



EURORDIS Answer to the European Commission Consultation on: European Pillar of Social Rights

(December 2016)

About EURORDIS

[EURORDIS-Rare Diseases Europe](http://www.eurordis.org/) is a unique, non-profit alliance of over 700 rare disease patient organisations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services. More information available at <http://www.eurordis.org/>.

About the European Commission Consultation on the European Pillar of Social Rights

The [European Pillar of Social Rights](http://bit.ly/EuropeanPillarSocialRights) was initially presented in 2015, by the President of the European Commission, Jean-Claude Juncker. The Pillar will identify a number of essential principles common to euro area Member States, focusing on their needs and challenges in the field of employment and social policies. The European Commission's (EC) online public consultation on the Pillar, carried out in 2016, sought to gather a wide range of stakeholders' views on the Pillar. More information available at <http://bit.ly/EuropeanPillarSocialRights>.

EURORDIS response to the European Commission Consultation

EURORDIS [Social Policy Advocacy Group](http://bit.ly/SocialPolicyAdvisoryGroup) (SPAG), composed of rare disease (RD) patient representatives from across Europe, built up the organisation's views and expectations from the Pillar. The SPAG contributes to the development of EURORDIS' activities to promote holistic care for RDs and the integration of RDs into social services and social policy, providing their grassroots experience and their expert advice on the social challenges experienced by RD patients/families. More information on the SPAG available at <http://bit.ly/SocialPolicyAdvisoryGroup>.

EURORDIS' answers to EC questionnaire

On the social situation and EU social "acquis"

1. What do you see as most pressing employment and social priorities?

RDs affect 30 million EU citizens. They are often chronic, highly complex, progressive and disabling, generating specific care needs. These factors combined with lack of treatment create **huge obstacles to the provision of holistic care** and generate **significant burden for patients/families**. This is **aggravated by the current economic situation in the Member States** (MS): patients/carers are often not able to find an adapted job/occupation and provide for themselves, increasing families' financial burden. However, due to the therapeutic/healthcare advances, people with RDs have longer life expectancy, higher functioning and greater expectations towards an autonomous-fulfilling life.

The need to provide social services/support adapted to RDs is recognised in [the Commission Expert Group on Rare Diseases Recommendations to Support the incorporation of RDs into social services and policies](#)" (2016), directed to the Member States and the EC.

In line with these recommendations, **the Pillar must integrate the challenges of people with RDs/their carers into employment and social policies by promoting:**

- **Adapted, flexible and non-discriminatory employment and adequate social services** to allow people with chronic/complex diseases and carers to actively contribute to society; the high poverty rate of people with disabilities can be reduced as their employment rate increases;
- **Adapted, non-discriminatory schooling for children with disabilities** /complex conditions;
- **Adaptation of MS' functioning/disability assessment systems** to take into account broader disabilities, incurring not only from the impairments but also from socially disabling situations like complex care pathways;
- **Accessible goods, services and built environment.**

Failure to meet the serious social needs of people with RDs/their carers affects their dignity, autonomy and fundamental rights expressed in the Universal Declaration of Human Rights and the UN Convention on the Rights of People with Disabilities.

2. How can we account for different employment and social situations across Europe?

The confrontation with a RD is a life changing and often a devastating event for people with RDs and their family, generating additional social support needs. Due to different MS individual constraints, people with RDs and their families can find themselves without an appropriate and inclusive social support framework or without access to the existing social benefits.

The different employment and social situations of people with RDs in Europe are accountable to national system organisations and the different ways in which the health and social systems assess and evaluate a person's level of functioning and disability.

The Pillar will evolve around competitiveness, a notion that has a high risk of leaving people with complex disabilities and health/care needs out of the picture. However, these people have the will and very often the capacity to contribute to society. It will therefore be **important that the Pillar raises awareness about the value of people with complex needs in a competitive environment**. The Pillar must provide for their socio-economic integration, supporting them to live independently and actively contribute to the economy and society.

