



Applied research concerning inclusion of persons with disabilities in systems of social protection

Qualitative Research Report, Peru



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1

Introduction

Technical assistant at a free cataract screening talking to patients.



Sociedad y Discapacidad – SODIS and CRONICAS, Centro de Excelencia en Enfermedades Crónicas de la Universidad Peruana Cayetano Heredia, led by the London School of Hygiene and Tropical Medicine (LSHTM) undertook the ‘Applied Research on Inclusion of Persons with Disabilities in Social Protection Systems’ project in Peru, commissioned on behalf of the German Federal Ministry for Economic Cooperation and Development (BMZ) by the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH. The objective of the research was to determine how persons with disabilities are and can be adequately included in social protection systems. To achieve this objective, the researchers carried out surveys and interviews among the population of the Morropón district in the department of Piura in order to analyse the inclusion of persons with disabilities in Peru’s social protection programmes.

In this context, a qualitative study was undertaken to investigate the experience of households containing individuals with disabilities enrolled in the Juntos programme, known formally as the National Pro-

gramme for Direct Support to the Poorest (*Programma Nacional de Apoyo Directo a los más Pobres*).¹ Juntos seeks to generate human capital in households in conditions of poverty and extreme poverty, in joint responsibility with the State, through conditional cash transfers consisting of 200 soles bi-monthly and the use of health and education services for persons under 19 years old, including minors with disabilities, and for expectant mothers. In addition to the interviews with Juntos beneficiaries, a complementary set of qualitative interviews were undertaken with recipients with disabilities of the Pensión 65 programme, which provides a pension to extremely poor people over 65 years of age, to enable their experiences to be compared and contrasted.²

Both studies included interviews with local stakeholders, including participants with and without disabilities, public officers within the programmes and related services, and the Municipal Office for the Attention of Persons with Disabilities (OMAPED)³ in Morropón.

¹ Created on April 7, 2005, as part of the Office of the Prime Minister of Peru, by Supreme Decree No. 032-2005-PCM. In 2012, the programme was transferred to the Ministry of Development and Social Inclusion (MIDIS) by Supreme Resolution 004-2012-PCM, published on January 1, 2012. More information at: <http://www.juntos.gob.pe>.

² Created on October 19, 2011, by Supreme Decree No. 081-2011-PCM. More information at: <http://www.pension65.gob.pe>.

³ Established through Law No 29973, General Law on Persons with Disabilities, the main functions of the OMAPED are to promote and propose that, in the formulation, planning and implementation of policies and local programmes, needs and interests of persons with disabilities are taken into account; and to coordinate, monitor and evaluate local policies and programmes on disability issues. In addition, they must coordinate and oversee the implementation of national plans and programmes related to persons with disabilities, and manage the Municipal Register of Persons with Disabilities.

2 Objectives

11-year-old child with Laurence-Moon syndrome, which causes cognitive impairments and progressive loss of vision, learning the Braille alphabet.



The overall objective of the study was to investigate the experience of persons with disabilities in Juntos and Pensión 65.

The specific objectives were defined as follows:

- To explore participants' knowledge of the functioning of programmes;
- To describe the experience of persons with disabilities and the problems they confront regarding access and enrolment;
- To describe the difficulties that persons with disabilities or parents of children with disabilities face to meet the co-responsibilities;
- To describe the difficulties persons with disabilities face during payment;
- To explore the level of satisfaction of participants and their understanding of the quality of the programme;
- To describe how funds are used by persons with disabilities and their perception of the impact of the programmes;
- To assess the adequacy of the approach of the programmes in meeting the needs of persons with disabilities;
- To explore the perceptions of those responsible for administering programmes regarding persons with disabilities.

3

Methodology

A blind girl at a regular private school where pupils with disabilities have a personal teacher who acts as assistant to the regular class teacher.



3.1 Juntos fieldwork

A total of 24 interviews were conducted on the experiences of persons with disabilities in the Juntos programme, in the district of Morropón, Piura. The interviews were limited to adults and were based on the following profiles:

- **PROFILE 1:** Adults from beneficiary households of Juntos with children with disabilities (5-17 years), both those whose children were exempted from conditions and those whose children were not. This group had 13 interviews, 7 mothers and caregivers of exempted children and 6 mothers and caregivers of non-exempted children. 7 of the children with disabilities were female and six were male.
- **PROFILE 2:** Adults from non-beneficiary households of Juntos with children with disabilities (from 5-17 years). There were 3 interviews in this category.
- **PROFILE 3:** Adults with disabilities from beneficiary households of Juntos who are responsible for children registered in the programme. There were 4 interviews in this group.
- **PROFILE 4:** Local actors linked to the implementation of Juntos. Two teachers and two public officials (one from the municipality and the other from Juntos).

