

Review Group on Transport Needs of People with Disabilities Public Consultation

Submission by the Citizens Information Board

1. Introduction

The Citizens Information Board (CIB) welcomes the opportunity to make a submission to the Review Group established by the Minister for Health with the purpose of "finding the most appropriate solution or solutions to address the priority transport needs of those who require supports, which will be fully compliant with equality legislation and can be delivered within available funding". The public consultation and the broadly-based membership of the Review Group is regarded by the CIB as particularly important.

The Board draws on feedback from its delivery partners (Citizens Information Services (CISs); the Citizens Information Phone Service (CIPS) and the National Advocacy Service (NAS) to inform this submission to the Project Group.

While welcoming the establishment of the Review Group as a means of identifying ways of addressing the issues arising out of the Government decision to terminate the Mobility Allowance and the Motorised Transport Grant, any alternative mechanisms put in place should be located in the context of longer-term mobility and transport supports and broader policy reforms relating to people with disabilities, in particular, the move towards an individualised supports system currently under consideration.

Transport and mobility support schemes play a crucial role in combating social exclusion and in enabling access to health and social services. The CIB is aware of the widespread concern expressed by people with disabilities and their families, the wider public and disability organisations about the Government decision to terminate the two schemes. Recent feedback from CIB delivery partners based on service users' experience reflects this concern.

2. Transport Assistance and the Cost of Disability

It is acknowledged nationally and internationally that people with disabilities incur many extra living costs as a result of their disability. Research has continually pointed to the fact that the cost of living for households with a person with a disability is generally higher than for the rest of the community – higher medical costs, paying for disability aids and home adaptations, the cost of transport, help with care and higher costs on day to day living. The Indecon Report on the Cost of Disability published by the NDA¹

¹ National Disability Authority and Indecon (2004), Cost of Disability Research Project, <u>www.nda.ie</u>

showed that people in Ireland face extra costs of living related to disability over and above those which are currently met by state services or supports, in particular, extra costs for heating or transport. Clearly, some people with disabilities have greater needs than others for additional mobility and transport supports and, clearly, some people are more reliant on such state assistance for this purpose than others.

The role of mobility and transport assistance as a type of 'cost of disability' payment will undoubtedly be a consideration for the Review Group, taking into account the additional transport costs incurred by people with disabilities. There is, however, a clear difficulty in doing this adequately in the absence of a more general cost of disability payment policy.

3. Advantages of Direct Cash Payments

There are a number of aspects of the direct transport assistance payments that need to be taken into consideration by the Review Group in looking at alternative mechanisms.

- (i) They provided people with some element of choice as to how deal with their specific transport and mobility needs;
- (ii) The cash payments provided additional income which acted to some extent as a 'cost of disability' payment;
- (iii) The allowances have the advantage of affording people maximum choice in how the money is spent this perspective obviously assumes that the money will be used for the purposes for which it is intended;
- (iv) The direct payments model reflected key concepts of choice and independence which underpin the UN Convention on the Rights of Persons with Disabilities;
- (v) The payments can be said to have made some contribution to enabling people to maximise participation in society through work, training, education or involvement in social and community activities.

4. The Particular Transport and Mobility Needs of Recipients of Cash Payments in Ireland²

People who have met the criteria for Mobility Allowance clearly have significant mobility difficulties and have had to meet other relatively stringent criteria.

- They cannot walk safely, even with the use of artificial limbs or other suitable aids:
- They have been unable to walk for more than a year:
- They need to be able to move and to change their surroundings from time to time to improve their quality of life;
- They have been required to pass a relatively stringent means test to avail of the allowance.

² These are broadly similar to the criteria that apply to the Mobility Allowance component of the Disability Living Allowance in the UK. Personal Independence Payments are due to replace DLA in the UK.

Similarly, persons in receipt of the Motorised Transport Grant have been required to have a disability which impedes their use of public transport and require a car or other vehicle in order to obtain/retain employment or who live in a very isolated location.

5. Replicating the Basic Principle of the Mobility Allowance

The essential principle underpinning the Mobility Allowance was that it provided a specific amount of money to an individual each month which s/he can use to buy a service tailored both to his/her particular needs and to available transport options. Such options vary significantly from one individual to another. For example, some may use it to pay for an occasional taxi/hackney service, others may use it to assist with the running costs of a vehicle which they own or which is owned by a family member. Others may use the allowance to put fuel in the car of a relative, neighbour or friend who provides transport to them on a regular basis.