To support the socio-economic integration of people with complex and sometimes highly disabling diseases, **it is key that MS develop indicators on access to healthcare services and to social support for people with chronic conditions**. These indicators should be based on elements that truly reflect the situation of these people and serve to promote policies that will improve their situation.

3. Is the EU "acquis" up to date and do you see scope for further EU action?

People with complex needs and their carers look forward to the future EC **initiatives that will modernise and adapt the current EU legal and policy framework to allow for parents of children with specific needs and those with dependent relatives** to better balance caring and professional responsibilities. They have great expectations from the EC employment strategy, youth employment strategy, proposal for carers' leave (DG Employment & Social Affairs). All these must be non-discriminatory, fully inclusive and offer provisions for people with complex needs as well as their carers.

The **European Semester and the country-specific recommendations must cover the concerns of populations with specific needs**. It is the responsibility of the MS to step up the implementation of the recommendations and make full use of opportunities such as EU funds and sharing of best practices. **EU funds can be used to support the uptake of social measures that answer the needs of people with complex and progressive conditions**.

The **UN Convention on the Rights of People with Disabilities** must serve as a guide for MS to articulate their social actions.

The 2017 Annual Growth Survey that recommends focusing on human capital and social infrastructure paves the way for action in the development of integrated care services, affordable and flexible childcare facilities. Sustained investment in education and life-long learning to support employability and redress the gaps in wages and working conditions should benefit people with complex diseases. The Survey recognises social policy as a productive factor: national social protection systems must be redesigned to improve labour market participation, provide adequate employment security and income replacement.

The Pillar should therefore promote coordination between health, social, economic and financial policies to make better use of existing funds and deliver meaningful results.

On the future of work and welfare systems

4. What trends would you see as most transformative?

New trends identified by EURORDIS: new skills requirements, technological change as well as another trend not mentioned in the list proposed by the Commission - **secure labour contracts that for people with special needs**. These can give people with rare diseases and their carers the opportunity to enter and remain in the labour market provided that the position and workplace are fully adapted to their evolving needs (working from home, allowing time for medical appointments, areas dedicated to rest, upscaling of competencies).

5. What would be the main risks and opportunities linked to such trends?

Over the years, attention around RDs has mostly focused on research, diagnosis, access to treatment, proper health care, orphan drugs or new treatment options, concentrating on urgent health issues. In the meantime, social issues have been reported as a major concern for people with RDs and their families, as people with RDs benefit from longer life expectancies and have greater life expectations.

These trends call for the **adaptation of social services to the needs of people with RDs** and fully include **these services into national and European social policies as recently recognised in the Commission Expert Group on RDs Recommendations to MS and the EC**: “Support the incorporation of RDs into social services and policies” (2016).

Social security systems are usually designed around common diseases and not flexible enough to consider unprecedented health needs. **Medical and social costs associated to RDs have to be fully apprehended and included in discussions on the sustainability of the healthcare systems.**

People with RDs are willing to join the labour market and have the capacity to do so provided that **supportive accommodation and access to the workplace** are facilitated. It is important to **evaluate the added value of these people’s contribution to the economy** and not just focus on the cost of the social support they receive.

At this point, it is **absolutely necessary to add that people with disabilities must not lose their social benefits when entering the labour market.**

Technological change has a huge potential to support people living with chronic complex and debilitating conditions such as most RDs and to manage their health conditions and care pathway. To achieve this, **new technologies will have to be designed to adapt to the specific needs of users**. Users should therefore be involved in the development of new accessible and affordable technologies right from the beginning.

