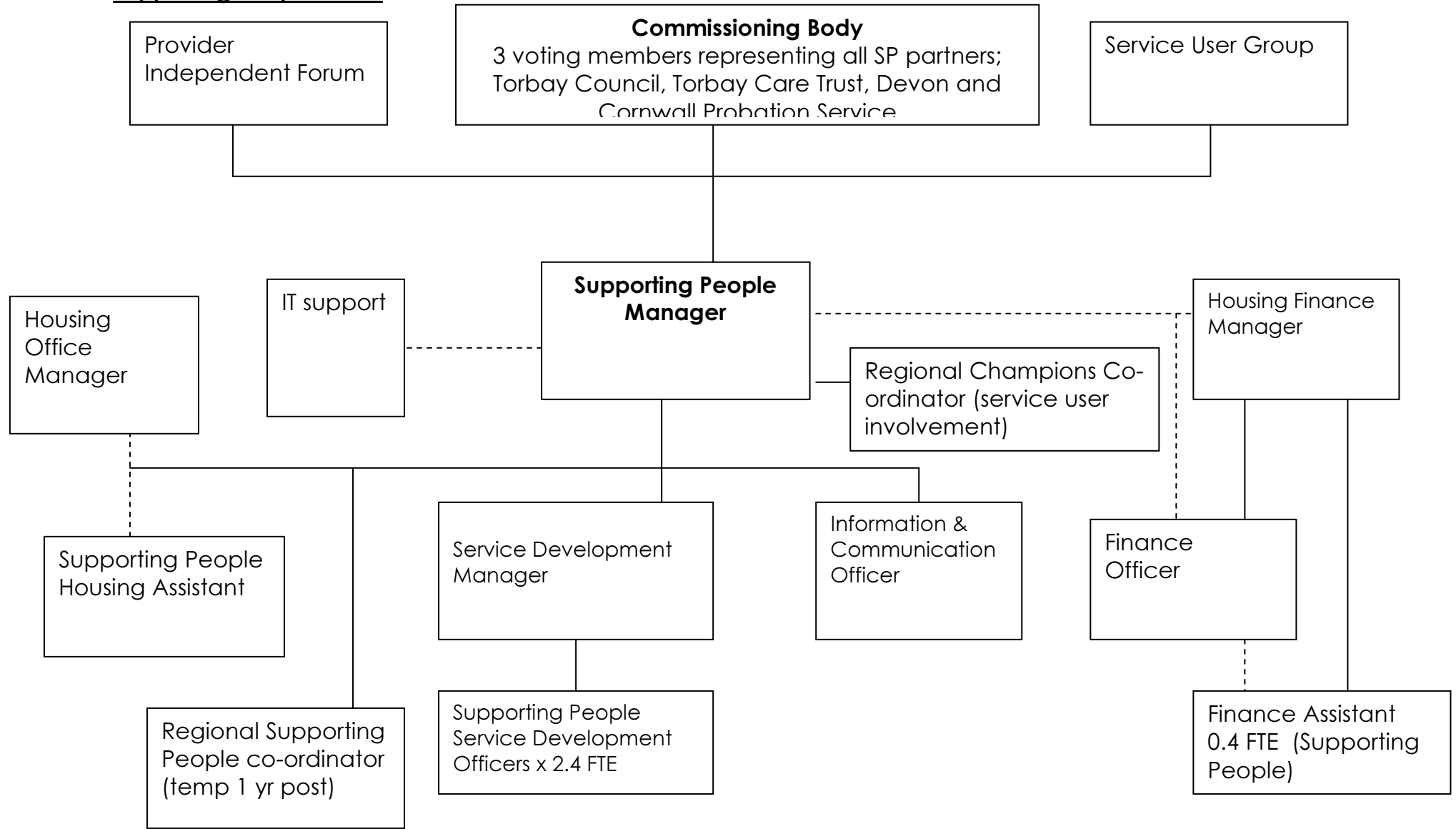


Supporting People Team



Torbay Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions Housing and Support Strategy Sub Group

Terms of reference

Overview and Aims

The aims of the Housing Group are:

- For people with a Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions to be offered a greater choice over where and how they live.
- To develop a local housing and support strategy for people with a Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions.
- To ensure all other strategies and plans that will influence the future commissioning of care and support services are linked together.

Objectives

- To work closely with other services to use a co-ordinated approach to housing and support options for people with a physical disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions.
- Maintain an oversight of how services are meeting the needs of people with Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions.
- To work in partnership with stakeholders to develop opportunities for delivering joined up approaches for service delivery, commissioning and monitoring services.
- To work in partnership with strategic stakeholders to ensure housing and support strategies / plans are co-ordinated across Torbay and to ensure Supporting People services continue to contribute to other key strategies on social inclusion, health and social care.

Accountability

The Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions Housing and Support Strategy Group aims to meet the requirements of the Supporting People Commissioning Body.

Role and responsibilities (of the group)

All Group members:

- To represent the views and experiences of the service user group / sector they work within.
- To ensure 2 way communication between the service user group / sector represented and other members of the group.
- To provide feedback on consultation / draft documents as required by the strategy group to ensure the aim of the group is achieved.
- To attend 75% of strategy group meetings. If the named person cannot come to the meeting, they should ask a representative from their organisation to come instead.

Chair Person

The Chair Person of the Strategy Group will be elected annually. When the Chair person is not at the meeting, the Deputy Chair Person will take on all responsibilities for that meeting. The Chair person will write the Agenda in consultation with members and will include any items agreed from the previous meeting. The Chair Person will make sure everything on the Agenda is talked about in the meeting. The Chair Person will make sure everyone has a chance to say what they think about items on the agenda. The Chair Person will attend the Supporting People Bi-annual Chairs Meeting.

Deputy Chair Person

The deputy chairperson will be elected annually and will undertake the duties of the Chair Person when the Chair Person is not available.

Minute Taker

The minute taker will be elected annually. When the minute taker is not at the meeting, the Chair will elect a minute taker for that meeting. The minute taker will take notes of the main points of the meeting and write action points that say who has responsibility for doing the piece of work. The minutes will be written so they are easy to understand.

Service user involvement and representation

Meetings will be made accessible to people who represent Supporting People service users. Accessibility will be considered when booking venues for meetings & preparing any written information. Aids & adaptations will be made available if required and service users representatives will be supported to take part. Service User representatives will be supported before and after the meetings by the Chair to prepare and de-brief and ensure active participation.

Guidance on making meetings easier to understand will be followed. (See Appendix B)

Membership

Due to the size of the sector represented at the strategy group, membership will be split between people who attend meetings, and people who are 'virtual' members and thus receive all paperwork but do not attend meetings. Responsibilities of membership are the same as those listed above, excluding attendance at meetings.

All members of the groups will receive minutes and papers relating to meetings and the development of the strategy.

The overall membership of the Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions Strategy Sub Group will include representatives of following bodies:

- Torbay Care Trust commissioning team

- Specialist service team representatives
- Supporting People provider organisations
- Voluntary Sector Services
- Representatives of people who use Torbay services, including Supporting People services
- Carers of people who use local Supporting People services
- Torbay Council Supporting People Team
- Torbay Council Housing Services
- Representatives of Torbay Housing Provider
- Care Trust Zone Representatives

Organisation

The membership of the group will be reviewed annually. The Group will be accountable to the Supporting People Commissioning Body. Requests for work will be recorded in the meeting minutes of the Commissioning Body and passed to the Chair of the Housing group.

Frequency and structure of meetings

Frequency

The frequency of meetings will be agreed by the Housing Group members and will reflect the needs of the group. Meetings will be held at least every 12 weeks.

Conflict of interest

Strategy Sub Group members will be subject to Torbay Council's code of conduct and procedure for registering outside interests. Group members will declare personal interest in any item under discussion and absent themselves from the whole meeting or part of the meeting while the subject is being discussed.

Structure

For the avoidance of conflict of interest, the meeting shall have a Part B closed session involving strategic partners not directly involved in Service Provision. Supporting People providers will not be admitted to the closed part of the meeting where sensitive information, including individual service reviews and tenders, will be discussed.

Agenda and Minutes

The Agenda will be sent by the Chair person. The Agenda will be sent to members no less than 7 days before the meeting date.

The minutes will be sent by the minute taker. Minutes of the previous meeting will be sent to members no more than 10 working days after the meeting is held. The minutes will be sent electronically (where possible) or where not possible, in the format preferable to individual members of the group.

Appendix A

Physical Disability, Sensory Disability, Acquired Brain Injury and Long Term Conditions Housing Strategy Group membership 2007/08

Group attendance membership details

Interest Represented	Name	Title	Organisation	Contact details
Supporting People	Shelley Brown	Service Development Officer	Torbay Council	Shelley.brown@torbay.gov.uk
Supporting People Service User Group	Anna Howlett	Service User Representative	Supporting People Service User Group	Via Supporting People service user involvement worker
Sensory Service	Katy Heard	Sensory Team Manager	Torbay Care Trust	Katy.heard@nhs.net
CFS/ME	Lyn Hunter	CFS/ME Service Manager/Lead Clinician	Torbay Care Trust	Lyn.hunter@nhs.net
Supporting People Provider representative	Marjorie Hodgson	Area Manager	Westcountry Housing Association	Marjorie.hodgson@westcountryha.org.uk
Supporting People Provider representative	Joanne Egan	Manager	Riviera Support Ltd	joanne.egan@btconnect.com
Disability sector	Steve Gale	Manager	Disability Information Service	Steve.gale@torbay.gov.uk
Acquired Brain Injury Team	Jacqueline Whittaker	Manager	Acquired brain injury team	Jacqueline.whittaker@nhs.net
Care Trust Commissioning	Lin Walton	Development Officer	Torbay Care Trust	Linda.walton@torbay.gov.uk

Care Trust Zone representative - Paignton North and South Zone Teams	Deserie Atkins	Social Care Lead	Torbay Care Trust	deserieatkins@nhs.net
Housing Services – Affordable Housing	Liam Montgomery	Affordable Housing Co-ordinator	Torbay Council	Liam.montgomery@torbay.gov.uk
Hospital Discharge	Tim Gainsford	Manager	Torbay Care Trust	Tim.gainsford@torbay.gov.uk
Housing Services – Housing Needs Service	Vijay Sirohi	Housing Needs Manager	Torbay Council	Vijay.sirohi@torbay.gov.uk
Voluntary Sector representative	Richard Shuker	Housing co-ordinator	Action for blind people	Richard.shuker@actionforblindpeople.org.uk
Carer representative	Vacant			
Housing Provider representative	Vacant			

Virtual Membership details

Interest Represented	Name	Title	Organisation	Contact details
Acquired Brain Injury Team	Jill Breeze	Occupational Therapist	Torbay Care Trust	Jill.newman@nhs.net
Carer representative	James Drummond		Torbay Care Trust	Jamesdrummond@nhs.net
Supporting People referral Hub	Faye Knowles	Interim Hub Manager	Torbay Council	Faye.knowles@torbay.gov.uk
Care Trust Zone Team	Alison Newell	Paignton North and South Team Manager	Torbay Care Trust	a.newell@nhs.net
Care Trust Zone	Mandy Seymour	Torquay South	Torbay Care Trust	Mandy.seymour@nhs.net

Team		Team Manager		
Care Trust Zone Team	Julie Hickey	Brixham and BEST Team Manager	Torbay Care Trust	Julie.hickey@nhs.net
Care Trust Zone Team	Dawn Collier	Torquay North Team Manager	Torbay Care Trust	Dawn.Collier@nhs.net

Appendix 2

Supporting People Service User Group

Making Meetings easier to understand guidelines

- Papers for the meetings should be sent out in advance so people can read them before they come to the meeting. There are often too many papers given out at the actual meeting.
- Papers for meetings should be put into a summary with bullet points
- Papers at meetings needs to use easier words instead of long words
- Refreshments should be provided
- Regular breaks should be taken – about once an hour
- People should be given a time limit on how long they can talk on 1 agenda item
- The Chair needs to keep everything concise
- The Chair should give a summary at the end of each item of what has been said and make sure everyone understands it and agrees with it
- A nice meeting room is important – enough space and a nice environment