The idea which has been mooted of allocating the budget available for transport and mobility assistance (10 Million euros) to service providers and requiring them to meet the range of transport needs of different individuals with different needs and living in different types of social contexts is in serious danger of falling short on a number of fronts:

- It is likely to significantly undermine the concept of individual choice and control by people with disabilities which has been widely promulgated nationally and internationally in recent decades and which is a key component of the UN Convention on the Rights of Persons with Disabilities:
- (ii) It is also likely to limit independent decision-making and spontaneity in that the number of transport options available to an individual will inevitably be restricted in terms of times, schedules and waiting times;
- (iii) People will inevitably become more reliant on administrative systems and resource allocation mechanisms totally outside their control;
- (iv) Changing the allocation system would clearly be at odds with recent Government policy towards people with disabilities which has been proactively promoting the concept of individualised funding;
- (v) An issue identified in reviews of the Rural Transport Programme (RTP) is a deficit in the administrative capacity of some voluntary/community organisations in relation to effectively managing the service.

6. Transport/Mobility Deprivation: Contextual Factors

Inadequate access to transport is a significant factor in maintaining the wider social exclusion of people with disabilities. The National Disability Survey (2010) shows that around three-quarters of people with a disability aged 5 and over did not regularly use Intercity bus, Rural bus, DART/LUAS, Commuter train or Intercity train services. A slightly lower proportion did not regularly use City bus (65%) and Taxi/hackney (64%) services. Difficulty getting on and off public transport vehicles was given by 16% of

persons aged 5 and over as a reason for not using or having difficulty using public transport. Difficulty transferring from one service to another was the next most cited reason (12%), while difficulty getting to the public transport was reported by 9%. Around half of persons with a disability experienced difficulty with going to town shopping (56%), going away for a break or holiday (53%), taking part in community life (54%) and socialising in a public venue (49%).

There are a number of factors that contribute to transport /mobility deprivation³:

- Households without a car are most at risk of mobility deprivation. The incidence of car ownership is lower among people with disabilities and older people;
- About one in four adults with a disability can neither use public transport nor drive a car;
- The lack of adequate and accessible public transport is one of the major factors contributing to mobility deprivation in rural areas – it impacts significantly on people's ability to access services necessary for daily living or health and social services, or to pursue education or attend training courses or work/training opportunities;
- Despite significant investment in the accessibility of public transport, the continuing poor accessibility of some public transport makes it difficult for people with physical/sensory disabilities to use such transport independently the reality is and will continue to be that not all journeys are feasible by public transport;
- There is a very significant contribution made to alleviate transport/mobility deprivation by the Free Travel Scheme (for those who can avail of it), the Rural Transport Programme (where it operates) and by the voluntary/community sector;
- The ongoing centralisation of services social, health, retail, education/training and recreational – is a significant issue for people who do not have access to transport;
- For many people in rural communities, access to health care and health related services is a difficulty because of the lack of public or private transport options in rural areas;
- Taxis are widely used by people who cannot use other forms of transport and provide a valuable, if relatively expensive, option for people with mobility difficulties in some instances, already low household or personal incomes are insufficient to meet the costs of private taxis;

³ See Citizens Information Board Report, *Getting There: Transport and Access to Social Services*

7. Conventional and Non-conventional Transport Services

The distinction between conventional and non-conventional transport services is important when addressing the question of how best to provide more inclusive transport services (Fitzpatrick and Associates 2006).⁴ Conventional services operate on fixed routes, with fixed departure and pick-up points. These can often be inaccessible for people who have difficulty getting to these points – for example, people with mobility, sensory and cognitive impairments, or people with young children. Conventional services in Ireland are constrained by the country's low population density and by its highly dispersed population, which limits the commercial viability of scheduled services and contributes to very high levels of car dependence in rural areas.

Non-conventional services, on the other hand, generally provide more demandresponsive or semi-scheduled alternatives which, using smaller vehicles, can collect people directly from their homes, bring them to local service centres or transport hubs, and return them home afterwards. Unlike conventional services, these alternative options are also more easily accessible to a wider range of user groups because of their ability to facilitate door-to-door service and passenger assistance. On the downside, these services are more expensive which is a crucial consideration in the current budgetary climate.