6. Are there policies, institutions or firm practices – existing or emerging – which you would recommend as references?

- [Commission Expert Group on Rare Diseases Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies](#) (2016);
- [Communication from the Commission on Rare Diseases: Europe's Challenge](#) (2008);
- [Council Recommendation on an action in the field of rare diseases](#) (2009): called for a plan or strategy to guide and structure relevant actions within the framework of the national health and social systems;
- [The Voice of 12.000 Patients](#) (EURORDISCare Survey – 2009);
- [EUROPLAN final report recommendations based on the 15 EUROPLAN National Conferences \(2010-2011\)](#): supporting the development of national strategies for RDs;
- [Communication from the Commission on 'European Disability Strategy 2010-2020'](#) (2010);
- [EUCERD Joint-Action paper 'Rare Diseases : Addressing the needs for specialised services and integration into social policies'](#) (2012);
- [INNOVCare](#) project - Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions;
- [European Parliament report on 'creating labour market conditions favourable for worklife balance'](#) (2016)
- EURORDIS [Fact Sheet on Adapted Housing](#);
- [Annual Growth survey published by the EC](#) (2016).

On the European Pillar of Social Rights

7. Do you agree with the approach outlined here for the establishment of a European Pillar of Social Rights?

EURODIS agrees with the outlined approach and would like to add that **the Pillar should apply to all MS (not just Eurozone countries) and should be binding.**

8. Do you agree with the scope of the Pillar, domains and principles proposed here? Are there aspects which are not adequately expressed or covered so far?

While the Pillar focusses on well-functioning fair labour markets and welfare systems, it must be comprehensive.

Employment as a vehicle for social inclusion is highly important for people with complex, progressive and disabling diseases, like people with RDs, and their carers. The Pillar must be inclusive and fully take into account the specific needs of these people who are most willing to contribute to the labour market and have the capacity to do so if appropriately supported. To ensure their autonomy and full participation in society, **the Pillar will need to include specific provisions to match the needs of these people** (e.g. work place accommodation, flexible working times, working from home).

Access to a fair and inclusive labour market must be twinned with adequate and sustainable social protection, to respond to the unavoidable and necessary social support. **Provisions must be made so that people with complex needs will never be deprived of their much needed social support when entering the labour market.**

People with complex needs and their carers call for a Pillar that will span the full life cycle, from childcare, education and training to entry and retention into the labour market, as well as smooth job transitions to delay exit from the labour market.

The Pillar should also push for the convergence of health and social systems across the EU in order **to support the development of holistic and integrated care pathways** and erase the disparities between MS, and sometimes between regions within the same MS.

Besides ensuring accessibility to goods, services and assistive devices for people with disabilities, **the Pillar should also be an opportunity to improve the assessment of disability and the accessibility** of sports, leisure, cultural/recreational activities, goods and quality community-based person-centred services.

The Pillar should not be limited to the Eurozone and should be binding to ensure meaningful uptake from MS.

Detailed comments by domain

- **Skills, education and life-long learning**

RDs are often complex, progressive, disabling and many of them affect children. Access to mainstream education for children with severe disabilities/complex care needs is difficult and sometimes segregated.

Obstacles in the education system can strongly affect future employment prospects and lead to social exclusion. **Legislators must remember that children and adults with RDs and disabling conditions have a right to education and life-long learning** (as per the UN Convention on Right of Persons with Disabilities), that most often their physical health does not affect their intellectual functions, that education and training allow them to fully participate in society and in the economy.

Therefore, **people with RDs must be fully integrated into the mainstream education system. Specific adjustments must be made to allow for full inclusion and equal opportunities:** physical access to the classroom, adaptation of the teaching methods/materials/evaluation process, support to teachers in the classroom for severe cases. To be prepared to deal with complex needs, the **teachers' curriculum should raise awareness about the specific educational and sanitary needs** of some pupils. An educational care protocol should be promoted.

The **education system must also be flexible enough to provide for necessary obligations such as attending regular health appointments or administration of treatments.**

The **teachers, educators and fellow students should be made aware of the specific medical and ambulatory needs** of people with RDs and be prepared to embrace and deal with the differences. Families of pupils with RDs are more than willing to participate in awareness/educational activities and promote non-discrimination, respect for differences and equal opportunities.

Additionally, education measures must go beyond school and include skills enhancement and life-long learning to allow people with complex conditions to enter and remain in the labour market for as long as possible.