February 2007

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

Issue	Solution	Comment
Knowledge/ skill		
Lack of knowledge by Zones/ frontline staff / the public re housing	<ul style="list-style-type: none"> • Housing Link Worker – improved training . information packs for Zones, housing handbook being produced by learning disability (how much can be generic / used?) • All agencies working cohesively – information / knowledge and clarity of roles – knowledge of what other agencies do • Not having so many anomalies – improved mapping and clarity • Improved information on bidding process – Riviera Housing Trust go out and meet Zones to understand the issues • Clarity of who pays for what (e.g. for a cleaner / for adaptations) • Independent housing with care/ support should be first solution • Independent Living centre 	
Not good knowledge / information sharing between practitioners, commissioners, service users	<ul style="list-style-type: none"> • Some Surgeries have support workers. Housing information / handbook to be made available / independent living centre for people to visit. Clear information to front line staff so they place people appropriately (knowing service expectations) • Improved knowledge of finance options e.g. Seeability support people to get mortgages • Plan ahead where possible – pro-active work with housing services 	
Lack of clarity on choice based lettings processes – who’s responsibility is it?	<ul style="list-style-type: none"> • Riviera Housing Trust to raise awareness of process including bidding, assisted bidding. • Active case management should ensure that bids 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

	are placed for people who need support	
Complicated process to get housing and support	<ul style="list-style-type: none"> • Housing handbook to help explain options. • Housing event to raise awareness. • Feedback to Housing Services to inform any future planned restructure of access to services 	
Understanding entitlement of people 'out of area'	<ul style="list-style-type: none"> • Awareness raising of Homeless statutory obligation on 'local connection' • Strategy to be clear about out of area 	
Information re the bidding process	<ul style="list-style-type: none"> • Riviera Housing Trust to undertake awareness raising. • Strategy to include process as appendix? 	
Peoples expectations unrealistic – clarity in information	<ul style="list-style-type: none"> • Managing expectations (e.g. not wanting 2nd hand goods) 	
Lack of clarity – who . which zone is responsible for individuals when they move around the Bay (e.g. when someone moves to re-hab)		
People believe there is an issue with how council stock is distributed – does this mean location or given out?		
Accessible/ affordable Properties		
Lack of adapted properties and range of adapted properties	<ul style="list-style-type: none"> • Adapted social housing should be for rental only – encourage people to move if they no longer need • Offer incentives to move on up to / down / out to free up adapted properties when no longer needed • Private provision of adapted property available to buy 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

	<ul style="list-style-type: none"> • More adapted properties • increase % of adapted housing • Build more/ More use of Brownfield sites? Do up empty properties • Bigger housing (3-4 bed) solutions so families can stay together • Sheltered accommodation to allow support dogs etc, and have facilities to enable this (garden space) • Involved OT at planning stages of accessible housing • Accessible housing from the start • Incentives to house share / rent out rooms • New housing – bespoke design • Adapted properties not to be re-let under general needs • Development of 3rd sector providers 	
Emergency Housing – not enough Hospital discharge process results in inappropriate use of residential placements	<ul style="list-style-type: none"> • more step up / step down • Temporary accommodation that is accessible (level access, walk in showers, pipe alarm etc) 	
Disabled Facilities Grant process – takes too long / individual at risk	<ul style="list-style-type: none"> • Knowledge about gadgets available • Discussion with DFG team about process / working together / improving processes 	
London 2 nd homes – people move in and this puts prices up		
Not enough places for young people	<ul style="list-style-type: none"> • Make sure young peoples services are accessible • Work with young people when leaving school to discuss housing options 	
Lack of suitable housing stock	<ul style="list-style-type: none"> • More choice of areas to live if improved use of 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

	<ul style="list-style-type: none"> private sector Better shared ownership schemes / knowledge of different ways of buying / renting etc – housing handbook Make better use of private sector 	
People use Disability Living Allowance to supplement housing	<ul style="list-style-type: none"> Ensure people are claiming all benefits they are entitled to Better understanding of housing benefit process 	
No spare capacity in housing	<ul style="list-style-type: none"> Scheme for sharing properties – linking people together (e.g. like a car sharing register) Need not just be people with Disabilities 	
Disabled Facilities Grant's not sufficient to access adaptations needs	<ul style="list-style-type: none"> Quicker, slicker Disabled facilities grant process 	
Best use of already adapted properties	<ul style="list-style-type: none"> Best use of already adapted properties Offer incentives to move on up to / down / out to free up adapted properties when no longer needed Need register of accessible housing in all tenures (nb. Is happening on properties in social housing sector as they come up – but what about all the others?) Register of people who are looking to move house (which is adapted) 	
People being stuck in housing no longer suitable	<ul style="list-style-type: none"> If have more adapted property you no longer need – get gold band to free up / move on for person who needs it? 	
Storage of wheelchairs / buggies	<ul style="list-style-type: none"> To be incorporated into new build design 	
Grouping people with similar difficulties particularly where there may be behavioural issues		

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

Private Sector		
Unethical landlords	<ul style="list-style-type: none"> • Compulsory accreditation of landlords – Scottish standard (Government decision not to make compulsory) 	
Vulnerable adults at mercy of unscrupulous landlords	<ul style="list-style-type: none"> • Working with landlords to encourage accreditation by only placing people with accredited landlords 	
Private landlords reluctant to take disabled people	<ul style="list-style-type: none"> • Increase work with private landlords • Work with private landlords to reassure them support will be available 	
Can't secure deposit – no credit, no fixed abode, stigma of being in re-habilitation	<ul style="list-style-type: none"> • Deposit guarantee scheme – to be available at the right time 	
People with mental health problems – private landlords reluctant to take people		
Private rental is expensive in the Bay	<ul style="list-style-type: none"> • ? will the changes to housing benefit make a difference to people's ability to rent in the private sector? • What is the scheme Teignbridge piloted? • Is there any leeway in Housing benefit system to allow greater rent for people with disability to get properties? 	
Appropriate Support		
Cognition issues in a range of conditions create additional problems within understanding housing processes – often hidden or not acknowledged difficult to give support	<ul style="list-style-type: none"> • Skill of Hub / professionals to identify people with cognition issues who need support and direct them appropriately Better advocacy support and identification of people who need it • Better advocacy support and identification of people who need it 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

	<ul style="list-style-type: none"> • High level floating support • Joining up care and support to ensure people needs are met 	
Lack of appropriate intensive support at point of life changing events produces poorer long term prognosis	<ul style="list-style-type: none"> • Improve levels of support through process (e.g. as done for re-hab of offenders) • Safety net in system • More enabling services 	
Lack of emergency support – when need increases		
Not enough high supported accommodation to move out of residential care / hospital	<ul style="list-style-type: none"> • Support / care workers move in with people – rapid response 	
Need for age concern handyman service for people with disabilities	<ul style="list-style-type: none"> • Find a way of extending the age concern type handy person scheme to cover other groups 	
Not enough step up / step down	<ul style="list-style-type: none"> • Halfway house to plan appropriate housing with focused move-on outcome 	
Problems when people have multiple conditions (drug / alcohol / ABI / Offenders)		
Sudden onset of conditions changes lifestyle / needs. Speed of possible change eg overnight with ABI / finance changes at time of great stress	<ul style="list-style-type: none"> • Baytree style training / assessment flat • Support / care workers move in with people – rapid response 	
Communication and accessing services particularly hearing impaired / no signing wardens /	<ul style="list-style-type: none"> • Hearing impaired support – Supporting People floating support service • Supporting People contract to increase level of 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

format of documentation	<ul style="list-style-type: none"> signers • Develop natural support for signing community • People choosing their staff • Less jargon 	
	<ul style="list-style-type: none"> • Support needs to be holistic 	
People offered unacceptable accommodation	<ul style="list-style-type: none"> • Information given by people needs to be checked / supported by Care Trust workers for accuracy or a practitioner needs to accompany person to housing / hub interviews 	
<u>Data/ long term planning</u>		
Complex cases often placed out of area – at great expense	<ul style="list-style-type: none"> • Reduce costs and bring back out of area placements to free up funding • Find out size of this problem • improve specialist housing options in Bay for complex cases to reduce number of out of area placements • More consultation with tenants about their needs • Supporting People accommodation based service for 4-6 units 	
Not enough young residential places	<ul style="list-style-type: none"> • Needs analysis – needs more reliable data inputting 	
Problem of people moving into the Bay?- How real is this / what is the size of this problem	<ul style="list-style-type: none"> • Clarity about ‘out of area’ policy / local connection and expectation management 	
To set a % of accessible housing need to know the need	<ul style="list-style-type: none"> • Needs data gathering – referral hub, Supporting People service performance data, commissioning officer gathering data • Plymouth building for 20% build for life – improved data to establish is our 5% enough 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

Rise in obesity levels – are we considering this?		
Not enough money invested	<ul style="list-style-type: none"> Increased awareness of issues at senior management / political level – shadowing / place stories in strategy 	
Process Issues		
Maintenance of equipment		
Move-on <ul style="list-style-type: none"> people in residential care not entitled to Supporting People If you're not homeless you don't get on housing list (myth – you will be prioritised in banding appropriate to your needs) People in Dragons Tail not urgent but if moved would free up space 		
People have to be homeless to be housed – particularly young people moving on from home		
People go round in circles	<ul style="list-style-type: none"> Good complaints procedures and support to access this 	
Systems reactive not proactive	<ul style="list-style-type: none"> Pro-active approach – discharge person needs to take ownership until the persons needs are met – ensure handover process in place – don't just send people to other departments 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

Rules get in way of common sense		
Hospital discharge process does not plan for housing from the start with relevant stakeholders. Discharge times do not allow for this either.	<ul style="list-style-type: none"> • Put housing advisor into hospitals – encourage people to start processes earlier rather than later • ABI – early intensive support to improve long term outcomes • Emergency / short term housing for when people leave hospital • Hospital discharge – half way house 	
Consistency – by the time people are reviewed their social worker has changed		
No robust move-on policy from SP / re-hab when service no longer needed		
'hidden' people – people living in inappropriate settings fall off the housing radar (e.g. people living in residential care)		
Sometimes long waiting lists for OT assessments		
? capacity within Zone / social care teams to reviews peoples needs annually (anecdotally this does not happen – why?)		
People make themselves homeless to get housing – is this true? Do the rules encourage this?		

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

Funding streams / budgets	<ul style="list-style-type: none"> • Increase use of Individual Budgets 	
People present at GP's but no-one to help them Timescales (forced sudden life changes)	<ul style="list-style-type: none"> • Benefits agency – community liaison officer 	
Residential homes are not contracted to provide move-on		
Waiting times / peoples needs vary whilst waiting		
Issue for active case management to monitor changes and support and ensure housing applications kept up to date If homeless, problems with jobs and benefits	<ul style="list-style-type: none"> • Person centred awareness training for staff (part of care trust training ensure assessments are individual and personalised) 	
Social and Community		
Culture has changed – not so helpful ?? Who / What		
Volunteers don't want to do CRB / Health and Safety		
Recruiting good staff is difficult		
Community perceptions / lack of community		
Isolation	<ul style="list-style-type: none"> • Work with communities to improve understanding and support networks Simplify volunteers process – build information community networks • Build appropriate housing at same time as community facilities – strategic planning 	
People don't want 2 nd hand		

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

goods		
Vulnerability of this group – most social housing that becomes available is in less desirable areas	<ul style="list-style-type: none"> • Better understanding by support workers of likely neighbourhood issues, to consider supporting people with bidding. Understanding of particular client vulnerabilities 	
Disabled people aren't allowed to take risks	<ul style="list-style-type: none"> • Education of expectation – the right of young disabled people to take the risks other young people take • Opportunity to try / experiment with options 	
People feel stigmatised by asking for support with housing	<ul style="list-style-type: none"> • Cultural attitude change 	
Not enough signers in the community	<ul style="list-style-type: none"> • Increase numbers and understanding of signing in the community Improve education and understanding- signing can now be studied as a second language at school., • Liverpool used to count signing and lip reading as a socially useful adult ed class like adult literacy and provide it at subsidised minimal cost to level I. 	
Other issues:		
People living in squalor invoking Section 47 ????- does anybody know more detail on this??	<ul style="list-style-type: none"> • Increase powers of local authority to increase housing standards (?how much of an issue? People need to understand current processes – poor housing would equate to gold band / emergency card) 	
People who own their own home can be 'poorer' than those in rented on benefits and eligible for less help		

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

	<ul style="list-style-type: none"> • Mayor – needs a caseworker ???- didn't understand this point? 	
	<ul style="list-style-type: none"> • More money • Ask people what I think would make a difference • Pro-active strategy • Mapping services / identify gaps / levels of need for strategy • Meaningful consultation and involvement of people with disabilities in consultation • Pick 1 or 2 projects / targets and see through thoroughly • Take a look at good practice in other areas • Improved commissioning / to ensure services clear about what they do / are paid for and how they fit with other services Disabled people getting involved in housing design • To provide statistics on need to support request for increase to 5% new build accessible target • Improve links between commissioners, SU's practitioner to ensure appropriate range of services are commissioned • Outcomes based commissioning to support moving people out of residential care • Good contract management 	

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

What housing do people want?