The Department of Transport Disability Sectoral Plan under the Disability Act 2005⁵ referred to mainstreaming in the transport context as meaning the adoption of an integrated approach to policymaking, transport planning and the provision of transport services for all. However, the plan also noted that "it is inevitable that some people, because of the severity or nature of their disabilities, will not be able to travel on public transport services (or may not be able to do so at all times). In these cases, specialised transport services are the most appropriate complementary form of transport" (Department of Transport 2006:13). Meeting this specific gap in an overall mainstreaming context remains a significant challenge.

8. Community and Voluntary Transport Services

In Ireland, the voluntary/community sector has played and continues to play a significant role in the development of innovative transport initiatives. A number of national and local voluntary organisations have fleets of accessible vehicles that are used to provide transport for their own members, mostly in connection with their own activities and to their own facilities. NGOs providing services to people with intellectual disabilities have generally have their own vehicles for transporting service users. Services provided by NGOs generally fit the description of non-conventional transport services discussed above. A pioneer in the development of accessible transport was Vantastic Dial-A-Ride Limited, established by the Centre for Independent Living in 1994 as a way of addressing the absence of accessible public transport. Vantastic⁶ operates a call centre booking and scheduling service for the Dublin area providing demand-responsive doorto-door transport services. It also provides self-hire wheelchair accessible vehicles, which can be hired by members to be driven by member-nominated drivers.

⁴ Fitzpatrick Associates (2006), *Progressing Rural Transport in Ireland,* Department of Transport.

⁵ Department of Transport (2006), *Transport Access for All: Sectoral Plan for Accessible Transport under the Disability Act 2005.*

⁶ Vantastic is supported by the Department of Justice and Equality and by Pobal.

9. Rural Transport Programme

The principles and *modus operandi* of the Rural Transport Programme (RTP) are worth considering in the context of exploring new support transport/mobility support structures at local level. Currently the RTP funds 36 community transport groups around the country. The RTP has as its overall aim to encourage innovative community based initiatives to provide transport services in rural areas, with a view to addressing the issue of social exclusion in rural Ireland arising from a lack of access to transport. ⁷ This has led to the introduction of a wide range of semi-scheduled and fully-demand responsive services, delivered via a number of different service models. The RTP provides localised non-conventional (flexible and demand responsive) transport which aims to meet specific local needs.

Five aspects of the RTP are relevant to the current deliberations:

- The contribution of local volunteers is significant to the RTP both in economic and social terms and their involvement is a critical success factor in the implementation of the RTP locally;
- Of the RTP passenger journeys in 2011, 84% were made on a door to door basis – the majority of these journeys are pre-booked by passengers in advance of the service running;
- (iii) Over half (54%) of passenger journeys were made by free travel pass holders (In 2011 there was an increase in the use of the FTP under 66 pass (13% to 21%);
- Services are operated by a variety of transport operational models in 2011 77% of services are delivered by private operators, a smaller number are provided by groups operating their own fleet (14%) and 8% operating a community car;
- (v) RTP services operate a model of passenger assistance whereby people are assisted – carrying shopping to their door, assisting them to get on and off the vehicles, buckling seat belts and responding to their individual needs;
- (vi) Most vehicles used are wheelchair accessible

Some combination of the types of services provided under the RTP will be required if some of the €10million funding is to be re-allocated to a new support mechanism. These are:

• Fixed services: including scheduled fixed services which run on regular timetables with fixed departure and destination points and which do not allow deviations from the route

⁷ Rural Transport Programme Performance & Impact Report 2011, <u>www.pobal.ie</u>

- Flexible services (partially demand-responsive) which run on regular scheduled timetables that have fixed departure and destination points, but which allow deviations, including advance booking and door-to-door service
- Fully demand-responsive services that respond directly to demand, through prebooked trips or "dial a ride" type services, which can also be delivered by cars through either voluntary car schemes or co-ordinated hackney services
- Specialist or once off trips: services that are usually run on short notice, for specific purposes or for a short period of time, but not on a regular, frequent or pre-planned run, e.g. for social events.