- **Flexible and secure labour contracts**

Men and women with complex conditions like RDs have the potential and the willingness to enter and remain in the labour market provided the position is fully adapted to their needs. This equally applies to their carers, who are often a close family member. Both call **for flexible work conditions/contracts** to ensure the **workplace is adapted** to the evolving situation of the person (working from home, allowing time for medical appointments, areas dedicated to rest). In countries where laws exist to accommodate people with complex needs and their carers, they may not always be implemented.

The legislators must bear in mind that it not easy for people benefitting from work adaptations to change work repeatedly. **Work adaptation could be done based on reporting of skills and limitations performed by the services responsible for assessing** disability and functioning with the support from RD associations.

The tax and benefits schemes mentioned in the EC 2017 Annual Growth Survey aim at providing adequate social support and work incentives. **Financial incentives should certainly be provided to employers who adapt work positions** and favour employee with specific needs entry and retention in the labour market.

Social economy, which has the potential to give severe cases the opportunity to access a larger variety of workplaces, **should be facilitated and supported by national authorities and possibly EU funds** whenever possible.

People with complex, progressive and disabling conditions must benefit from training and upscaling of their competences on equal footing as their fellow workers.

Degradation of the person's health status must not be a reason for discontinuation of contract. Normative labour, with equal remuneration and holiday benefits, possibilities to take a given number of days off for medical appointments without wage loss must be applied to allow people with complex needs reconcile their private and professional lives.

- **Secure professional transitions**

The **Pillar should call for specific employment and social measures to accommodate the needs of people with complex and sometimes highly debilitating health conditions**, such as RDs, and support the provision of secure professional transitions due to deteriorating health conditions:

- **Flexible work conditions** to adjust to the evolving condition of people with RDs to avoid premature exit from the labour market and ensure continuity in the workplace, bearing in mind that it not easy for people benefitting from work adaptations to change work repeatedly.
- **Specific accommodation for return to work after a period of inactivity** due to illness or un-adapted workplace;
- **Professional re-orientation** as an alternative when the state of health deteriorates;
- **Disease-awareness raising to change the employers' mind-set** to move towards the understanding of creating social value rather than focusing on creating immediate profit;
- **Financial incentives to facilitate employment** of people with specific complex needs, accompanied by meaningful penalties systematically applied to employers who are not compliant;
- **Promotion of a social responsibility seal** as a driver for company to engage in measures that specifically accommodate people with complex health conditions and needs.

- **Active support for employment**

Active support for employment starts at school: **people with specific and complex health and care needs must have equal access to education** to secure at least basic academic and digital skills or professional training. **This is a pre-requisite to support subsequent entry in the labour market.** Life-long learning must also be proposed to ensure these people can remain in the labour market. Not only their contribution to the economy and society will give them a sense of achievement and pride, they will increase their autonomy (and financial emancipation from their parents).

To support entry and retention of people with complex needs in the labour market, the creation of a new profession (job coach) financed by national authorities could be envisaged. The job coach would act as a facilitator and case manager to help patients find a job, accompany patient accommodation in the workplace, facilitate job transition, raise awareness and trigger dialogue between the employee, employer and work colleagues so the specific needs of the person are fully understood. Besides, the job coach could also provide information about the employment rights people with RDs and their carers are entitled to.

Flexible and adapted work provisions must be guaranteed to ensure people with complex needs and their carers have access to secure employment and are not discriminated against. In addition, there must be a follow-up that guarantees the permanence of such provisions.

Potential employers should be able to benefit from national or EU financial support to provide young people with severe disabilities with sheltered employment schemes. This support would enable the adjustment of the work environment to the person's capacities, allowing them to work to their fullest potential.

- **Gender equality and work-life balance**

The primary carer role for people with complex and debilitating health conditions, such as RDs, is mostly assumed by women. Parents/mothers perform their caring role beyond childhood and adult childhood into adulthood. **Women carers are often forced to reduce/stop a professional activity to take care of the patient.** That most often excludes them from society, impacts their capacity to contribute to the economy, denies them of a decent pension and generates loss of income for the family. When available, carers' allowances are often insufficient to replace loss of a fulltime income. Specific attention must also be paid to single-parent families. In the majority of cases, women are responsible for both household support and care of their relative.