ENVIRONMENT

- Secure
- Safe
- Bus route / post office / health care
- Part of community – mixes, people not segregated
- Some groups may want to co-locate – deaf, older, younger
- Support in the community / floating support / domiciliary care – emotional, physical understanding and practical support
- Access to support to be 24 hours
- Own space
- Range of environments – some people struggle with noise etc – e.g. ABI
- Close to original home / community – maintain familiar environment and social networks
- Social environment – young people in younger community. Age specific accommodation
- Housing with opportunity for live-in support
- Accessible properties near family / friends and not be shunted off
- Personalised

ACCESSIBLE

- Level
- Dropped curbs
- Wheelchair accessible – all above not just in the stipulated properties but in the area so people can visit friends etc
- Telecare
- Improved door entry systems from build – cheaper in long run
- Incorporate equipment into refurbishment schedules – don't wait for things to break
- Street lighting
- Paint curb edges
- Wet rooms
- Door width
- Properties for life
- Storage – bulk storage space (e.g. medical supplies)

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

- Consider needs of bariatric (obese) – wider wheelchairs etc

CHOICE

- Temporary
- Family properties
- Single parent families
- Single people
- Step up / step down
- Independent Living flats
- Small shared housing
- Range of tenures / purchasing
- Affordable
- Choice
- Better information for parents of choice, including inheriting tenancies, Trusts
- More flexibility in criteria for sheltered housing

What works well

- Aid Call / community alarm
- Telecare
- Housing support officers
- DIS
- Health centre information
- CAB
- Folks @ Home – Supporting People floating support service for older people
- Age concern handyman service – older people only
- Points system – old way of allocating housing
- Fire officer / local police / street wardens / Ward Partnerships
- FAB
- Living Options
- Advocacy

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

- Specialist services are good but need better links to other services
- SPLASH
- ACE
- We need to ask people who are using services
- Buckland Estate – Teignbridge – has a warden that pulls together a supportive community
- Enham Estate – Completely adapted village – factories, ind - ??? more detail please???
- Carers breaks / sitting
- Carers register
- Plymouth DAN – Disability Action Network
- DIAG – Disability Information Advice Group
- Rent / Buy
- Seeability – mortgage
- BIRT – housing for people with ABI – is this out of area could they move in?
- Dragons Tail – supporting people accommodation based service
- Direct payments
- Transitional services, e.g. BIRT, Phoenix House, Hill Mount
- New strategy group
- Accredited landlords
- Supporting People referral hub
- Floating support services
- Neighbourhood network schemes, e.g. Keyring
- Stepping Stones – Plymouth
- Trusts are Us – Somerset
- Teignbridge move-on
- Sandwell – supporting people to buy properties individually or as a group

Myths?

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

- People 'at risk' of going into rehab / prison are higher rating than for example someone with a visual impairment – Choice based lettings medical / vulnerable panel awards higher bandings for people based on information received with application in support of higher banding request
- Political reason not to put people on emergency list – Housing Services have a statutory duty to accept homeless applications. Emergency cards in choice based lettings are awarded based on information received with the application.
- People will lose benefits if they volunteer
- Not having so many anomalies ?
- Housing floating support workers not available for people in private rented – floating support workers can work with people living in any tenure except registered residential care / nursing care.
- Disabled facilities grant not available to owner occupiers – DFG are based on financial assessment and levels of savings, this is the same for people who own their property of rent in the private sector. People on benefits would have had savings assessments to be eligible for benefits.
- Levels of empty properties? – We need to find out the statistics on this
- Support to ensure form are filled out correctly – people don't always tell the truth

Issue Park

Need more knowledge about older people. – There is a housing and support older persons strategy group like the one for this sector. Each strategy group recognises there is cross-over between sectors. The Chairs of each strategy group meet with each other to discuss common themes and joint working opportunities. Supporting People Officers are also able to work together to highlight any cross-over. The following strategy groups are in operation:

- Physical disability, sensory disability, acquired brain injury, long term conditions
- Learning disability
- Children and families (includes young people and domestic abuse)
- Homelessness and criminal justice
- Older people
- Mental health

Additional support

Physical disability, sensory disability, acquired brain injury and long term conditions – flipchart notes from meeting on 11th January 2008.

- Day care
- Day activities
- Employment
- Benefits trap
- Social activities accessible
- Transport

Appropriate training for emergency crews, e.g. hoists

Need for 3 to 4 bedroom properties that are accessible

Feedback on accessible housing specification

- Do new build specifications fit in with local authority housing targets? Limited land space dictates houses built on as small an areas as possible not allowing for car parks etc. are planning department and edevelopment control council members on board with this strategy?
- Rumour hs it that private landlords cannot refuse any request for an adaptation to be done on their property (by social services etc). Is this true?
- All properties to have background wiring for:
 - Community alarm
 - Fire alarm which can have vibrating alert plugged in
 - Decent door entry system
 - Portable door bell
- Need a minimum specification for lighting – both inside and out
- Need different specifications for community areas, e.g. shared areas, community rooms
- Drop kerbs need to be in whole development otherwise people can't visit other people – drop kerb shouldn't just be outside the 'accessible house'
- Needs to be higher than 5% especially as increasing age of population and moving people out of residential care

Dragons Tail and SPLASH service user meeting (11-02-08) – 10 service users
Torbay Council – Disability Community Group – (02-02-08) – Torbay residents 9

Problems

- Lack of accessible family properties
- Properties not suitable for disabled facilities grant
- Homefinder – some people don't have access to a newspaper or can't get out of the house to get one
- Variability of information given by Homefinder
- Assumption that disabled people don't have families
- Size of 1 bedroom flats don't reflect needs of couples
- Living in dragons tail is meant to be a stepping stone, but there's no where accessible to move on to
- Hidden need – people don't join Homefinder because don't see the point as there's so little housing
- Homefinder website doesn't say the date for the next set of available properties – only says closing date.
- Need support to learn how to live independently, how to set up house – gas, electric, applying for telephone etc
- Riviera Housing have not been helpful
- Trying to get the right carers – there are a limited number of carers in Torbay
- Carers who do not have English as a first language – can make it difficult to explain what care / support people want. Its very tiring for people to try and translate / make themselves understood
- How do young carers find having paid carers in the house
- Training for home care seems to be hit and miss
- Services are arranged around the service provider, not the service user.
- Getting to shops – can / do shops come to you?
- DWP, not helpful
- Lack of knowledge about services - you have to receive a service before you find out what other support could be available.
- Not everyone is on the internet.
- What does floating support mean?
- People want to move to residential care
- Not always appropriate for people to stay in their homes
- Any accessible housing is in sheltered schemes, people are too young to live here
- Developers are allowed to build housing that is not suitable for wheelchair users – steps leading up to property, lack of turning space inside housing
- No level thresholds
- Accessible housing needs to be in all areas
- RADAR toilets are too low
- Disabled people need to be involved in the design of new builds (but are wheelchairs allowed on site?!)

- Disabled Facilities Grant process is long process, but is it realistic to be able to speed the process up? The outcome is good.
- Equipment budget – things are too expensive so Occupational Therapists can't buy them
- Minor things can be achieved but big adjustments more difficult
- People using DFG are given the list of approved builders and its for the person to liaise with direct – some people will struggle with this
- People don't always know what grants are available
- Accessible housing needs to take account of environment, e.g. views – as disabled people spend more time at home so don't want to be looking at brick walls
- Lack of information about accessible housing – should be available in all formats
- Little knowledge on appeals for banding on Homefinder – people don't know how to have their banding increased
- People listen to complaints but don't do anything about it
- When new housing plans go for approval, who is consulted about how accessible it is?
- Sometimes people need 2 bedrooms – 1 for a carer
- If you have a disabled facilities grant you have to stay in the property for a certain amount of years unless you have special circumstances – people can understand this
- Peoples needs change over time
- New builds need to consider the needs of people with hearing impairment
- Build for life standards are not compulsory
- Who enforces the rules about the number of accessible properties and what are the consequences for not following the rules?

What types of housing and support do people want?

- Housing needs to be in the community
- Access to facilities – community centres
- Close to town centre
- Less need to use taxis (which are expensive)
- Near bus routes – need more bus routes
- Range of properties
- Services closer to home in different areas, like education opportunities
- Support to join community activities / groups
- Help understanding letters – its confusing getting letters from different organizations, some letters are worrying (automated)
- More information about services –Annual calendar produced by the Council with useful contact numbers.
- Information from Connections.

What works well? / ideas for future

- Distribute housing newsletter

- Support worker has helped
- In Reading they have a disability register that holds information on all available accessible housing (social housing, private rented, properties for sale). People who want information about accessible housing can use this to inform choices.
- Handbook of how to set up house
- Support workers
- Increase the capacity / number of carers available with good training
- More choice and in control of carers who support people
- More training for care / support workers
- Your own space – own front door to shut
- Independent living
- Support to learn independent living skills – little things like using ‘helping hands’
- Being on your own at night
- Big jump residential care to independent living – need another Dragons tail that is short term
- Step down and move on
- When paying own staff better control over hours workers because not on rota so not rushing to other clients
- Better communication within organizations / offices – offices don’t know what other offices are doing
- Isolation ???
- 0870 phone numbers are expensive – need someone to explain phone numbers.
- Disabled people / wheelchair users to be involved in new housing build to be realistic about how wide doors need to be. How much turning space is required etc
- Tweenaway service works well – 24 hour on-call, care delivered to meet peoples needs (workers can notice deterioration)
- Improved choice
- Mixed communities
- Lots of people need to be consulted
- Should design new build housing around individuals
- In Cornwall they are building flats that have a bedsit space above the property for a carer to stay in, so they are on-site but not invading the persons home

Don't push me around!

Disabled children's experiences of wheelchair services in the UK

Neera Sharma with Jan Morrison

Whizz-kidz
move a life forward


Barnardo's
GIVING CHILDREN BACK THEIR FUTURE

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Foreword

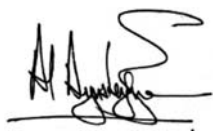
Barnardo's and Whizz-Kidz have collaborated in the production of this report to highlight their concerns about the current state of wheelchair provision for children in the UK and the need for urgent action.

There are around 770,000 disabled children in the UK, (Department for Work and Pensions, 2005) which equates to around one in twenty children. Although reliable statistics are hard to come by, it is estimated that at least 70,000 disabled children would benefit from wheelchair and mobility equipment that meets their physical and lifestyle needs (Social Policy Research Unit, York University, 1995).

A number of official reports and publications over the past 20 years have highlighted the shortfalls (McColl, 1986; Audit Commission, 2000, 2002; emPower, 2004; Prime Minister's Strategy Unit, 2005), yet in that time there have been no significant changes in the delivery of wheelchair services, with the result that disabled children and young people are still facing numerous difficulties in being provided with the right mobility equipment at the right time.

Despite a policy and legislative framework that supports better mobility provision, and evidence of the importance of mobility in a child's development, the experience of many disabled children is that the NHS does not provide them with a wheelchair that meets their needs. *Ordinary lives: disabled children and their families*, from New Philanthropy Capital (Langerman and Worrall, 2005) found that 'many disabled children do not get the equipment, therapy or communication aids they require. This can slow their development and limit their capacity to take part in everyday activities.'

Barnardo's and Whizz-Kidz want to ensure that disabled children who need wheelchairs are provided with the right equipment, when they need it and without undue delay. Without a change in the way wheelchairs are currently provided, disabled children will continue to lose out on vital opportunities to develop their potential and to achieve the outcomes envisaged for all children in the United Nations Convention on the Rights of the Child. We believe that disabled children do matter and through this report are calling on those who can make a difference to ensure that disabled children don't lose out.



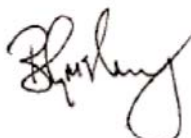
Professor Al Aynsley-Green
Children's Commissioner for England



Peter Clarke
Children's Commissioner for Wales



Kathleen Marshall
Scotland's Commissioner
for Children and Young People



Barney McNeany
Acting Commissioner and Chief Executive
Northern Ireland
Commissioner for Children and Young People

Summary

This report has been written by Barnardo's and Whizz-Kidz in order to bring about change in wheelchair service provision for disabled children with mobility needs in the UK.