A 2011 Review of the Rural Transport Programme⁸ called for better targeting of transport to the target groups of people with unmet transport needs, including women, older people, people with disabilities- sensory, cognitive and physical, and people on lower incomes and greater spatial coverage of RTP services in rural areas where there is identified unmet transport needs.

10. The Need for Different Transport Support Structures

A key consideration in the current economic climate is clearly the effective use and targeting of resources. The present situation where State funding is provided for a range of parallel and fragmented transport and mobility support initiatives frequently operating independently of each other is unlikely to be the best use of resources.

A More Integrated Policy Response

The CIB Report, referred to above, called for more synchronisation between the various transport/mobility schemes to ensure both efficient resource utilisation and equality of access to transport and mobility supports across all categories of disability and mobility deprivation. The need for a more integrated policy response to the needs of people experiencing mobility/transport deprivation has been suggested in a number of reports in the past decade, including the Interdepartmental Review Group on Disabled Drivers and Disabled Passengers (Tax Concessions) Scheme (Department of Finance 2002); the Working Group on the Review of the Supplementary Welfare Allowance Scheme (Department of Social and Family Affairs 2006) and the Review of the Rural Transport Programme (Fitzpatrick and Associates 2006). The Interdepartmental Review Group referred to possible inequities between people with various disabilities in terms of State subvention for private transport expenses. The Review Group also concluded that the scheme could not be looked at in isolation but had to take into account parallel developments in regard to accessible public transport, transport initiatives by the voluntary/community sector, the role of the other mobility support schemes and the broader question of addressing the cost of disability.

The Interdepartmental Review Group on Disabled Drivers and Disabled Passengers (Tax Concessions) Scheme suggested that in the long term the solution may lie in some combination of the following options:

⁸ <u>http://www.transport.ie/uploads/documents/feature/20110630%20VFM%20FINAL%20REPORT.pdf</u>

- Concentrating public funding on making the public transport system more accessible for all people
- Funding voluntary groups that can provide a locally based, flexible and accessible transport system for persons with a mobility impairment

Integrated Planning at National Level

The CIB has in the past suggested that, in line with the Government's commitment to mainstreaming and service integration, cross-cutting issues relating to different Government departments and agencies involved in the provision of transport and mobility supports should be identified and addressed by the Department of Transport. Such a requirement could be made explicit in the remit of the National Transport Authority. The Authority has, among a number of specific functions, a general role of overseeing the development of national transport services in a planned and integrated manner in the future. In developing a more integrated approach there is a need to evaluate further transport provision by voluntary organisations and the HSE and how these fit with the Free Travel Scheme, the Rural Transport Programme and other State-funded local transport initiatives.

Enhancing the Role and Potential of Voluntary/Community Organisations The development of a more integrated approach requires an evaluation of transport

provision by voluntary/community organisations and by the HSE and how these fit with the Rural Transport Programme and the Free Travel on public transport system.

Integrated Transport/Mobility Subsidy

In terms of ensuring equality of access to public transport, in the longer term, options other than a Free Travel Pass should be considered. For example, vouchers could be made available for use in taxis, hackney cars, community bus schemes and private buses. The introduction of both Smartcard based integrated ticket systems and passenger information systems with accessibility features should be expedited by all transport providers.

Integration at Local Level

A key aspect of international best practice in rural transport provision is the coordination of different schemes at local level and the integration of these with mainstream provisions. There is potential for greater rationalisation and joint working between transport service providers at regional and local levels through maximising the use of information technology to enhance demand-responsive services. It is reasonable to assume that, even in the short-term, there is scope for more collaboration at local level to optimise existing transport resources and to ensure that no one experiences a socially unacceptable level of transport/mobility deprivation taking into account their health, social and social living needs and their individual preferences. The experience of the Rural Transport Programme and related pilot initiatives and that of other voluntary/community organisations should be used in a proactive and timely manner to develop creative and sustainable responses to transport/mobility deprivation.

Consideration should be given to asking each Local Authority, in consultation with the HSE and relevant voluntary/community organisations, to examine, as a matter of

priority, the current transport infrastructure as it impacts on people experiencing mobility/transport deprivation.