Women carers report high stress levels, high physical and emotional strain. The challenges imposed on families by complex conditions and subsequent stress can lead to the fragmentation of the family (separation). **Families need to be further supported to allow women to continue contributing to the labour market, reduce their stress levels and care for their health.**

The Pillar will need to include practical provisions to support the integration of women carers in the job market. Concrete and sustainable solutions must be found to support families with daily childcare, with flexible work schedules and respite care.

It is essential for carers of people with complex and debilitating health conditions **that working schedules and patterns are adapted to their needs and other flexible working arrangements** are found to allow them to join the labour market while not compromising their work-life balance.

Access to respite care is also crucial to limit stress, exhaustion and social exclusion. It can also be a factor to retain the carer into the labour market, thus avoiding economic hardship associated with job cessation. However, respite is in critically short supply, sometimes inaccessible, or often unaffordable.

- **Equal opportunities**

The gaps in equal treatment in the workplace are painfully striking for people with complex diseases, mostly due to the different definitions and assessment of functionality and disability across Europe. When they exist, legal provisions are all too often not respected, thus exacerbating stigma, exclusion and discrimination.

With sometimes minor adjustments, people with complex health conditions can have access to the workplace and thus contribute to society on an equal footing with other citizens.

Hiring of people with disabilities and complex health conditions as well as adaptation of work place must therefore be legally binding and financially encouraged. Non-compliance to legal frameworks must be penalised, including economic sanctions.

It is important to raise awareness towards employers and employees about the discriminatory attitudes that can be inflicted on people with complex need (e.g. inappropriate disclosure of their condition, lack of support when returning to work after a sick leave, or side-lining after a long-term absence). **The UN Convention on Rights of People with Disabilities calls for appropriate rights and legislation to prohibit discrimination related to health conditions.** It must be fully implemented and used to seek redress. Employees, employers and trade must be informed about these existing rules and rights and strive to enforce them.

People with complex diseases must be informed about their rights and receive guidance towards health and social services so they can operate on equal footing with their fellow citizens, having equal access to school, leisure activities or vocational training.

Labour inclusion of carers of people with RDs must also be addressed. Specific rights must be granted to carers such as absenteeism when having to accompany a minor to medical appointments, check-ups, tests, treatment and medical and complementary interventions.

- **Health and safety at work**

Adaptation of the work place for people with disabilities or complex needs must comply with **health and safety measures** that have to be in place.

Controls should be established for the maintenance of accessibility measures to ensure the permanent and relevant purpose of these measures. Specific provisions must be made for emergency measures to ensure less agile people are not endangered or put at risk. This equally applies to the school environment.

Colleagues or teachers of people with disabilities or complex needs must be trained to understand the disease and be in a position to help when needed.

It is important to **work with experts who really understand the limitations of people with complex needs and how to address them.** Experts may come from health services (e.g. Centres of Expertise for Rare Diseases), social services (e.g. Resource Centres for Rare Diseases), patient organisations and other services involved in care provision. These professionals should inform workers about their rights to accessibility and occupational health.

- **Social dialogue and involvement of workers**

Mainstream social services often respond inadequately to the expectations and needs of people with rare and complex diseases, especially when the demands are specific to the disease or to the complexity of the care pathway. This inadequacy of the social assistance is more severe for people with RDs who have a low income.

Patients are experts with their disease and most willing to share their needs and experiences to support the design and implementation of services and benefits, and drafting of social policies (employment, social services, and insurance policies) that are adapted and respond to those needs. **Patient involvement in decision making regarding the development and implementation of services and policies must therefore be required.**

Additionally, **patients' contribution must be supported financially,** as is the case of the contribution of the other experts informing decisions.