In the absence of rigorous evidence in this area, the report is based on the experiences and difficulties of disabled children and young people known to both charities. Whilst the report recommends that the Government commissions research into the organisation, delivery and impact of wheelchair provision for children, Barnardo's and Whizz-Kidz believe that the voices of disabled children and their families must be heard now, as reform and improvement is urgently needed. Without it, disabled children with mobility needs will continue to lose out, not only on their personal development and childhood, but on opportunities to become more independent as adults.

Supported by the Children's Commissioners in each of the four nations, the report firstly examines how wheelchair services are organised across the UK, and the variations in provision and eligibility criteria which result in geographical inequalities. Through surveys and case study information the report then outlines the difficulties children and young people experience, including waiting times for assessment, provision, replacement and adaptation; and the unsuitability of wheelchair provision which is based solely on clinical need, does not always include essential accessories, maintenance, insurance and training, and fails to take account of the choices and preferences of children and young people.

In order to bring about change, all four nations need to implement now the recommendations on equipment contained in the report from the Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*. Barnardo's and Whizz-Kidz are further recommending that a system is put in place for collating data on the number of children needing wheelchair provision and that adequate funding, specifically for children's provision, is made available. The report also calls for benchmarking of wheelchair provision, to include specific targets against which services for children are monitored, and concludes with recommendations which are specific to each nation.

Barnardo's and Whizz-Kidz are calling for the voices of disabled children and young people concerning their experiences of wheelchair provision to be heard and acted upon now. If they are not, they will not achieve the positive outcomes and equality of opportunity envisaged by the Westminster Government and the devolved Governments for all the UK's children.

Chapter 1

Introduction

Barnardo's and Whizz-Kidz have produced this report in order to achieve better outcomes for disabled children and young people who need wheelchairs. This includes those who use or would benefit from both powered and manual wheelchairs, and those who require a wheelchair either some or all of the time.

Currently, the experience of many disabled children is that they are unable to get a wheelchair appropriate for their needs, when they need it. Whizz-Kidz only provides mobility equipment to children and young people whose needs have not been met by the statutory services. An increased demand on its service gives a clear indication that the NHS is failing many families. 1541 families who have been helped by Whizz-Kidz were sent a postal questionnaire in August 2005. Of the 350 families who responded, 54% said their local services could not provide the desired equipment and 47% were told that budget restrictions prevented their child's individual needs being met.

Although there have been local initiatives and a wide variation in service commissioning, the funding formula for wheelchair services has not been reviewed since 1991, despite the increase in the numbers of disabled children and improved wheelchair technology: an electrically powered indoor outdoor chair (EPIOC), for example, can cost anything between £2,500 and £18,000. A description of the different types of NHS wheelchairs can be found in Appendix 2. The previous Government introduced a voucher scheme into NHS wheelchair services in 1996 and, at the same time, announced additional funding for the provision of EPIOCs. However, this additional funding was only ring fenced for four years, after which it became absorbed into general wheelchair funding. Vouchers continue to be offered by many wheelchair services but, under the scheme, families usually have to top up the funds themselves (either through their own income or charitable funds) as the amount awarded rarely covers their child's holistic needs.

The under-funding of wheelchair services, which must cater for the needs of both adults and children within their localities, has led to strict eligibility criteria. This often discriminates against young children in particular, leading to inadequate or no provision, despite all the evidence of the importance of early intervention. Early intervention is emphasised in Standard 1 of the *National Service Framework (NSF) for Children, Young People and Maternity Services*, which states 'The health and well-being of all children is promoted and delivered through a co-ordinated programme of action, including prevention and early intervention wherever possible, to ensure long term gain, led by the NHS in partnership with local authorities'.¹

Additionally, provision focuses too heavily on clinical need and often fails to take into account a child's individual developmental, educational and social needs. The inability to participate fully in science or sports lessons or to take part in the social side of school life, due both to access issues and the need to have an adult assistant permanently present, makes friendships and inclusion much harder to achieve.

¹www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/ChildrenServicesInformationArticle/fs/en?CONTENT_ID=4089111&chk=U8Ecln

Although many staff working in NHS wheelchair services, and the Complex Disability Exemplar¹, recognise an inadequate service is provided to children, they are restricted by a lack of adequate funding and often support families to apply for charitable funds instead. The absence of benchmarking or a target-driven agenda for wheelchair services means that there is often little incentive or commitment for change at a strategic level and within commissioning processes. A recognition of such issues in wheelchair provision led to the establishment of the Wheelchair Services Collaborative in November 2002 to bring about significant improvements in services. Forty-five teams were set up at the end of November 2002 to bring about significant improvements in services. Developed in partnership with the NHS Modernisation Agency, the Department of Health and the Audit Commission, the programme made on average at least 25 per cent improvements in baseline performance in four areas: overall experience, minimising delay, efficient use of resources and outcomes. Although the work has been summarised into a good practice guide, further resources have not been made available to enable all wheelchair services to replicate the good practice model developed by the Collaborative (National Health Service Modernisation Agency, 2003).

The right wheelchair, when they need it, is obviously essential if children with mobility impairments are to achieve the outcomes needed by all children. Each of the four nations has a relevant strategy:

- England has the five outcomes of *Every Child Matters*: being healthy; staying safe; enjoying and achieving; making a positive contribution; and achieving economic well-being.
- Scotland has the *Vision for Children*, which includes achieving and being active.
- In Northern Ireland, a ten-year strategy is being developed by the Office of the First Minister and the Deputy First Minister. It will cover outcomes in relation to: health; education; learning and enjoyment; economic and environmental well-being; making a positive contribution to society; and safety and stability.²
- Wales has the *Seven Core Aims for Children and Young People*.³

The important characteristic of both powered and non-attendant manual wheelchairs is that they are operated by the children or young people under their own volition, thus enabling them to be as independent as is consistent with their age. The argument for early interventions where there are significant mobility impairments (particularly in the case of young children) is that such interventions can facilitate normal psychosocial development and help approximate the development pattern of non-disabled children (Warren, 1990). The NSF sets standards for early intervention.⁴



¹ DH/OFES, 2005

² <http://www.allchildrenni.gov.uk/strategy.pdf>

³ www.wales.gov.uk/subchildren/content/core-aim-e.htm

⁴ www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPAmpGBrowsableDocument/fs/en?CONTENT_ID=4094329&MULTIPAGE_ID=4865614&chk=ZKP5mL

Don't push me around!

The field of powered mobility for disabled children and young people is under-researched, although there have been a small number of studies looking at how children learn to use powered wheelchairs and the effects of wheelchair use on their overall development. The research evidence suggests that even very young children can learn to use powered wheelchairs and that enhanced mobility leads to positive benefits in other areas of development (Butler et al, 1983; Bottos et al, 2001; Jones et al, 2003).

Another area which is under-researched is the role of wheelchair professionals and their interaction with parents and children and to what extent they have differing perspectives. A study comparing parents' and therapists' views of their child's individual seating system (McDonald et al 2003) showed that parental concerns over their children's seating systems concentrated on functional day-to-day management issues, whereas therapists' concerns focused on technical issues and postural management.

However, both clinical studies and expert opinion support the view that children who lack independent mobility from an early age can develop 'learned helplessness', a condition that leads them to become uninterested, withdrawn and reliant on others. This condition can often last into adulthood. Disabled young people are over twice as likely as non-disabled young people not to be in education, employment or training (Godfrey et al, 2002).

A life without independent mobility means that disabled children essentially miss out on their childhood and it diminishes their life chances. Clearly, this has to change.



Chapter 2

The legislative and policy framework and the structure of services across the UK

This chapter sets out the legislative and policy framework and looks at how wheelchair services are organised across the UK. It is clear that variations in legislation and policy as well as in service provision, especially the implementation of different eligibility criteria for the provision of wheelchairs to children, is resulting in geographical inequalities.

The legislative and policy framework across the four UK Nations

Please see Appendix I for a detailed examination of policy and legislation across the UK.

A set of comprehensive recommendations in the report from the Prime Minister's Strategy Unit *Improving the Life Chances of Disabled People* (2005) is relevant across all four nations. In England, Standard 8 of the *National Service Framework for Children and Maternity Services* (Department of Health and Department for Education and Skills, 2004) sets out a number of actions for commissioners and providers of equipment, including wheelchairs. However, the NSF for Wales is much clearer and more prescriptive than the NSF for England as it sets out specific timescales for delivery. Scotland's recent *Additional Support for Learning* legislation places new responsibilities on Health and Education departments to work together to provide mobility equipment, if this is required to enable a child to access education. Scotland's current review of NHS wheelchair services has identified that children and young people represent a 'major gap' in existing provision. The provision of wheelchair services in Northern Ireland (NI) has been guided by legislation which includes disability legislation and children's legislation. Over a period of time, a number of reports have indicated a level of dissatisfaction among wheelchair users in NI.

The structure of wheelchair services in the UK

In England, the amount of funding to be allocated to wheelchair services is decided by Strategic Health Authorities, and Primary Care Trusts (PCTs) are then responsible for commissioning local providers of service. The responsibility for commissioning in Scotland lies with Local Health Boards, in Wales with Local Health Boards and Health Commission Wales, and with Social Services Boards and Trusts in Northern Ireland. Wheelchair services vary considerably in size from 1,500 to over 42,000 users. Their allocated annual budget has to cater for the mobility needs of both children and adults within their locality and, whilst age discrimination on its own is not permissible, many wheelchair services have adopted eligibility criteria that prevent children from being prescribed the equipment they need. Children who live in areas where wheelchair service provision is located within acute services fare particularly badly, as funding for their mobility equipment needs is competing with funding for acute needs, resulting in geographical inequalities of wheelchair provision.

Don't push me around!

In England, Children's Trusts should play a key role in commissioning wheelchair and mobility equipment across health and education and ensuring that it is provided by a workforce that is skilled in the equipment needs of disabled children. In Scotland, the Lothian Wheelchair Service (Enabling Technology for Children) has responded to users' concerns by separating children's provision from adult provision. It is disappointing that this service dedicated to children, the only one of its kind in the UK, has never been evaluated and still suffers from funding concerns.

Examples of the variations in criteria used by wheelchair services

In August 2005 Whizz-Kidz conducted a survey of wheelchair services in the UK, and the following summaries of the criteria used show the variations between different localities. Even where there is not a wide gap between different eligibility criteria, how the criteria are interpreted by professionals is key to whether children will get the service they need.



A wheelchair service in the South of England

Criteria for paediatric provision

The wheelchair service will endeavour to meet the child's clinical and lifestyle needs when the mobility is long term and he/she requires a wheelchair or buggy for independent mobility to self-propel or for transit purposes.

- When a child is unable to self-propel or has the potential to drive a powered wheelchair, that option will be considered.
- If a child cannot sit unsupported, or has the potential to develop a deformity, special seating is required, either cushioning or a seating insert to provide postural support. This could take the form of a commercially available item or a custom-built system.
- Buggies will only be provided for children less than 3 years of age if there is a specific need for postural support.
- Only one manual wheelchair or buggy will be supplied per child, to be used in all environments ie school, home.
- Double buggies are only provided when both children have specific clinical needs. Trays are provided for postural needs only.

A wheelchair service in the Midlands Region

Criteria for paediatric provision

'Non-powered wheelchairs are supplied for children following a clinical assessment. Provision will be made for all children who require special seating. Commercially available buggies will not be provided by the Wheelchair Service.'

EPIOC: 'Users who are assessed as able to use an EPIOC safely and independently within their home and local environment ... users who have the ability to manage the chair without supervision, except in the case of children, where parental supervision is needed.'

A wheelchair service in the South-West of England

Buggies and wheelchairs for children: 'The NHS criteria for standard wheelchair provision apply where the child 1) is unable to walk or has delayed walking ability or 2) has a medical condition that limits his mobility as compared to his peers, eg a heart defect, or 3) has postural requirements that cannot be met by a standard commercial buggy.'

Double buggies: 'their issue will only be considered in exceptional circumstances eg where both children have a mobility problem'.

EPICs [Electrically Powered Indoor Chair] (for children): 'will not normally be issued solely for use in a school environment'.

Some services set age limits. For example, one wheelchair service states that 'clients must be over 30 months of age'. The rationale behind this is that young non-disabled children will be in commercially available buggies or push-chairs at this age and therefore their mobility needs will be met in the same way as for all disabled or non-disabled children. It is therefore important to change this attitude so that independent mobility within the home is seen as important by professionals.