The fieldwork was carried out in two periods, in October and December 2014.

3.2 Pensión 65 fieldwork

A total of 12 interviews were conducted on the experiences of persons with disabilities in Pensión 65. In addition, two public officers related to the implementation of the programme were interviewed, the local programme manager and the head of the OMAPED.

Interviewees were selected on the basis of the following criteria:

- Gender: interviews were gender-balanced (six women and six men).
- An initial group of 47 persons with disabilities identified during the quantitative study (see below).
- Time spent enrolled in the programme: only those persons with a minimum of eight months' participation were selected to ensure they had sufficient experience of the programme.

The type, number and characteristics of the interview partners were as follows:

Table 4: Interview Partners and Characteristics

Interview Subject Type	Nº	Impairments
Female older person	6	Mobility, vision, or cognitive impairment
Male older person	6	Mobility, vision, or cognitive impairment
Pensión 65 local coordinator	1	None
Head of OMAPED	1	None

Source: SODIS/CRONICAS.

The fieldwork was carried out in November 2014.

3.3 Common elements

DATABASE. For both sets of interviews, the quantitative household survey undertaken by SODIS/CRONICAS was the primary source for the identification of the interviewees. This database was complemented by information provided by Juntos and OMAPED.

INTERVIEW METHODOLOGY. Semi-structured interview guides were used and these were developed in consultation with experts as well as a focus group

Table 1: Interviewees by characteristics of the Juntos member children

Interviewee	Caregiver	Period of time enrolled	Gender of child	Age of child
1	Grandmother	3 years	Female	6
2	Mother	Less than 1 year	Female	7
3	Father	2 years	Female	8
4	Mother	1 year	Male	7
5	Mother	1 year	Male	12
6	Mother	Less than 1 year	Male	13
7	Mother	1 year and a half	Female	7
8	Mother	2 years	Female	8
9	Mother	2 years	Female	13
10	Mother	Less than 1 year	Female	15
11	Mother	2 years	Male	11
12	Aunt	1 year	Male	13
13	Mother	2 years	Male	18

Source: SODIS/CRONICAS.

Table 2: Interviewees by characteristics of non-Juntos member children

Interviewee	Caregiver	Gender of child	Age of the child
1	Mother	Male	10
2	Aunt	Female	9
3	Grandfather	Female	12

Source: SODIS/CRONICAS.

Table 3: Interviewees JUNTOS participants with disabilities

Sex	Age	Impairments	Time of Affiliation	Affiliated children
F	60	Difficulty speaking, comprehension, and walking	8 months	1
F	64	Difficulty walking, due to arthritis	Over 2 years	1
F	n.a.	Blindness	2 years	1
F	n.a.	Difficulty walking, uses a walker. Epilepsy	1 year	2

Source: SODIS/CRONICAS.

with representatives of organizations of persons with disabilities. The interviews were conducted in the homes or workplaces of participants and were recorded after obtaining the consent of the participants. In a small number of cases, the interview process included the participation of a close family

member who lives with or cares for the person with disabilities being interviewed, for example where the interviewee indicated a desire to participate but had difficulties communicating or recalling specific information.

ANALYSIS OF INFORMATION. Audio recordings were transcribed and an initial codebook of themes and categories was developed from a critical reading of a small group of randomly-selected transcripts. The programme ATLAS.ti 6 was then used to search for similarities and differences between the groups interviewed.

ETHICAL CONSIDERATIONS. The study was approved by the Institutional Ethics Committee of the Universidad Peruana Cayetano Heredia. All identifiable names and references of participants have been replaced in the writing of this report to preserve the confidentiality of the participants and the following codes have been assigned:

- a. Caregivers of children with a disability enrolled in Juntos are 'enrolled caregiver' followed by a number.
- b. Caregivers of children with a disability not enrolled in Juntos are 'unenrolled caregiver' followed by a number.

- c. Caregivers with disabilities of children enrolled in Juntos are 'caregiver with disabilities' followed by a number.
- d. Older persons with disabilities enrolled in Pensión 65 are 'older persons' followed by a number.
- e. Public officials, regardless of their position, are 'official' followed by a number.