Patient organisations' role in informing decisions and creating informative and educational materials for general public (raising awareness, reducing stigma and improving the social integration of patients) **must also be recognised and supported.**

At workplace level, trade unions should either have a patient representative among them or a patient contact to guide their work.

- **Integrated social benefits and services**

The care of people with complex conditions such as RDs should not be restricted to (para)medical aspects but take into account social inclusion and educational development. Persons with RDs often need care support from different categories of health professionals, social workers and social services. These **multidisciplinary needs require coordination of health, social and community services.**

Integrated care can address the gaps in the coordination between medical, social and support services and must be developed to promote the autonomy and the quality of life of people with complex diseases and their carers. This includes the recognition of the diagnosis and its consequences on the daily life of patients and carers: recognition of the degree of disability/dependency and access to corresponding resources (school and social benefits, employment and housing provisions).

Innovative holistic and integrated care pathways will need to link up health services with the social and support services that people with RDs and their families use on a daily basis (e.g. school, transport, leisure services) and ensure the transfer of information and expertise between service providers.

The setting up of **one-stop-shop services** (e.g. Resource Centres for Rare Diseases) and/or of case management services that centralise the coordination of care can relieve the burden of care management for patients and families (cf. EU-funded INNOVCare project).

The various ongoing **reforms of integrated care across Europe must take into account the need to support people with complex conditions and disabilities**, and not just focus on hospital-based models which evolve around less complex and common chronic diseases.

National plans for RDs, now being developed and implemented in most EU countries, need to guide and structure integrated care for RDs within the framework of their national health and social system (including job entry, work place accommodation and job retention).

- **Health care and sickness benefits**

Improving access to better, more affordable, therapies/care for RDs is a priority, as is the adoption of national policies promoting specialised care through Centres of Expertise. Sharing of expertise via the new European Reference Networks and the promotion of integrated care pathways are cutting-edge solutions which prove to be cost-efficient, contributing to added resilience and financial sustainability of health systems.

However, these ongoing systemic changes do not translate yet into a full access to care/therapies: people with RDs still experience difficulties due to lack of information and access to experts/services, costly treatment/care, poor information on cross-border rights, lack of coordination between services. Access to high quality healthcare is not yet guaranteed to people with RDs and major health inequalities need to be addressed.

The Pillar could promote Resource Centres for RDs and the new European Network of Resource Centres for RDs developed by the DG EMPL INNOVCare project, **a one-stop-shop** providing information, guidance, training, social services and rehabilitation and **creating a bridge between people with RDs /families and health, social/support services. Case management services can also undertake similar bridging roles** supporting patients/families to navigate complex care pathways, access their rights and raise awareness of teachers and employers for their specific needs. These have an essential role to support the social integration of people with RDs and complex conditions and are complementary to the Centres of Expertise, as suggested by the Communication from the Commission and by the Council Recommendation on an 'Action in the Field of RDs'.

Adequate sick leave during illness of both employees with a RD or employees who are carers must be possible without wage loss. It should also be possible to take a number of days off for medical appointments without wage loss.

- **Pensions**

On-going discussions about statutory retirement age, late exit from work, difficult working conditions totally ignore the fate of people like carers of people with complex, progressive and disabling diseases like RDs. The needs of people with RDs are not fully met by the health, educational and social systems. This

often forces one of their parents to stop work thus putting them and the family in a precarious financial situation and depriving them of a pension they get older.

It is essential that the Pillar officially recognise the carer's role and provide for adequate support, including a specific pension scheme. This should make up for different situations: 1) the caring role is very demanding and does not allow the carer to work and contribute to a pension, 2) the carer has to stop work and cannot return to work because of advanced age, health problems or un-adapted skills, 3) the carer can return to work but will have lost a few years to contribute to a pension scheme.

The Pillar should call for a minimum pension that will allow the carer to live a decent life as they get older. Social solidarity must be an integral part of the Pillar.

- **Disability benefits**

The lack of common EU framework and tools for the assessment of functionality entails that patients' entitlement to disability benefits vary widely across the MS. The international classification system in the assessment of disability in all the MS would remove the existing inequalities in the recognition of disability.