Many impose criteria for the use of EPIOCs which are the same as those used for adults, for example: 'All applicants will have a minimum of 6 months [sic] experience of using EPIC before they become eligible for an EPIOC assessment, unless they are already successfully using an electric wheelchair indoors and outdoors... clients will be assessed and be able to demonstrate road safety awareness'.

Clearly such criteria fail to take into account the fact that young disabled children, just like other children, are protected from risks such as road traffic by their parents. Whereas non-disabled children have opportunities to learn how to ride bikes or roller-skate under parental supervision, disabled children are prevented from engaging in activities which enable them to explore their surroundings by taking age-appropriate 'risks'. Denying disabled children mobility equipment when they need it means that they miss out on important developmental experiences, and this sets them apart from their non-disabled peers.

Chapter 3

Getting mobile: the experience of children and families

This chapter examines the findings from surveys carried out by Barnardo's and Whizz-Kidz. It is evident that disabled children are experiencing long delays in getting an initial assessment. This is often followed by a further protracted wait for the wheelchair or a replacement wheelchair to arrive. Even when the wheelchair finally arrives, there is no guarantee that it will be suitable and have essential accessories. Assessment is usually based on clinical need rather than on the voices and choices of children and their families. The entire process is stressful for the families involved. Most critically, it impacts on the outcomes for disabled children and denies them positive childhood experiences.

Introduction: the basis for this report

There is no substantial research on the effect of wheelchair provision to disabled children and young people and the commissioning of research should be considered as a high priority by the Government (Krey and Calhoun, 2004).

Statistics are not kept across all wheelchair services and levels of need (which might be reflected in referral patterns, waiting lists and receipt of service) are confounded by assessment and referral systems and local service criteria. All of these can influence whether a referral takes place (Nicholson and Bonsall, 2002; National Health Service Modernisation Agency, 2004; National Wheelchair Managers Forum et al, 2005; Stancliffe, 2003).

In the experience of Barnardo's and Whizz-Kidz it is not just the number of wheelchair-using children that is problematic to pin down. Data on the number of disabled children as a whole shows a worrying variance.

In the absence of such evidence, the information in this report is based on case studies, feedback and information from children, young people and their families known to Whizz-Kidz over the past three years and from a survey undertaken by Barnardo's during autumn 2005. Families known to 60 Barnardo's services throughout the UK were sent questionnaires relating to their experience of wheelchair services, and 35 completed questionnaires were returned. In addition to this, an audit conducted by Barnardo's of its services during summer 2005 showed that out of 45 services for disabled children, 448 children participating in these services used wheelchairs. From this number, 68 used powered wheelchairs, 58 children used both powered and manual wheelchairs and 322 children used manual wheelchairs. Only 18 of this total number of wheelchair users were aged under five. Nine children were waiting for wheelchair provision. The case examples from this report are from across the UK, but have been anonymised.

A synopsis of the findings from Barnardo's and Whizz-Kidz

The findings from these surveys show that despite the legislative and policy frameworks in each of the four UK nations, many children are not receiving timely and appropriate wheelchair services. Information from both organisations identified the following issues:

- Time delays: disabled children experience long waiting times for new wheelchairs, for assessments and for replacement wheelchairs and adaptations
- The right wheelchair for the right child: many children and families are not getting the right wheelchair and the essential accessories they need from the NHS
- The family's perspective and their needs as a family are rarely considered: related issues such as maintenance, insurance and training are often given low priority or are overlooked
- The voices and choices of children need to be given a much higher priority.

Time delays

Waiting times for new wheelchairs

“Why does it take so long when someone says it's a priority? Does it take nearly a year to get a chair? I had to be uncomfortable and sometimes housebound because it took so long to supply my chair, which is still not complete. Ideally I need an electric wheelchair as I am really heavy now for mum to push.”

(Child, aged 9, who has severe impairments and epilepsy)

The responses to the Barnardo's survey showed that families were experiencing variations in service, especially for receiving wheelchairs, referrals and replacement of existing wheelchairs. These children and young people waited a long time from the point of referral to getting their wheelchair. The average waiting time for respondents was six months, and this was followed closely by waiting times of between six and nine months. A 10-year-old boy waited 10 months for a powered wheelchair and 14 months for a manual on different occasions, although he was given a replacement. The shortest waiting time was for an 11-year-old child who received a wheelchair within four to five weeks from the order date.

Even when a wheelchair has been delivered there is no guarantee that the waiting is over:

“Current wheelchair approximately 4 months but it arrived and was wrongly fitted, had to be amended twice and we are still waiting five months later for the proper cushion ... we had assessments and then when the wheelchairs are delivered each time they have had to be readapted”

(Girl, aged 15, who has spina bifida)

Families can also experience difficulties when they need services in different geographical areas. The anomalies of wheelchair services, including different eligibility criteria, the geographical inequalities and repair and maintenance arrangements, mean that children and young people experience considerable problems if they change schools or go away from home to university. There is no standard agreement about which wheelchair service is then responsible.

Don't push me around!

“The system of having specific NHS areas dealing with the relevant wheelchair repair companies means that it becomes needlessly bureaucratic when a child moves temporarily out of the area, say to school or hospital/respice/hospice”

(Parent of a child, aged 6, who has multiple impairments)

It is evident from our findings that the good practice *Health Care Standards* for wheelchair services under the NHS are not being followed. These state the following minimum response times: orders from locally-held stock should take 15 working days; orders from manufacturers 30 working days; and made to measure between 30 and 65 working days (National Wheelchair Managers Forum et al, 2005).

Waiting for assessment

Many families experienced delays in being referred for assessment. For example, a girl aged 2 years and 9 months, diagnosed with non-ketotic hyperglycaemia (NKH), received an initial referral in the summer of 2005, had a fitting in October and was expecting her wheelchair to be delivered in February 2006. This child will experience a wait that equates to almost a quarter of her lifetime so far. The *Health Care Standards* (National Wheelchair Managers Forum et al, 2005) recommends a minimum waiting time of 15 working days from the receipt of the referral to assessment.

The parents of a twin aged 9 who has cerebral palsy and had been referred in August 2005 was still waiting for an appointment in December:

“Assessments need to happen much quicker as children grow fast and an ill fitting wheelchair can be damaging and painful”

(14 year old, who has cerebral palsy and vision impairment and waited eight months)

“The referral system must change, the time waiting to see someone regarding special seating is too long”

(Parent of a 5 year old child, who waited nine months)



Waiting for replacement wheelchairs and adaptations

As children grow or their needs change they require replacement wheelchairs. Again, responses to the Barnardo's survey showed that waiting times are often protracted. For example, one 6-year-old waited four months originally for a wheelchair and then two months for a replacement when it broke. Another 6-year-old who lives in foster care is using a broken wheelchair as he is expecting to wait three to four months for a replacement.

Whizz-Kidz will review the equipment it has provided as the child's or young person's needs change. Reviews can be requested by the family or local therapist and will be carried out in conjunction with the local wheelchair service where appropriate. However, Whizz-Kidz is dependent on charitable donations and therefore cannot always respond as quickly as it would like to.

The importance of early intervention

The Westminster Government and the devolved Governments have recognised the crucial role of early intervention. This is reflected in the English 10-year Child-Care Strategy and in Standard 1 of the NSF and, in Wales, in Standard 1 of the Welsh NSF and the Seven Core Aims for Children and Young People. The next phase of Sure Start will see local programmes being extended into a national network of 3,500 Children's Centres. These will build on the best of the Sure Start Local Programmes (SSLPs) which have been offering a wide range of early years, health, parenting and family support services to children and families in disadvantaged areas (Treasury and Department for Education and Skills, 2005).

The early lessons from the National Evaluation of Sure Start (NESS) show that high quality early education makes a real difference to the lives of children, particularly those growing up in disadvantage (www.ness.bbk.ac.uk). Disproportionate numbers of disabled children are growing up in poverty – 28 per cent of people with a disabled child in the household live in poverty⁵ compared with 21 per cent of households with no disabled children (Department for Work and Pensions, 2005). If the cycle of poverty and deprivation is to be broken it is imperative that disabled children have prompt access to appropriate equipment and that providers of early years services ensure their inclusion. The Sure Start Unit has published guidance for disabled children; this is to be welcomed but needs to include specific reference to mobility equipment.

The argument for early intervention where there are significant mobility impairments (particularly in the case of young children) is that such interventions can facilitate 'normal' development and help approximate the development of non-disabled children (Warren, 1990). However, this is dependent on the provision of the right equipment at the right time.

For young children, powered mobility is often the required response but it may be denied for reasons of training and safety. However, there is evidence that powered mobility is an intervention that provides young children with the means of independent movement and enables them to explore their environment. For example, a 20-month-old girl with type II spinal muscular atrophy was provided with a powered wheelchair; within six weeks she operated the wheelchair independently and, within six months, improved mobility and developmental changes were perceived (Jones et al, 2003). The majority of children can achieve a good enough driving competence, even those with a severe learning disability or motor deficit. Powered wheelchairs should not be seen as a last resort but as a means of providing efficient self-locomotion in children with a severe motor deficit (Bottos et al, 2001).

Disabled children who do not have adequate mobility for ordinary everyday childhood activities when using a manual wheelchair should be considered for powered mobility. Powered mobility for these children, especially young children, is crucial for cognitive development (Paulsson K et al, 1987).

⁵ Using the standard measure of 60 per cent of median income after housing costs.

The following case study illustrates the difference the right wheelchair can make to young children:

Sam is a 4-year-old boy who has cerebral palsy, which for him means he is unable to walk and is dependent on a wheelchair or being carried to get around. Before contacting Whizz-Kidz, Sam had an NHS wheelchair that he could only use inside. It was very difficult for his family to take him out and enjoy family activities together. He had to be pushed everywhere in a buggy. The NHS was unable to fund a wheelchair that would give him the freedom to become more independent.

A Whizz-Kidz therapist assessed Sam for a powered wheelchair that he could use anywhere – from small spaces in the house to outside in the park. His new wheelchair also has a riser to enable him to reach his easel to paint at school and be the same height as his friends. As soon as Sam received his new wheelchair, he showed how bright and inquisitive he is. One of the first things Sam did was to explore the kitchen for the first time. He was delighted when he discovered that he could reach his drink and fruit on his own.

Disabled children risk developmental delay if they lack the specialist equipment they need. The provision of specialist equipment – including communication aids, wheelchair services and prosthetics – can be delayed and may not be adequately adapted as the child grows (Audit Commission 2003). This means that it may not fit the child when it does arrive, and this has developmental implications for the child. This is important given the increase in numbers of technology-dependent children.

In a survey of 3,000 families with a severely disabled child, 77 per cent reported unmet needs for community equipment (Beresford et al, 2003).

The report from the Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People* (2005), makes a number of recommendations that we endorse:

- Equipment should be provided to disabled children promptly, based on a multi-agency assessment that occurred as soon as possible after the child's needs were identified
- Local Authorities, PCTs and, from their inception, Children's Trusts, should work together and with their partners to commission services strategically
- Disabled children and their families should have timely access to the equipment they need, when and where they need it. This will require common assessment processes and funding across health, education and social services, and will mean equipment must be updated and maintained without delay.

Messages from our findings

Children are waiting for long periods of time for initial referrals, assessments for equipment and actually getting their wheelchair or a replacement. Even when it does arrive it can be wrongly fitted. Better nationally collected data is needed on referrals and how they are processed, and how many children either experience unnecessary delays or are never referred for assessment because they do not meet the eligibility criteria of their local service.

The right wheelchair for the right child

“More choices of types of chair please. Give the right chairs to match children’s needs... re-design them so they are far more easy to lift and load, they fit the child better and are easy to adjust. Seats should always be padded! The seatbelt tangles in the arms, wheels and get trapped under the seat as it’s very poorly designed... oh and please do it quickly, before my daughter’s tumour claims her life, I’m not so altruistic I wouldn’t appreciate having it whilst we need it. Surely in this day and age, it is possible to design wheelchairs which pack away easily, are lightweight, robust, COMFORTABLE, ergonomically sound and aesthetically pleasing, trendy even!”

(Parent of a child, aged 6, who has severe impairments)

Just as parents are anxious to ensure that their child has properly fitted shoes, parents of disabled children want their children to have wheelchairs that ‘fit properly’ and are replaced as their children grow.

