“Personal Assistance Services in Ireland”

1. What does section 4.1 “Level and Nature of PA Support” talk about?

* Results suggest that there is higher PA allocation among those with higher levels of education, among those living in urban city areas and for those with lower levels of natural support. Overall, more hours of assistance received from family is linked to a lower package of hours, while difficulty getting help from a neighbor is linked to a higher package of hours.
* More hours were widely called for. Many of the responses were just general calls for more hours, while some specified that they specifically wanted hours in the evenings and during weekends.
* The nature of support received was mainly for personal care and activities of daily living, followed by assistance with social activities and less prevalently with regards to assistance in the workplace and in education or training. Others asserted that they were unable to get any workplace support hours and that this was a significant factor in preventing them from working.
* Using personal assistance services for personal care and daily activities was higher where people had lower levels of social or familial support. Assistance with social activities appears strongly related to the package of hours received – with greater hours enabling people to access support for social activities.
* Transport was also an area of concern for many respondents, with difficulty in accessing medical appointments, going shopping and getting out of the house reported, as well as travel more broadly to events like concerts and on holidays. Issues around the number of hours were also raised in relation to the lack to time to travel somewhere, do something there and return home within the PA hours available. Non-PA factors, such as the lack of accessible transport and the lack of a grant to acquire an appropriate vehicle or the capacity for the service user to divert funds away from other services like PA to do so were also issues.
* Families (generally parents or partners) were often left to fill the gaps in support, putting relationships under strain and constraining these family members’ own capabilities in terms of time and energy to put to other valued ends. The prohibition on using PA funding to pay family members for care work was noted by several respondents as making their life more difficult.

1. What does section 4.2 “Satisfaction with Supports” talk about?

* Overall, 40% of respondents disagree with the statement that their needs are being met by PA supports. There is clear relationship with age – with the percentage indicating that their needs are met increasing to 47% among those over 60 years.
* Almost 4 in 5 believe that the personal assistance services they currently receive increase their independence.
* Nearly two-thirds feel they have a high level of control over how the hours are used.
* The vast majority indicate that the quality of services they receive are of a high standard.
* Just 15 percent indicate that managing their service (including governance and regulatory compliance) is a significant burden.
* A majority wish a broader range of supports were available to them.
* Those over 60 years of age and those in Munster are more likely to agree that their needs are met. Those who are not satisfied with life and those who indicate they have no one they can count on are more likely to disagree that their needs are met. Those using PA for social activities are less likely to wish a broader range of supports are available.
* The results suggest that respondents with more complex impairments (based on the number of conditions/difficulties indicated) are less satisfied with their services.
* Significant dissatisfaction with the number of hours currently allocated to respondents, as well as with the constraints on when those hours could be used and what they could be used for was expressed.
* Relationship with individual personal assistants figured prominently in how the respondents expressed satisfaction and dissatisfaction with PA more generally. Issues with service user choice, control of their own PA and specific negative experiences were also raised.

1. What does section 4.3 “Quality of Life” talk about?

* Females, those living in rural areas and those who completed higher education show higher levels of satisfaction with their personal relationships. Life satisfaction is substantially higher among those in employment, and in this group are also more likely to be satisfied with their financial situation. Those who score highly on life satisfaction are also more likely to be receiving a higher package of PA hours.
* Those aged over 60 years are more likely to indicate they are satisfied with their life. Those who indicated that they experienced multiple impairments were less likely to indicate they are satisfied with life compared to those who only reported one impairment, while those with fewer people they can count on are less likely to indicate they are satisfied with life. Those who are in employment are nearly three times more likely to score highly on the life satisfaction scale. Those who would like a broader range of PA supports are less likely to score highly on the life satisfaction measure. Higher PA packages are associated with higher life satisfaction.
* The greater proportion of survey respondents in the low satisfaction group for financial situation and personal relationships highlights two areas where PA may be particularly weak. The impact of insufficient PA on service users’ families, as well as the difficulty in using supports for social purposes may explain some of the low satisfaction in personal relationships. The lack of PA support in the workplace, meanwhile, and the greater difficulty in finding employment as a result, is likely to increase the financial pressure on service users.

1. What does section 4.4 “PA Relationship” talk about?

* Those involved in the selection of their PA were slightly more likely to agree that they have a high level of control over how PA hours are used.
* Difficulty in finding and keeping high quality PAs were highlighted.
* The first challenge to personal assistance arising from personal assistant relationship has to do with the lack of choice perceived by many respondents in selecting their personal assistant and the resulting lack of rapport or chemistry. The second challenge has to do with facing personal assistants themselves – chiefly the low pay and poor conditions in the short term and the lack of progression opportunities in the long term, increasing turnover and causing stress in PAs and making it difficult to attract sufficient numbers of suitable applicants at all.
* The support aspects, in relation to professionalism, ability and willingness to follow directions and respect service user’s autonomy were central to some participants’ appraisal of PA. For others, however, the aspects which are closer to care, in terms of the warmth of the relationship and the PA “taking charge” while present were key strength of PA.

1. What were the recommendations for the future of PA provision

* Nearly ¾ indicate that the system needs reform – establishing statutory/legal rights to PA, increasing regulation of provision and minimum training level/qualification for PA’s.
* Older cohorts are less likely to feel there is a need for reform of PA provision. Those residing in urban town areas are more likely to seek reform, as are those currently in employment. Those who did not have any involvement in the selection of their PA are more likely to look for reform, as are those with weaker social supports.
* Calls for greater breadth and depth of supports were common – for more hours, more types of support and greater funding in general as well as for better links to non-PA supports.
* More fundamental systematic change was needed, in the form of greater service user input and direction, and so was a rights-based model of PA, distinguishing PA hours from home care hours and increasing access to personalized budgets.
* Calls for a channel for feedback to service providers, the HSE or an independent body as well as suggestions around auditing and monitoring the quality of PA services, PA service providers and personal assistants. The planned model of regulation for home care in Ireland would focus on regulating providers rather than carrying out inspections in people’s homes.
* The suggestion for reform included making PA easier to access in the first place, both through making more information about it available for people who might be eligible and through improving the assessment and allocation process.

1. What were the main points of Discussion?

* Personal assistance in Ireland exists under severe fiscal pressure; reform calls for adequate funding of PA.
* Standardizing how PA is allocated across the country and drawing up best practice guidelines for putting service users in charge of their own PA were also suggested.
* Putting in place channels for service users to provide feedback and report problems without fear of retaliation is also vital in ensuring that services are performing as they are intended to.
* A vital step towards improving the PA system is improving the conditions for PAs.
* Some of the interviewees who were not engaged in such networks emphasized difficulties in areas such as knowing what supports exist and how to access them and dealing with loneliness and feelings of helplessness.