11. Specific Areas Needing Attention

Priority Groups and Eligibility Criteria

People who have been in receipt of the Mobility Allowance or the Motorised Transport Grant are clearly people who have been assessed as experiencing significant mobility deprivation. Any new mechanism must, therefore, ensure that the needs of this group are identified and responded to in an individually-tailored and meaningful manner. Similarly, the needs of people with similar levels of mobility deprivation who were excluded from eligibility for Mobility Allowance on age grounds must be identified and addressed. People who have significant mobility difficulties and who cannot manage from their own resources – individual, family, neighbourhood/community, friendship networks – clearly need support from the State and should be provided with such in the most cost effective way possible.

Specifically, provision should be made for those who would be eligible for a Mobility Allowance but who did not apply within the specified time limit (See Case Example 1).

The Role of Individual Cash Payments

The advantages of individual cash payments have been set out earlier in the document (Section 3). The two key advantages of individual payments is that they allow for individual choice and control and that they reflect a policy aspiration of a general move to a service delivery structure based on the concept of individualised payments. While additional income is clearly an important factor for most people with disabilities, how such income relates to other support services provided directly or indirectly by the State must be a key consideration, particularly at a time when there has to be a strong emphasis on the rationalisation of resources. Individual transport/mobility support payments should, in the view of the CIB, remain a clear principle of support and the enhancement and better integration of such payments should remain a key policy goal (see Case Example 2).

Transfer of Transport/Mobility Cash Payments to the DSP

The CIB believes that there are individuals, probably a high proportion of those currently in receipt of Mobility Allowance, whose transport/mobility needs will not be met by any means other than direct cash payments.

In this regard, the Board recommends that responsibility for transport/mobility cash payments to individuals should lie with the Department of Social Protection. This would be in keeping with a recommendation made as part of the Transfer of Core Functions⁹ discussion conducted in the early part of the present decade and accepted in principle by the Government at that time.

The transfer of transport/mobility payments to the DSP would result in a more integrated response to individual needs and a more streamlined approach to all of the income support needs of such people (many of whom will already be in receipt of social welfare payments and/or Free Travel). It should also improve the service to those who need it

⁹ <u>http://www.dohc.ie/publications/pdf/core_functions.pdf?direct=1</u>

by having more integrated means testing and processing of applications. Also, under the DSP, the payments would be subject to the same right of appeal (Social Welfare Appeals Office) as other social welfare payments. Locating the transport/mobility payment in the DSP is likely to provide better value for money to the Exchequer in that all income support payments would be administered by a single agency which should result in greater efficiencies. In the longer-term, a model similar to that which operates in the UK where there is provision for a mobility allowance component to the Disability Living Allowance could be introduced. In such an eventuality, separate provision would have to be made for people not in receipt of a disability-related social welfare payment (which would be a relatively small number).

Respective Contributions of Cash Payments and Tax Concessions

There is a need for further analysis of the resource contribution of the tax concession scheme (Disabled Drivers and Disabled Passengers (Tax Concessions) Regulations 1994) compared to the contribution of the direct cash payments in order to establish if available resources are being allocated to those most in need. Such an analysis should look at the objectives of both support schemes with a view to achieving the optimum impact in terms of prioritising transport/mobility support needs.

Transport/Mobility Supports as Part of an Integrated System of Individualised Supports A policy of individualised supports¹⁰, currently under consideration by Government, would provide a valuable framework for assessing the transport/mobility supports within a broader policy context. This would also provide a model for tailored responses based on individual needs assessment taking into account not only the individual's transport and mobility needs but also the strengths or otherwise of family, neighbourhood/community and friendship network support.

The core components of the proposed individualised support approach are:

- (i) State funding would be allocated based on an independent assessment of individual needs
- (ii) Following the needs assessments, individual support plans would then be drawn up and individualised budgets allocated from which the supports and services needed would be paid.

Short-term, Medium-term and Longer-term Provisions

The CIB acknowledges that the Review Group is likely to have to focus on more shortterm solutions to the difficulties arising from the recent Government policy change. However, the Board believes that the Group must do this in the context of, not only addressing short-term difficulties but, also, and, equally importantly, of keeping in sharp focus the medium to longer-term requirement to enhance the mainstreaming transport approach, to maximise individual choice in accordance with the UN Convention on the

¹⁰ "Individualised supports are a personal social service which includes a range of assistance and interven tions required to enable the individual to live a fully included life in the community" (p.15). See Report of Expert Reference Group on Disability Policy.