Professionals play a key role in working with parents to ensure that children are assessed for the right type of wheelchair and that regular assessments take place so that children can progress to different types of wheelchairs – for example from manual to powered. There are reasons why parents may not want their children to progress to a powered wheelchair and see it as a ‘last resort’ option, but there is evidence, although limited, that parents’ initial concerns are usually overcome when they see the positive effects of powered mobility. This includes increased personal control, independence and opportunities to participate in social activities (Wiaart et al, 2004).



However, there are complex reasons as to why children are not recommended a powered wheelchair by clinicians or why they don’t receive one even if recommended. These include funding restrictions, strict eligibility criteria and reasons related to risk and the need for supervision. Furthermore, professionals will often only provide a wheelchair once all attempts to get a child to walk have been frustrated (Guereete et al 2005; Nicolson et al 2002; Staincliff S. 2003).

The three major reasons why a child does not receive a powered wheelchair after having been recommended one include funding issues, lack of family support and transportation issues (Guereete et al, 2005).

The issues for children

Both the Barnardo’s survey and Whizz-Kidz data show that the criteria used by NHS wheelchair services impact on children in several ways:

- Children and young people often receive unsuitable wheelchairs or through assessment processes that often fail to look at the child’s future maximum potential, social, educational and developmental needs as well as assessing for physical comfort such as posture and seating
- Children and young people are often not provided with essential accessories or are provided with inappropriate ones.

Don't push me around!

The suitability of wheelchairs

The responses to the Barnardo's survey showed that four children were using powered wheelchairs, five were using independent manual wheelchairs and the remaining twenty had manually assisted wheelchairs.

There were 24 responses to the question, 'If you have received a wheelchair, does it meet your needs?' Nine respondents replied that it did, with some positive comments:

"Very impressed with the support, style and design"

(Parent of a child, aged 2 years and 9 months, who has had an initial referral and has been waiting for several months)

"Yes, my wheelchair meets my needs and helps me get to places ... it has made it easier for me to get around, and it has made me independent"

(Young person who has spina bifida)

"Yes, it has been adapted for my needs. I now have a chest harness, foot plates and some better wheels that don't puncture"

(Girl, aged 11, who has learning difficulties)

However, 15 parents, or children, stated that the wheelchair did not meet their child's needs:

"This Kid Active does not allow her to sleep in the wheelchair without difficulty"

(Parent of a child, aged 7, who has scoliosis of the spine and severe learning disabilities)

"No. It's uncomfortable. The handles are too low for pushing without bending. They are also too close together. The brakes constantly 'pop' off!"

(Single parent of two children, a boy aged 11, and a severely disabled girl, aged 6)

"Good for our daughter, but very heavy to be lifting in and out of the car"

(Parent of a 5-year-old child, who has multiple impairments)

"We need a proper wheelchair ... that I can push without hurting my back"

(Parent of a 22-month-old child, who has spina bifida)

"I HATE IT – NO – it's too big to fit into my spacious boot properly. I always catch some part of my body – fingers, legs, on it when loading it. It's very difficult to lift, as it's an awkward shape. I get dirty from the mud on the wheels"

(Parent of a girl, aged 6, who has severe multiple impairments)

The following case study from Whizz-Kidz illustrates the difference the right wheelchair can make:

Suzanne lives with her parents and older brother and sister, and although only 15, has multiple sclerosis, a deteriorating condition that has left her unable to walk. Whizz-Kidz has provided her with a manual standing chair which allows her to raise herself to the same height as her family and classmates, making it easier for her to join in lessons and conversations. Before this, she relied on an NHS light manual wheelchair and a standing frame that was so large and cumbersome that it was really difficult for her to use and it took up most of the space in the family's living room.

Essential accessories

Even when an NHS wheelchair has been delivered, parents can find themselves waiting for essential accessories such as footplates, trays, lights and indicators. Many parents end up paying for these themselves and they can be very costly. The average cost for a tray, for example, is £110, a full set of lights and indicators costs around £170 and an electric powered recliner £220.

“Still waiting for new footplates and brakes to be fitted and a power pack to help carers to push me”

(child, aged 11, who has severe epilepsy)

“Why are the accessories that are needed so expensive and why do these have to be bought? Why can't they be provided?”

(parent of a 6-year-old boy who has cerebral palsy)

The impact on families

Paying for additional accessories impacts on families with disabled children, many of whom already experience higher levels of poverty:

- Of all families in the UK who care for disabled children, 55 per cent either are or have been living in poverty (Gordon et al 2000)
- Research has shown that it costs on average three times as much to raise a disabled child as a non-disabled child (Dobson and Middleton, 1998; Gordon et al, 2000)
- Parents are often forced to go into debt to meet their disabled child's basic needs, while other non-disabled siblings simply go without (Dobson and Middleton 1998).

The Government has pledged to end child poverty by 2020 and to halve it by 2010. The latest figures show child poverty standing at 3.4 million – a reduction of 700,000 since 1996/7. However, the latest research shows that for any given level of qualification, disabled people are much more likely to lack work or to be in low-paid work. Of working-age disabled adults, 30 per cent live in income poverty, more than the 27 per cent a decade ago and double the rate for working-age non-disabled adults (Palmer et al, 2005).

Messages from our findings

The majority of children who responded to our survey are using wheelchairs which are unsuitable for their needs and those of their families.

Families are having to pay for essential accessories or go without, even though over half of them will experience poverty at some time. If the Government is to meet its target to end child poverty for all children, then no family should have to pay for any wheelchair equipment or accessories.

The perspective and preferences of children and families

Findings from the Barnardo's survey and Whizz-Kidz' data showed that when children and young people were assessed for wheelchairs by NHS services, the lifestyle needs or preferences of the family were rarely considered, and the educational and social needs of the children or young people were not taken into account. For example:

“No provision made for younger siblings when providing wheelchairs. We shall have to clip G's wheelchair to the baby's buggy”

(Parents of a girl, aged 2 years and 9 months and a son aged 5 months)

“It could do with a smaller tray. A modified headrest was also ordered and is being used now. That also took 3 to 4 months to arrive... and I am reluctant to order a new cover for his headrest, for instance, as I know it will take so long to arrive”

(Parent of a boy, aged 14, who has cerebral palsy and severe impairments)

“In many ways it has made life more difficult. Storage in the house is such a problem that it is kept in the boot of the car, more lifting and handling, as it is used every day, for going to school etc”

(Parent with four children, including 12-year-old twins)

The following case study highlights the importance of taking into account lifestyle and family needs:

Peter is a lively 7-year-old boy who has cerebral palsy, which affects his ability to walk; he can only walk short distances with assistance and gets tired very quickly. Before contacting Whizz-Kidz, he had a manual wheelchair supplied by the NHS, which meant that whenever he wanted to go outside, he relied on other people to push him. He was unable to join his friends for sports or at playtime at his mainstream school. Peter also has a disabled twin brother, which made it very difficult for his mum to take both boys out together since she could not push two wheelchairs at once.

The NHS was unable to provide the powered wheelchair Peter needed, primarily due to financial constraints. The powered wheelchair provided by Whizz-Kidz is suitable for indoor and outdoor use. It has a joystick so Peter is able to drive it on his own and his mum has her own joystick so that she can provide extra support if needed. Now the family can enjoy trips out together. For Peter the difference is huge as he has much more independence and can join in and play with his friends. At school he can join in at playtime, take part in PE and do the everyday things, like hanging up his coat.

Messages from our findings

Many children receive wheelchairs which are unsuitable for their needs and also do not meet the lifestyle needs of their families. This has particular implications for the health of parents who are lifting and handling heavy wheelchairs, and is a barrier to the social inclusion of disabled children and their families in everyday leisure and social activities.

Maintenance, training and insurance

The *Health Care Standards* for Wheelchair Services provided by the NHS recommend that, as good practice, the minimum waiting time for non-emergency repairs should be three working days, and 24 hours for emergency repairs/responses. However, our findings showed regional differences in the way that wheelchair services offer maintenance as well as training and insurance. Again, this results in geographical inequalities. For example, the responses to the Barnardo's questionnaires showed that eight parents, who all used the same NHS wheelchair service, were satisfied with the maintenance and training provided. However, responses from parents in other regions showed geographical variations:

“Training would be good if we were shown best ways to transfer our children in and out of chairs in a safe manner”

(Parent of an 11-year-old child, who has learning disabilities)

“No training – just shown how to open and close”

(Parent of a boy, aged 11, who has learning disabilities)

“NO! They do maintain the wheelchair but I have to wait weeks for an appointment and if I miss that it takes weeks again. I have to take the wheelchair to them. I think they should come to my home to maintain the chair and visit within 7 days ...the company should arrange regular servicing and take responsibility for that not leave it to parents (who usually have 100s of appointments to arrange!). Maintenance should be done quickly in the home or at school. WHEELCHAIRS SHOULD NEVER BE TAKEN AWAY FOR REPAIR ETC. UNLESS A PROPERLY SIZED REPLACEMENT IS IMMEDIATELY AVAILABLE” (Parent of a child, aged 6, who has multiple impairments)

“Maintenance is through a company contracted to do repairs for the wheelchair service. This contract is so poor and inflexible they are only available in the area for one day a week (Thursday). When the wheelchair needs repairing from the first visit to final repair, may be several weeks, from Thursday to Thursday ... to Thursday ...”

(Parent of a disabled child, aged 12)

The correct maintenance of a wheelchair is essential to ensure that maximum benefits are gained. Parents and carers require professional training to gain the competencies to do this. (Sawatzky B.J and Denison I, 2006)

Currently, if a child is provided with an EPIOC or outdoor powered wheelchair through the NHS or through Whizz-Kidz, the family must take out their own insurance. A five-year maintenance and insurance package for an individual family costs on average between £1,500 and £3,000, depending on the make and type of chair. Whizz-Kidz is looking to provide a maintenance and insurance package in the future to support families who struggle to meet such costs, ideally in conjunction with their local wheelchair service.

Whizz-Kidz runs wheelchair skills training for children using powered and independent manual wheelchairs.

Messages from our findings

The parents of disabled children lead busy and stressful lives with many hospital and other appointments to keep. Waiting for repairs disrupts the lives of children, stopping them from their daily activities such as going to school. High quality maintenance, training and insurance must all be part of the service package for children and families.

Children's voices and choices

Parents and children responding to the Barnardo's questionnaire were asked 'Do you like your wheelchair?' There were several positive replies:

Parents

“Yes. It's adjustable and easy to push” (Parent of a twin, aged 6)

“Without A's wheelchair we would not be able to go anywhere as A does not walk at all”
(Parent of a 12 year old girl, who has epilepsy and severe impairments)

“Actually, the family would like to say a big thank you to the Government and the local service”
(Parents of two boys, aged 19 and 13, who have severe multiple impairments)

Children and young people

This 11 year old was not completely happy with her wheelchair and wanted to 'see more good quality wheelchairs', but added:

“Because I can get tired quickly my wheelchair has allowed me to rest, and has also enabled me to go out with my family”

Another boy added:

“I can go out at anytime sitting in a good position, so that I am comfortable”
(Boy, aged 5, who has cerebral palsy)

Just as children and young people prefer to choose their own clothes, disabled children also have a right to choose their wheelchairs. Assessments based purely on clinical needs do not take into account their personal choices and lifestyle:

“Teenagers need a nice looking chair and one that's light for parents to push and lift into a car”
(Girl, aged 14, who has ADHD and epilepsy)

“But in the past I feel that I've always received an old fashioned chair and not one that appeals to children”
(Young person, aged 16, who has cerebral palsy)

Some examples of the positive impact of taking into account the choices and lifestyle of children and young people:

“My wonderful powered wheelchair from Whizz-Kidz has done what I hoped it would. It has helped with my choir and I can now sing at the same height as everybody else. It has helped my independence too. I love being able to tilt my seat backward to give my back a rest in the evening. My friends love the wheelchair too as I can now talk to them eye to eye instead of having them look down on me and I can drive along at the same height as them”

(Young person, aged 16, who has spinal muscular atrophy)

“My new powered wheelchair means that I can go in the playground and not get so tired – it is fantastic! I can go shopping without someone having to push me all the time and I can play basketball at my Saturday Club all by myself”

(Young person, aged 10, who has cerebral palsy)

Damian is a 16-year-old who is passionate about basketball. He plays matches twice a week, attends training sessions and is already a member of the Great Britain under 23s squad. Damian has a musculoskeletal disorder resulting in degeneration of the femur and severe pain on walking. He needed a high quality, high performance chair that would allow him to make the most of his skills and compete at a higher, possibly international level. Whizz-Kidz and the Lord's Taverners jointly funded a high spec sports wheelchair made to his specific size that meets sports regulations and his personal preferences.

