at the London Spinal Cord Injury Centre (LSCIC) shows that over a 16month period (September 2016- January 2018) 81% of people with motor complete injuries did not receive a wheelchair to meet their clinical needs at the time of discharge. In addition, 50% of people did not receive a wheelchair to meet their clinical needs within 18 weeks of referral, see appendix 2.

A 52 year old with high tetraplegia who achieved independent mobility in a power wheelchair during rehabilitation was told there is a one year wait for provision of same by his WCS. Where previously he had been independent in accessing his environment and then able to collect prepared food and drink he was now dependent and needed carers for discharge.

Two years post discharge an 8 year old child with tetraplegia and ventilator dependency is still waiting for power wheelchair provision from her WCS despite being able to drive a power wheelchair independently during her rehabilitation.

In 2015, the National Wheelchair Managers Forum published Healthcare Standards for NHS-Commissioned Wheelchair Services. Within these 'minimum' standards they cite 'the service will provide a comprehensive service for people of all ages with long term mobility problems and associated postural needs' and that 'the service will provide for not only the clinical needs but will also consider the holistic needs of the user (including social, educational, lifestyle and family/carer requirement) (5).

WCS advised that "postural management is not the role of the WCS and patients should be hoisted into an alternative seating system if they need postural management when not moving in their wheelchair."

In 2015 an All Party Parliamentary Group on Spinal Cord Injury conducted an inquiry into the provision of local health services for people being discharged from SCICs. In doing so they produced 'A Paralysed System' which identified numerous issues with Wheelchair Service provision for people with spinal cord injuries; 'evidence submitted to the inquiry indicates that increasingly people are being discharged with unsuitable, basic wheelchairs

jeopardising the entire rehabilitation outcome.' Within this document it is recognised that while 'the Wheelchair Service therapists have knowledge and experience of a wide range of disabilities, they are unlikely to have the same in-depth understanding of SCI as this group constitutes less than 2% of the wheelchair using population' (6). With this, SCICs and Wheelchair Services can often find themselves at odds e.g. a Wheelchair Service definition of an 'active user' i.e. a full time wheelchair user who can lift a wheelchair in/out of a car are generally the only individuals who are considered for provision of a rigid, lightweight wheelchair. This shows no consideration for those who can be more independent from a more responsive wheelchair but who do not drive and negates the needs of those who can stand and maybe even take steps but will not have independent outdoor mobility on their feet. These are often the individuals with the greatest need for a rigid frame, lightweight wheelchair with the greatest scope to reengage in societal norms including work but who are penalised in terms of provision for having some use of their legs.

Patient provided with folding frame wheelchair that lacked configurability to allow him to reach the wheels for efficient self-propelling leading to shoulder pain and postural kyphosis.

Most recently, in 2017, NHS England published a Model Service Specification for wheelchair and posture services where the need to improve wheelchair commissioning was acknowledged. Within the specification, the aims were outlined to again achieve 'reduced waiting times and reduced secondary complications' (6). Within this document there is the clinical acknowledgement that 'children and adults with complex, long term conditions need to be able to access the right wheelchair, quickly and with appropriate support' and that 'getting the wrong wheelchair leads to re-referrals and the development of other health complications (6).

In referring a gentleman with a C4 AIS C tetraplegia advised by their Wheelchair Service that they cannot accept referrals for a manual wheelchair "more than two weeks before patient discharge". There was no acknowledgement of complex requirements for tetraplegic provision.

Another Wheelchair Service states it does not provide a wheelchair until at least 18 weeks after receipt of the referral. No rationale provided for decision process.

Many Wheelchair Services will not provide equipment into Nursing Homes even when complex postural needs are identified.

It should be acknowledged that there are examples of exceptional provision from Wheelchair Services; one SCIC can cite a Wheelchair Service that consistently provides power chairs for use during a patients' rehabilitation to support discharge. Another Wheelchair Service provides a stock of discharge wheelchairs that the SCIC therapists select from to also ensure timely provision for discharge. Whilst effective and collaborative, these services are rare and the inequity across the country needs to be addressed nationally to ensure appropriate equitable provision for all.

Where we are now

Despite all the contemplation and ambition to improve Wheelchair Services there has been no up lift in resource and instead there has been a steady decline in service delivery for the last twenty years. Alarmingly, and the reason for writing this request for urgent attention, there has been an accelerated decline in the last five years where all service users are assessed on the same criteria regardless of potential for physical deterioration, loss of

independent mobility, the potential to return to/engage in vocational and social roles from inadequate provision. Timeframes for provision are extending and clinical need not being met is the norm. Policies of service provision being quoted by some Wheelchair Services are often frustrating, time wasting for all healthcare professionals involved, a source of constant anxiety for the user and in extreme cases life threatening when posture and skin integrity are compromised.

The latest plan to meet service users' needs is the planned introduction of Personal Wheelchair Budgets (7) to 'support people to manage their own health and care and have more choice and control of the wheelchair they are able to access' are concerning. This does not acknowledge that this was the very reason the Voucher Scheme was developed, has clearly failed, and more worringly puts the responsibility for understanding the complexity and consequences of inadequate management on the user with no mention of meeting identified clinical need/s.

Options

So, what solutions do we have? A number of options exist:

1. Do nothing, and continue to watch the investment of resource and time into SCI individuals be wasted with physical deterioration and secondary injury often necessitating readmission and loss of reintegration.

OR

2. Develop national policy with Wheelchair Services to accept wheelchair and seating prescriptions, carried out in conjunction with the Wheelchair Services' preferred wheelchair provider and stock range, to support timely identification of a prescription that meets initial clinical need and supports ordering for provision in time for discharge. This will identify nationally agreed key performance indices for wheelchair provision to factor in timelines and quality indicators. Whilst this option has the potential to support timely provision, and manage the current national post code lottery, it includes multiple contacts between the SCICs and the Wheelchair Services where administration inevitably slows the process. At best, the issue of one service spending another services money is unlikely to be a welcome solution for Wheelchair Services.