Rights of Persons with Disabilities and to progress in a meaningful manner the social inclusion agenda as it applies to people who experience transport/mobility deprivation.

12. Overview

The CIB recognises the significant challenge that exists in developing and applying a national standardised approach to transport/mobility deprivation. A question arises as to how the overall needs of an individual can be assessed and responded to in a more holistic manner than is currently the case, taking into account the range and diversity of individual needs. An important consideration is the fact that the situation of people with disabilities generally does not compare favourably with that of those who do not have a disability in relation to, for example, educational outcomes, employment opportunities, activation supports and public transport.¹¹ To this end, and as part of the income support system, it is important that there is a clear focus on providing the necessary supports to maximise participation in society. Where a person is assessed as not being able to work (in the conventional sense), but is able to engage in alternative activities which enable him/her to participate in society, (e.g., through training, education or participation in social and community activities), supports should be available to assist in this regard.

The social model of disability defines disability as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers s/he may face. This is an important perspective when looking at the provision of additional transport/mobility supports.

It is reasonable to suggest that the transport needs of people with disabilities should be included as part of an overall assessment of needs. The assessment of transport needs is best considered in the context of factors relating to social inclusion, equality of access, choice, independent living and changes over the life cycle. It is the case that family, neighbours and friends can be a vital support to people with mobility difficulties living in the community and this is an area of support that could be further stimulated and enhanced.

¹¹ See A Social Portrait of People with Disabilities (2011), ESRI and Department of Social Protection.

Illustrative Case Examples

Case Example 1

A client wanted to apply for Motorised Transport Grant to have his car adapted for his wife who has a disability. From the 26 February 2013 no further applications were accepted, including from applicants who may have received a grant in the past. There have not been any interim solutions for a grant put in place, so therefore the client has to wait for a solution.

This family is on social welfare payments and cannot afford to have the car adapted. The man's s wife finds it very difficult, almost impossible to get in and out of the car.

Recommendation

- 1. An interim solution to be put in place before the Grant is taken away.
- 2. Allow applications to be processed until there is a new solution.

Case Example 2

A CIS client is in receipt of Disability Allowance. She experiences great difficulty when walking any distance. She has a car of her own and had availed of the Motorised Transport Grant with the intention of looking for employment. She had applied for the Mobility Allowance after the cut off date of 27th Feb. 'The reason she had not applied for The Mobility Allowance before Feb 27th is due to the fact that, one of the conditions of the Transport grant meant that she had to wait 3 years to apply for the Mobility Allowance.

The woman has recently moved into independent living accommodation, and, in order to help pay the household bills she had hoped that she would be able to take up employment locally. Getting to work would, however, present significant difficulties because of the absence in the area of accessible public transport for people with significant mobility difficulties. The fact that she now is in independent living accommodation means that she has a greater need for her car in order that she has access to employment to help with household bills, and enable her visit her family and friends which would in turn help her to remain in independent living. A weekly or monthly payment, along the lines of the Mobility Allowance would make a big difference in this woman's life.

Case Example 3

A person with a significant mobility difficulty who is not working receives Disability Allowance and Mobility Allowance and has no other income. A van was purchased to enable him to leave his house. This van needs a lift to ensure that he can get in and out of the van safely. A second hand lift was secured and state funding was sought to help with the cost of the lift and its installation.

An OT assessment carried out stated that the person with the disability should apply for 'a car adaptation grant'. Since there is no such grant available from the State, it was concluded that the OT was referring to the Motorised Transport Grant which was not appropriate in this case as it would have involved the person with the disability losing the Mobility Allowance.

An application for funding was submitted to the Disability Unit of the HSE. No information was forthcoming from the HSE for two months and attempts to find out the status of application were unsuccessful. The HSE decided eventually not to provide funding for the lift out of the disability budget and suggested that the applicant should apply for an SWA Exceptional Needs Payment.

The CWO would not accept an application for the lift under the Exceptional Needs Payment scheme as it was deemed ineligible.

Following further correspondence with the HSE, the Disability Unit wrote a letter stating that funding for the lift was not going to be provided by them and that the application should be made under the Exceptional Needs Payment.

A further application under the SWA Exceptional Needs payment (inclusive of the letter from the Disability Unit) was rejected. Currently, a decision is awaited on an appeal against this decision.