Messages from our findings

Wheelchair services need to take account of children's preferences and give them genuine choice – and wheelchairs that are fashionable and trendy!

Achieving positive outcomes for disabled children: the importance of listening to children

Listening to children and families is crucial if positive outcomes for disabled children are to be achieved. This includes promoting participation and independence:

“I think the sooner a child gets a chair the more independent they get as the longer they wait the more they rely on parents and it is a lot harder to get them to be independent”

(Parent of a 22-month-old girl, who has spina bifida)

“It would make a considerable difference to increasing our child's independence and be included similar to his twin eg when on outings – currently he depends on an adult to push him”

(Parent of 9-year-old twins, one of whom has cerebral palsy, and has been waiting five months for an appointment to be assessed for a powered wheelchair)

Don't push me around!

Clearly, parents want independence for their children. Historically, disabled people have been treated as being dependent and in need of 'care' rather than being recognised as full citizens. This has meant that:

- Responses to needs have often created dependency, rather than promoting independence and extending opportunity
- Disabled people have been expected to fit into services rather than services being personalised to respond to individual needs
- Disabled children and young people are expected to fit into wheelchair services which are largely geared towards adults.

Independent living is about providing disabled people with choice, empowerment and freedom (Prime Minister's Strategy Unit, 2005).

There is evidence that providing appropriate equipment and adaptations increase independence, reduces the need for personal assistance and prevents or reduces health problems (Prime Minister's Strategy Unit, 2005).

There is a need for further research into what promotes independence and how it is defined. There are arguments for context-specific outcomes, defined by the young person and his or her family, which focus on meaningful outcomes such as levels of participation in home, school and community life (Palisano et al 2003).

The importance of participation is also emphasised by Law et al (2005). In a study of the factors that influence the leisure and recreational participation of children and youth who have physical impairments, the authors relate participation to children's health, well-being and development. They also argue that all children are different in how they participate in everyday activities, and that participation is best understood by exploring the perspectives of children and families within their unique environments.



Messages from our findings

Children's participation is key to achieving the positive outcomes for children set out in the UN Convention on the Rights of the Child (Article 12).

Conclusion

This report shows that wheelchair service provision across the UK is still failing many disabled children and young people:

- Disabled children are waiting for unacceptably long periods of time for assessments and for receiving wheelchairs or replacements – this impacts on their development and childhood experiences
- Wheelchairs are often unsuitable and lack essential accessories
- The social and other needs of the children and families, especially for training, maintenance and insurance, are often not met
- Children's voices and choices are seldom listened to
- There is a failure to assess potential
- There are geographical inequalities in the provision of wheelchair services.

The shortfalls were highlighted as far back as the McColl Report in 1986, yet despite increasing numbers of disabled children, an advance in wheelchair technology, progress towards inclusion and a developing rights agenda, there has been no major restructuring or resource investment into wheelchair services.

Disabled children with mobility needs will continue to lag behind their non-disabled peers unless this is addressed as a matter of urgency. They will continue to lose out on developmental opportunities and experiences during childhood, which for many will lead to dependence on others in adulthood.

As this report shows there are examples of good practice where services are bringing about the desired outcomes from the perspective of the child and family, and these good standards need to be translated throughout wheelchair services.

The policy and legislative framework to drive and support the modernisation of wheelchair service provision for disabled children is in place. What is needed now is a change in culture and commitment by the Westminster Government, the devolved governments across the UK, service commissioners and service providers to ensure that disabled children get the essential wheelchair services they need to enable them to participate more fully in the day-to-day experiences which could enrich their lives.

The way forward

Barnardo's and Whizz-Kidz make the following recommendations:

UK-wide

The UK Government and the devolved Governments are strongly urged to implement the following recommendations from the Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People* (2005):

- Equipment should be provided to disabled children promptly, based on a multi-agency assessment that occurred as soon as possible after the child's needs were identified
- Local Authorities, PCTs and Children's Trusts from their inception should work together and with their partners to commission services strategically
- Disabled children and their families should have timely access to the equipment they need, when they need it. This will require common assessment processes and funding across health, education and social services. All equipment must be updated and maintained without delay.

In addition, Barnardo's and Whizz-Kidz are calling on the Government and the respective devolved Governments in Northern Ireland, Scotland and Wales to work with their respective health service commissioners to undertake the following:

- To ensure that the geographical inequalities for the provision of wheelchair services to disabled children are ended through adequate funding, as well as requiring all wheelchair services to work to common eligibility criteria
- To ensure that the forthcoming comprehensive spending review looks at funding specifically for wheelchairs for children. Funding to be sufficient to enable all wheelchair services to provide a comprehensive service, including accessories, training, replacement wheelchairs, maintenance and insurance
- To establish and enforce benchmarking of equipment provision, including specific targets against which wheelchair services for children are monitored by the Health Care Commission. Standards do exist but they have not been endorsed by the Department of Health (DH)⁶
- To ensure that professionals receive training and guidance on the fair and consistent interpretation of eligibility criteria and other policies
- To ensure that practitioners carry out assessments using the principles of the Framework for the Assessment of Children in Need, where consideration is given to potential to develop skills, age-appropriate activities and family needs (Department of Health et al, 2000).

⁶ National Wheelchair Managers Forum (2005)

England

- Wheelchair Service commissioning and provision for children must take account of the White Paper, *Our Health, Our Care, Our Say* (DH 2006). The recommendations on Children's Centres becoming the major delivery mechanism for children's health, the requirement on increased joint commissioning and greater involvement by young people must be followed
- The Department of Health and the Department for Education and Skills (DfES) must collaborate and put new resources into wheelchair provision for children and young people so that child-centred services which cater for clinical, educational and social needs are developed – in line with Standards 5 and 8 of the children's National Service Framework
- The DH and DfES must ensure that the requirements on equipment in Standard 8 of the *National Service Framework* (Department of Health and Department for Education and Skills, 2004) are implemented.

Wales

The Welsh Assembly Government should closely monitor the progress of the implementation of its *National Service Framework Standards* in relation to disabled children and wheelchair provision via its inspection system and the Self-Assessment Audit Tool process and report publicly on its findings.

Scotland

- The current NHS Review of Wheelchair Services must produce a comprehensive picture of service provision in Scotland, and Ministers must ensure that recommendations are acted upon, with provision of appropriate funding
- The wheelchair service in Lothian, which deals with children's needs separately under the 'Enabling Technology for Children' service, should be fully evaluated to consider the benefits to children of this separate approach and how these could be replicated elsewhere.

Northern Ireland (NI)

- The Department of Health, Social Services and Public Safety (DHSSPS) should coordinate a strategic review of wheelchair services for children and young people in NI. This must include a review of maintenance and repair services
- The DHSSPS should ensure that there is a greater range of information available to children and young people and their families and professionals regarding the kind of wheelchairs available to ensure that children receive the best wheelchair for their needs
- The Government must provide funding specifically for children and young people who require wheelchairs
- The DHSSPS must ensure that there are additional technical officers if wheelchair services in NI are to continue to be provided from one site
- The DHSSPS must ensure that clear standards are developed for the provision of wheelchair services in NI.

Appendix I

The legislative and policy framework across the four nations

The UN Convention on the Rights the Child

(The UK is a signatory to this)

Article 12

State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 23

States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.



UK-wide

Policy

Improving the Life Chances of Disabled People (Prime Minister's Strategy Unit, 2005). This key policy report sets out the Government's vision for improving the life chances of disabled people across the UK. There are two specific recommendations relating to equipment services:

- The Department of Health should assess, by 2006, whether integrated community equipment services, communication aids provision and wheelchair services are able to deliver the NSF recommendation on children's equipment and, if not, make recommendations for improvement
- From 2006, the Joint Area Review should consider, in consultation with local authorities, using equipment services as a key performance indicator of local social care, education and health services. The indicator should be consistent with the NSF recommendation on equipment. (The Department of Health and the Department for Education and Skills are jointly required to lead on this recommendation.)

England

Policy

In England, Standards 1-5 of the *National Service Framework for Children and Maternity Services* emphasise the importance of early intervention and child-centred services. Department of Health and Department for Education and Skills, 2004 states:

Standard 1: Promoting health and well-being, identifying needs and intervening early

The health and well-being of all children and young people is promoted and delivered through a co-ordinated programme of action, including prevention and early intervention wherever possible, to ensure long-term gain, led by the NHS in partnership with local authorities.

Standard 2: Supporting parents or carers

Parents or carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe.

Standard 3: Child, young person and family-centred services

Children and young people and families receive high quality services which are co-ordinated around their individual and family needs and take account of their views.

Standard 4: Growing up into adulthood

All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.

Standard 5: Safeguarding and promoting the welfare of children and young people

All agencies work to prevent children suffering harm and promote their welfare, provide them with the services they require to address their identified needs and safeguard children who are being or who are likely to be harmed.

In addition, Standard 8 of the NSF states

Living in suitable housing and having appropriate equipment and assistive technology are key factors in promoting the well-being of families with disabled children. These factors support optimal development and help children to enjoy childhood activities such as play, developing independence and contributing to family life.

This requires multi-agency working and Standard 8 therefore requires Local Authorities and Primary Care Trusts to work together in the commissioning and delivery of services in all settings where children spend time, eg at home, school and short-care settings.

There is also a requirement to ensure that community equipment stores are integrated across health, social services and education, and to develop multi-agency protocols that set benchmarks for the assessment and provision of children's equipment, including wheelchairs. Pooled budgets and the use of other Health Act 1999 flexibilities are to be used to integrate and improve services.

Wales

The National Assembly for Wales has a statutory duty under the Government of Wales Act to promote equality of opportunity for disabled groups and others whom society constantly disadvantages. This has a bearing, not just on the Assembly and its working, but on the public bodies in Wales who are sponsored by, and answerable to, the Assembly. The Assembly Government has adopted the *UN Convention on the Rights of the Child* as the basis of all its work with children and young people. This has informed *The Seven Core Aims for Children and Young People* and the strategic frameworks *Early Entitlement* (0-10s yrs) and *Extending Entitlement* (11-25 yrs).

The National Service Framework for Children, Young People and Maternity Services (NSF) (2005)

The *NSF* has two clear standards which should ensure improved wheelchair provision and services to disabled children and their families. They are:

- All disabled children and their families receive accessible information about, and equitable and prompt access to, high quality coordinated services appropriate to their assessed needs
- Disabled children are provided with appropriate high quality, timely services in an environment that is suited to their needs, age and stage of development. Well-coordinated multi agency services are delivered to address all types of need.

To achieve these standards, the *NSF* identifies the following key core actions by named lead agencies, some of which have to be met by March 2006 and others within a ten-year timeframe:

- There are integrated community equipment services that supply equipment to disabled children and young people, managed by a designated lead agency. The lead agency monitors that the following criteria are met:
 - Assessments for equipment for disabled children are carried out by the most appropriate person in the multi-disciplinary team within four weeks of referral
 - Equipment is supplied within six weeks of assessment according to jointly agreed eligibility criteria for essential equipment
 - The equipment store has dedicated resources for children which are distinct from adult resources
 - The child's equipment requirements are reviewed at least annually in accordance with individual assessed needs.
- Disabled children are able to use the equipment they need in all the places where they spend time, eg school, home, leisure settings and during short break care.
- There are agreed protocols and standards for wheelchair/specialist seating services that include:
 - Providing a comprehensive service which meets the particular needs of disabled children
 - Provision of clear information for professionals, parents, carers, children and young people
 - A single referral process which encompasses services provided through the Artificial Limb and Appliance Services and those provided by rehabilitation engineering
 - Assessment within six weeks of the referral being received
 - Provision of a wheelchair or equipment within eight weeks of assessment
 - Quality assurance systems
 - Repair and maintenance procedures
 - Review of the child's needs as a minimum on an annual basis in accordance with individual assessed needs.

- Parents/carers and other non-professionals are offered appropriate and on-going training to assist them in meeting the needs of their disabled child. As a minimum this includes:
 - Appropriate training in the use of equipment. The arrangement of this training and support is coordinated by the person ordering the equipment in collaboration with the supplier
 - Manual handling training.

Framework for Partnership: Early Entitlement and Extending Entitlement

Children and Young People's Framework Partnerships have been formed in all 22 local authorities in Wales and following the Children Act (2004) these are a statutory requirement.