OR

3. The final and preferred option would be to include the cost of an initial wheelchair and seating equipment (see Appendix 1) that meets clinical and social need within the financial contract for the first episode of care for rehabilitation. This equipment can then be 'adopted' by the individuals' Wheelchair Service (equipment identified from their preferred range) where ongoing maintenance can be continued through normal channels. This will also facilitate the prescribing of these wheelchairs by a specialist SCIC team with deep understanding of the users' needs at no extra cost.

Summary

After 20 years of evaluation, Wheelchair Services' abilities to meet their clients' needs has not improved. The reality for many is that provision, service and timeliness has deteriorated and no longer meets minimum clinical need. It is requested that urgent and serious consideration be given by the CRG to this situation and the sustainable, preferred

option 3 be implemented so that SCI individuals can be provided with wheelchair and seating equipment at discharge that continues to support functional independence, reduce secondary injury and allow reintegration by initial provision being included within the tariffs for first episode of care.

References (PDF copies can be provided on request)

1 Dean SG, Siegert RJ, Taylor WJ. Interprofessional rehabilitation: a person-centred approach. Chichester, West Sussex: Ames, Iowa: Wiley-Blackwell; 2012, xviii, 195 pp.

2 Care Services Improvement Partnerships, (2006). Out and about. Wheelchairs as part of a whole-systems approach to independence. London. Department of Health

3 https://www.england.nhs.uk Model service specification for wheelchair and posture services, 2017

4 NHS Improving Quality: RIGHT CHAIR RIGHT TIME RIGHT NOW, eDigest 2014

5 www.rightwheelchair.org.uk

6 https:www.england.nhs.uk/wheelchair-services/ accessed on 10/05/18

7 National Wheelchair Managers Forum Healthcare Standards for NHS Commissioned Wheelchair Services, 2015,

8 A Paralysed System, 2015

9 https://www.england.nhs.uk personal wheelchair budgets

Appendices

Appendix 1
Costs of wheelchairs and seating equipment against bed days within SCICs

Appendix 2
Audit summary on time from referral to first long-term wheelchair that meets a persons' needs

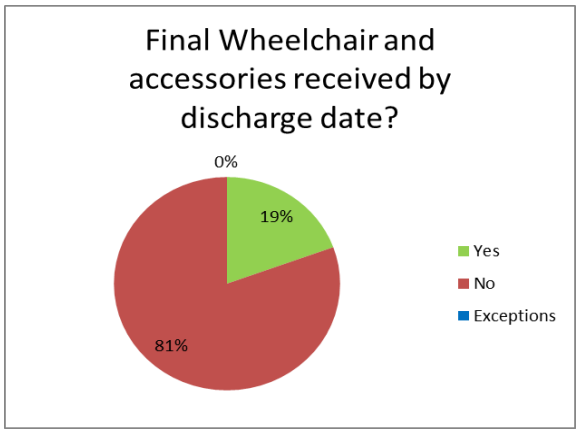
APPENDIX 1

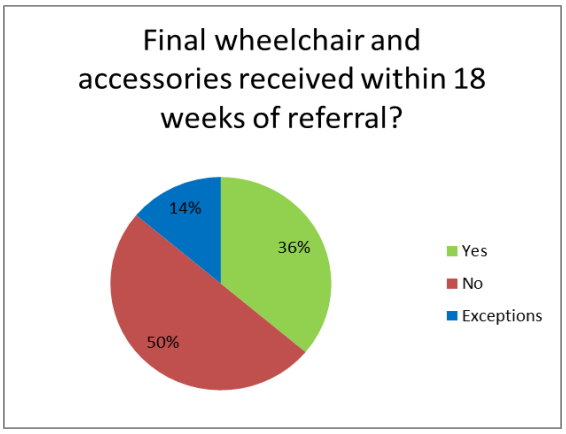
Cost comparison between provision of wheelchair, posture and skin integrity equipment versus delayed hospital discharge days and cost of treating a pressure ulcer

Equipment	Cost	LSCIC bed day (average)	MTC/ITU bed day (average)	Hospital cost of treating a pressure ulcer
Cost to NHS for Action3 folding frame wheelchair	£280.00 - £400.00	£600.00	£2000.00	£60,000.00-£120,000.00
Cost to NHS for Argon2 rigid frame lightweight wheelchair	£895.00 - £1400.00			
Cost to NHS for high pressure relieving cushion	£250.00-£500.00			
Cost to NHS for modular deep contour backrest	£350.00-£500.00			
Cost to NHS for tilt-in-space power wheelchair	£1155.00 - £3000.00			
Cost to NHS for tilt-in-space power wheelchair with Head Controls	£5500.00 - £6600.00			

APPENDIX 2
Audit on time from referral to first long-term wheelchair that meets a persons' needs

The information below has been collated for all first episode of rehabilitation adults admitted to the London Spinal Cord Injury Centre between September 2016 and January 2018 with an AISA level of A or B only (motor complete). A 'long-term wheelchair' has been defined as one which meets a persons' postural, mobility and lifestyle needs; for example a rigid frame, lightweight wheelchair for a person with complete paraplegia, or a powered wheelchair for a person with a complete high level tetraplegia.





Final wheelchair and accessories received by discharge date?	Subtotal
Yes	7
No	29
Exceptions	0

Final wheelchair and accessories received within 18 weeks of referral?	Subtotal
Yes	13
No	18
Exceptions	5

Exceptions:

- Unable to contact 4 people to determine if their wheelchairs had been received.
- One person used the voucher process so timescale not included in the results.