Functionality assessment should take into account issues beyond physical and mental impairment, to comprise issues of 'social disabling' situations, often happening in complex chronic conditions.

Additionally, **RD specificities should be integrated into national systems assessing a person's level of functioning, in line with the United Nations Convention on the Rights of Persons with Disabilities.** These specificities relate to, for example, degenerative aspects and acute disease periods.

Access to disability benefits shall not create barriers to employment.

Specific situations experienced by some people in a couple of EU MS (HR, NL) who have to choose between receiving social benefits and accessing a job must be avoided. The provisions that will be enshrined in the Pillar must guarantee that employees with specific needs due to their health status and benefitting from social benefits must not lose out on those benefits necessary to their conditions when taking up a job. People with specific needs who engage in volunteering must also be able to do so without losing their benefits

Functionality / incapacity should be properly assessed and supported with adequate compensations measures.

- **Long-term care**

People living with RDs frequently need long-term care. Although physical or intellectual impairments require long-term care, other less physically and mentally disabling health conditions also require long-term and holistic care pathways to overcome the complexity of the disease and support patients' autonomy and carers' support.

MS should promote measures that empower patients in decision making and **support patients/families affected by RDs to participate in decisions regarding their care plan** and their life project (develop information and training tools for patients and families to empower them and increase their capacity to undertake a participative role in care provision; care providers to give non-directive assistance and support patients and families to express their wishes, set priorities, take decisions and direct their own services if they wish to do so).

MS should also promote coordination and networking between all parties involved in the care provision of persons affected by RDs, including public, private and civil society organisations as well as between providers and patient/disability organisations.

Socio-economic research in the field of RDs care provision/organisation should be supported both at Member State and EU level to better understand:

- The socio-economic burden of RDs;
- The accessibility and appropriateness of healthcare services, including social services for people living with a RD and their families;
- The effectiveness and cost-effectiveness of social services and support, as well as rehabilitation and assistive technologies for people with a RD;
- Innovative care practices in health and social services and their impact on the quality of life of people living with RDs.

As described in the detailed comments on Integrated Care, integrated care may provide cost-effective solutions that deserve being explored and adopted in MS.

- **Childcare**

The Pillar must have a long-term vision encompassing childcare, education, training and entry into the labour market. Children must have equal opportunities right from birth that will help them be better integrated in society.

Children must be integrated into mainstream school and adaptations to their specific needs must be implemented.

Carers of children with specific needs need support: child-keeping to allow **respite, childcare facilities** with opening hours that match the parents working hours, **properly trained staff**. This will enable parents keep their job for as long as possible and secure financial sustainability of the family. **Adequate coordination between the health, social and education services** is key to support such schemes.

- **Housing**

Housing adaptation is the 6th main investment made by patients/families affected by RDs (Federación Española de Enfermedades Raras' study on the Situation of Social-sanitary needs of PLWRD, 2009).

Housing adaptation is necessary to support people with complex health conditions and disabilities. This allows for independent living and autonomy.

Provisions for 'Adapted Housing Services' must be made as they make it possible for a person living with a RD to live as independently as possible, while being monitored by supportive staff habilitated to provide assistance for any daily routine activities that cannot be performed independently.

People with RDs can thus enjoy a high level of independence and autonomy, while being integrated into a community of peers without jeopardising their safety or their clinical and therapeutic needs.

On average, 16% of people with RDs (up to 24% for the low income group) are forced to move house because of their disease. The Pillar should also consider Adapted Housing in the form of a specific local/regional grants or tax deductions awarded to the patient's family to cover any house adaptation work, prevent families from moving into other facilities or adjust regular buildings to certain specific needs (wheelchair, small size, hearing disabilities, autistic spectrum disorders...).

Bridges should be made with building promoters: innovative initiatives such as making new buildings (like schools for instance) accessible to people with complex needs right from the beginning to avoid expensive modifications afterwards must be promoted.