Local Framework Partnerships and their sub-groups have responsibility for delivering the WAG strategies for children and young people, 'Early Entitlement' (0–10 yrs) and 'Extending Entitlement' (11–25 yrs), these promote the seven Core Aims for all children and young people in Wales.⁷

The Welsh Assembly Government (WAG) has subsequently published *Children and Young People: rights to action* (2004) which sets out all of its commitments and identifies the changes it wants to see put in place to put these commitments in practice. This includes the commitment that 'as many disabled children as possible have a full education and take part in activities with other children'.

Children First Programme Wales Circular 05/2005: Guidance for 2005/06

The Children First programme is central to delivering better outcomes for those children in greatest need. The programme aims to improve the management and delivery of local social services to children and young people who are in need and their families, in particular disabled children, looked after children and care leavers. The Children First programme aims to make sure that children who are disabled or have long term health conditions are able to live with their families and use local services where their needs can be met.

One of the eleven objectives of the programme is:

'to ensure that children with specific social needs arising out of disability or a health condition are living in families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.'

Priorities for 2004–06 include: strengthening services for disabled children and supporting implementation of those elements of the NSF which are complementary to the Children First programme. Local authorities and their partners must make every effort to ensure that in taking action on this priority the issue of access to wheelchairs and mobility equipment for disabled children and young people is addressed.

⁷The Core Aims can be found at <http://www.wales.gov.uk/subchildren/content/child-pov-strategy-e.pdf>

Stronger partnerships for better outcomes: draft guidance on local co-operation under the Children Act 2004

Under the provisions of the Act Local Authorities, Local Health Boards and NHS trusts are required to identify a lead director and lead member for children and young people to take responsibility for driving forward planning under the Framework. Currently, the commissioning of wheelchairs and other mobility equipment is the responsibility of Local Health Boards and Health Commission Wales. Health Commission Wales has specific responsibility for the provision of equipment for people with complex physical impairments, including specialised wheelchair provision such as complex postural seating and powered wheelchair controls.

Scotland

Legislation

The Education (Additional Support for Learning) (Scotland) Act 2004

This Act, which came into force on 14 November 2005, places new duties on education authorities to provide adequate and efficient education for each individual child. The Act introduces the term 'additional support needs', which is much broader than previous definitions and refers to any child who requires additional support for learning, including because of disability. The Act clearly places a responsibility on Education and Health to work together to produce a package of support that will allow, for example, a disabled child to access education. This would cover the provision of mobility equipment.

National Health Service (Scotland) Act 1978

The duties that form part of the NHS provision of services, including equipment and adaptations, are vague and general in nature. They are unlike those applying to Local Authorities, which may in some circumstances find themselves under an absolute duty (irrespective of resources) to provide equipment or adaptations. Consequently, the NHS has in the past successfully argued, in a number of key cases in the English Court of Appeal, lack of resources as a lawful excuse for not providing services.

Policy

The Scottish Executive Physical Activity Task Force report *Let's Make Scotland More Active: a strategy for physical activity* (2003) has a specific focus on disabled children:

We recommend that all children and young people, including children with disabilities, should take part in at least one hour a day of physical activity.

This physical activity should include physical education, play, sports, exercise, dance, outdoor activities, active travel and support to be active in their daily tasks at home, at school and in the community.

All of which is clearly impossible without provision of appropriate mobility equipment.

Current consultations

NHS review of wheelchair and special seating services in Scotland (Consultation paper November 2005)

This is part of an ongoing review of wheelchair services, which will issue its final report during 2006. Services for children have been identified as a 'major gap' in existing provision.

Northern Ireland

Legislatively, the Disabled Persons Act (NI) 1989 and the Children (NI) Order 1995, as well as the Disability Discrimination Order 2005 have been the basis for the development of policy on wheelchair provision and the vehicle for ensuring that each Health and Social Services Trust has made funding available:

- The Disabled Persons Act (NI) 1989 aimed to give people with a disability more control over their lives by giving them rights to representation, consultation and assessment of need
- The Children (NI) Order 1995: under Article 17, a child is defined as being in need if his health or development is likely to be significantly impaired.

Over a substantial period of time a number of reports have indicated a level of dissatisfaction among wheelchair users in Northern Ireland regarding the kind of service they receive.

Appendix 2 Wheelchair definitions

Manual wheelchairs

Basic

Transit wheelchair

Designed to be pushed by a carer. The user will usually require the wheelchair for indoor and/or outdoor use.

Self-propelling

Designed to be propelled by the occupant.

Specific purpose

Heavy duty

These are manufactured for occupants who weigh in excess of 127kg. Wheelchairs are available with a weight limit of 310kg. Heavy duty wheelchairs can be either transit or self-propelling wheelchairs.



Don't push me around!

Energy efficient

These are self-propelling wheelchairs designed for active independent users. These models tend to be highly configurable. Sometimes these are also provided for the ease of the carer, as they are lighter to push and lift.

Postural support

These models are designed for users who require postural support. The features may include a tilt in space facility or a reclining back.

Other types include standing wheelchairs, power-assisted wheelchairs and sports wheelchairs.

Powered wheelchairs

EPICs

These are 'electrically powered indoor chairs'. Most chairs produced in this category are manufactured for the NHS market.

EPIOCs

These are 'electrically powered indoor outdoor chairs'. This type of wheelchair can be issued by the NHS. It will (usually) be the only piece of equipment issued to the user, so it will need to be able to manoeuvre around a user's home.

Other wheelchairs are classified for outdoor-indoor use and are usually available if purchased privately. These have heavy duty motors and batteries to give a longer mileage and can cope with more demanding terrains. Additional functions on wheelchairs that are rarely available from the NHS include powered tilt in space and recline to change the seat position for comfort, and seat elevation and standing chairs to provide a method of changing position and accessing the environment. These can enable the user to have more independence.

Outdoor powered wheelchairs and scooters

These will tend to have a longer range than the EPIOCs, so they will have heavier duty motors and batteries, and will cope with a wider range of terrains.



Outdoor attendant-controlled wheelchairs (including powerpacks)

These are powered chairs that are controlled by a carer. The controls are mounted on the wheelchair's push handles. Dual controls are available so that a chair can be switched between occupant and attendant control.

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ANNEX X

SPECIFICATION FOR DWELLINGS FOR PERSONS WITH DISABILITIES

In the case of conflict between this specification and any statutory requirement (eg planning permission/conditions, Building Regulations), the statutory requirement shall take precedence. Subject to that, no waivers will be allowed in respect of this specification except with the consent in writing of Torbay Council's Assistant Director of Housing Services.

External environment and entrances

- Drop Kerbs
 - Provide sufficient drop kerbs at suitable locations around the property and surrounding approach to the development to provide adequate access for a wheelchair user.
- Car Port
 - Provide a carport for transferring to a wheelchair and negotiating the entrance in the dry.
 - Minimum dimensions - width: 3600mm, length: 5800mm, height: 2800mm.
- Ramps & Paths
 - Maximum gradient for ramps and paths over 5m in length: 1:20
 - Maximum gradient for ramps and paths under 5m in length: 1:15
 - Maximum gradient for ramps and paths under 2m in length: 1:12
 - Minimum width of all ramps and paths: 1200mm
 - Provide safety edges to all ramps and paths minimum: 100mm where there is a level difference between ramp and surrounding area.
 - Level platform by entrances: 1500x 1500mm
 - Surfaces to be smooth but slip resistant.
 - Handrail to one side of ramp 800 – 1100mm high.
- Scooter Store
 - Provide scooter store minimum size: 1200mm x 800mm(vented)
 - Alternatively provide suitable charging point at the rear of the car port
 - Provide an internal wheelchair and hoist storage and charging area - minimum 1200mm x 800mm (vented).
- Gardens
 - Should be level with a paved area min 2400mm x 3600mm wide
 - Accessible clothes drying facilities. Paths should meet the standard above.
 - Rotary drier should be height adjustable.

Internal environment

- Entrances and internal doorways
 - Maximum threshold on all doors: 15mm
 - Lighting, with PIR detectors at all entrances.

- Clear opening width: 850mm minimum (unobstructed)
- Door locks to be easy to operate with one hand. Thumb turn internally.
- Door handles to be lever type
- Provide additional Spy hole 1100mm from the floor.
- Provide a box to catch the mail under letterbox.
- Make provision for installation of a remote controlled door opener as an adaptation on the main entrance door.
- Fire doors to have remote control door openers.
- Provide door intercoms from bedroom and main living area for the main property entrance and any communal entrance.
- Passages
 - For a straight passage minimum width: 900mm
 - To allow 90 degree turn minimum width: 1200mm
 - Next to main entrance: 1500mm x 1500mm
- Windows
 - Bottom of windows should be 810mm from the floor
 - Sills should be shallow
 - Lever handles positioned at the bottom of the window.
 - Any locking mechanism needs to be accessed from a seating position with minimum strength and dexterity.
 - Window over kitchen worktops to have remote opening.
- Components
 - Switches should be between: 700mm and 1000mm from ground.
 - Sockets should be: 600mm from the ground.
 - Meters should be between: 1200mm and 1400mm from the ground.
 - Heating controls should be between: 750mm x 1000mm from the ground.
 - Other internal features such as mirrors, hooks, shelving should be usable from a seated position
 - Heating should be adjustable and available on demand.
 - Residential sprinklers should be provided to all rooms within the accommodation.
- Bedrooms
 - Minimum sizes: double: 3900mm x 4850mm, single: 3900mm x 3000mm
 - The bedroom designed for the wheelchair user should be situated next to bathroom with a demountable partition to allow a ceiling track hoist to run from the bed to over the toilet and bath.
 - Ceiling joists should be of sufficient size and strength to allow for possible fitting of ceiling track hoists. Any strengthening should allow for flexibility of track layout.

- Joists to run at right angles to anticipated direction of track travel.
- Fused spur outlet at ceiling level at one end of the anticipated position of track.
- Minimum four double sockets one either side of bed.
- Provide sensor light with remote control
- Provide a door entry intercom system to give access to the properties front door and any communal door.
- Bathroom
 - Properties with two or more bedrooms:
 - Minimum size: 2700mm x 3500mm
 - To include a bath and level access shower.
 - Properties with one bedroom:
 - Minimum size 2700mm x 2500mm
 - To include a level access shower.
 - All properties:
 - Fused spur to allow for the installation of:
 - geberit or closomat automatic cleaning drying toilet
 - body drier
 - specialist bath
 - height adjustable washbasin
 - height adjustable shower seat
 - Additional wall mounted fan heater.
 - Folding shower seat with legs.
 - Shower should be thermostatically controlled.
 - Controls to be reached from a sitting position.
 - Shower head on slide bar to allow adjustment suitable for a seated or standing person.
 - Allow for two x 600mm rails and one drop down rail in shower
 - Allow for one 600mm rail and one drop down rail by toilet
 - Allow for one 600mm rail by basin.
 - All walls in bathroom to have sufficient fixing points for flexible positioning of rails to suit individual requirements.
 - Walls to have additional 18mm WPB plywood sheeting internally where timber or metal stud used.
 - Washbasin to be wall mounted on adjustable brackets with flexible plumbing and no pedestal.
 - Provide lever mixer taps.
 - Shaver socket next to washbasin, accessible from a seated position.

- Mirror to be long enough to be used from a sitting and standing position.
 - Baths to be 1700mm long , of standard design and of sufficient strength to allow the fitting of specialist bath equipment.
- Living room
 - Minimum size 4000mm x 4000mm.
 - Allow for sufficient dining area ie 2500mm x 2500mm if this is not provided in the kitchen or separate dining room.
 - Allow for a minimum of four double sockets.
- Kitchen
 - All worktops should be on adjustable brackets to range from 700mm to 900mm.
 - The kitchen design should allow for knee clearance under the sink, hob and a section of work surface.
 - Separate hob and oven housing.
 - Oven should have a side-opening door and pull out shelf beneath.
 - Sink should to be insulated underneath to protect the user.
 - Sink should have lever mixer taps.
 - Provide a minimum 4 double sockets above worktop at an appropriate position for using the kettle, microwave, toaster and other labour saving equipment.
 - Corner units should have carousels.
 - Space and plumbing should be provided for a minimum of four standard sized white goods.
 - Wall cupboards should be fitted as low as possible but not to impede on space that may be required for equipment.
 - A minimum of 2.5m cubed should be provided beneath the worktop.