LANGUAGE. The present report use 'persons with disabilities' to refer to persons who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. Nevertheless, different documents and interviews quoted use 'disability' instead of 'impairment', which is a common practice in Spanish.

4 Results

84-year-old man at a free cataract screening by volunteers in a community hall with support from a local clinic.



4.1 Eligibility and enrolment

4.1.1 Eligibility criteria

The eligibility criteria and enrolment process for households in the Juntos programme is stipulated in Directive No. 003-2013-MIDIS/PNADP-DE, 'Enrolment Process Directive' (*Directiva de Proceso de Afiliación*).⁴ According to the Directive, the specific population served by the programme (target members) are families in poverty and extreme poverty whose members include pregnant women, children, adolescents and/or young persons (until they have completed secondary education or until their 19th birthday, whichever occurs first).

In November 2014, the Juntos directive was amended to include persons with disabilities who do not have educational or health opportunities, recognizing them as a specific target group for the programme.⁵ The new rule states that:

- Target members with no educational or health opportunities and target members who have an impairment, whether single or not, will be recognized.
- Households composed of target members with disabilities who have no accredited educational opportunities, whether single or not, will be recognized.

However, this change was not yet communicated to interviewees within the district so their responses reflect the previous approach to disability within the programme.

In the case of Pensión 65, enrolment is regulated by Directorial Resolution No. 024-2013-MIDIS/P65-DE.⁶

The selection criteria for entering the Pensión Programme are:

- To be 65 years or older;
- To be in a condition of extreme poverty;
- Not to be receiving any pension or grant from the public or private sector;
- Not to be receiving benefits from other social programmes, with the exception of Juntos, the Integral Health Insurance (SIS), literacy programmes, food assistance programmes, and reparations programmes;
- To have a national ID.

4.1.2 Enrolment process – Juntos

The identification of eligible households in Juntos is based on a two-stage verification process. The first stage involves analysis and error-checking of the initial census information in the SISFHO (with which potential users are identified). The second stage is public consultation at the Concerted Community Assembly Verification (*Asamblea Comunal Concertada de Validación – ACV*), in which representatives of the programme, local authorities and residents of the community participate.

In Morropón, the information-gathering step to determine the inclusion of households within the SISFHO database took place in early 2011. According to officials in the programme, there was no distinction made at this stage between households that contained persons with disabilities and those that did not. After completing the census, the first list of potential beneficiaries was published on the basis of which a communal assembly was carried out in order to validate the potential beneficiaries among the local population. Once these steps were completed, the first beneficiaries were identified. Afterwards, in the case of households whose eligibility was queried in the assembly or who were not registered by the SISFOH, the enrolment process could continue by direct request of the interested persons or the local community 'madre líder' (lead mother).

'Lead mothers' form a key element of the operational organization of the programme at the local

⁴ Approved by the Executive Direction Resolution No 045-2013-MIDIS/PNADP-DE, on June 13, 2013. In 2014, several points of this directive were modified, such as the requirements for enrolment, without modifying the principle guidelines.

⁵ Approved by the Executive Direction Resolution No 138-2014-MIDIS/PNADP-DE, on November 14, 2014.

⁶ Approved on May 10, 2013.

level, contributing to the dissemination of information about the programme and to its ongoing operations. They help to train caregivers in relation to health and education conditionalities associated with the programme, to disseminate the programme's objectives, and to assist in monitoring compliance of households. Their work was well known among participants interviewed. It is also important to note that the Juntos enrolment directive prioritizes women aged between 18 and 70 years old as the head and responsible of the household. Indeed, the requirements for affiliation state that 'la titular' (female beneficiary) must have an original and current national ID, implying that the head of the household will be a female. In the case of Moropón, from all the households interviewed, only one responsible adult was a male.

Mothers and caregivers of children with disabilities and caregivers with disabilities were asked about the eligibility requirements and process of enrolment for the programme in order to identify their level of knowledge and perceptions about the process. Their responses indicate that community meetings were the principle mechanism for the diffusion of information about the programme, but that knowledge and understanding of the overall enrolment process was quite limited (although in some cases additional meetings following enrolment helped to address this issue).

'After the lists were published, the governor called us to a meeting to inform us that money comes from [...] the government. We will be given this money every two months.' (Enrolled caregiver 8)

'My name was part of a list, and I wonder myself why, but they didn't tell me it was for the programme.' (Enrolled caregiver 5)

'After collecting the allowance we had meetings, I understood it by then. Before I didn't get it.' (Enrolled caregiver 4)

However, while understanding of the process itself was quite limited, Juntos participants were aware that the programme was focused on children and/or

'poor people' rather than being intended specifically to benefit persons with disabilities.

'Well, the engineer told us that it was for the poorest people, people who need this support.' (Enrolled caregiver 1)

'The engineer said that the programme was for children who were in school and not particularly for disabled children, because the disabled children had another programme, that is, other things that they wouldn't come here for, but that if the child was a student, yes, but primarily they were for normal children, that is to say, not for special children.' (Enrolled caregiver 8)

This was also understood by the mothers of children with disabilities not enrolled in Juntos, who said they were not considered for the programme because they receive income that disqualifies them as poor, are affiliated with 'EsSalud' (Social Security Health Insurance), or receive a pension. One individual, the aunt of a child with visual impairment, had attempted to enroll but was not considered eligible, because the head of the household (the grandfather) receives a state pension. In another case the mother of a child with an intellectual impairment who owns a small business selling gas said she had not even attempted to approach the programme.

'So, they come to see what little you have at home, and you can't have anything, not even a TV, for them to enrol you in Juntos [...] If they see you have good living conditions they don't enrol you. Lead mothers are in charge of supervising it, if you have means to live, they won't enrol you.' (Non-enrolled caregiver 1)

In terms of items required for registration, interviewees said that they had to present the national ID of parents and children and information regarding the health centres and schools of the children, which is consistent with the requirements stipulated in the regulations of the programme. In addition, a small number of users reported providing other documents for the enrolment process, such as their water or electricity bill.

'My national ID, my parent's national ID, the children's birth certificates, a copy of the utility bills and other papers.' (Enrolled caregiver 6)

In at least in one instance, staff members of the programme eased the requirements to facilitate the enrolment of households of children with disabilities by allowing them to bring the required documentation later.

'I told them, you know what, I only have three children with disabilities. I gave them the three birth certificates of the children with disabilities, and mine. That was it, they didn't ask me for a ton [of documentation]. Now I have the national ID for all of my children.' (Enrolled caregiver 9)

In addition, some users said they presented the certificate of disability and school certificate in order to corroborate the status of their children. This information was used to determine the type of enrolment of the child in the programme, either 'exempted' or 'not exempted' from conditionalities according to the condition or severity of their impairment.

'When we place an exemption in the system, we will in fact request a document that demonstrates the child's disability. As we are monitored and auditable we also have to prove that the student is not attending school because the child is exempted [...] The health sector is the one that usually gives that evidence, but sometimes there would be a district welfare office who is also normally responsible for addressing the issue of the disabled.' (Public official 1)

The majority of children with disabilities from the households interviewed were registered at the OMAPED and held a disability card, although caregivers and public officials were critical of the application process to get a disability ID card. Where children were exempted from educational conditionalities, they still had to be registered at a health centre to enable the household to be enrolled. Or, alternatively, if they had siblings then registration could be completed for them instead, enabling the household to join the programme.

'You must be enrolled [at school] or go to the health centre. If the mother says 'my son is not going to the health centre' we cannot finish the enrolment, because that's what we will check [...] Now, if they have more siblings, he can be exempted if the siblings are enrolled. Then the household receives everyone's benefits.' (Public official 1)

This situation is reinforced by the 2014 regulations referred to above in which it is stated that compliance with the programme will be verified in health facilities in the case of children with 'severe disabilities'. The updated regulations do not however include guidance regarding children with less severe impairments who are excluded from school or considered 'exempted'.

Overall, the Juntos enrolment process was reported as easy and straightforward by interviewees, in contradiction to one of the working hypotheses of this research. The four types of problems described by interviewees (delays in the enrolment, administrative problems, unfinished identification of potential beneficiaries, multifamily households considered by the programme as one family) were not linked to presence of children or caregivers with disabilities. In addition, programme officials appeared to display a degree of flexibility during the enrolment process to ensure households were able to join the scheme smoothly.

4.1.3 Enrolment process – Pensión 65

In the case of Pensión 65, which has operated in Morropón since October 2012, interviewees reported finding out of about the programme in one of three ways: firstly, through the media during the campaign of the current President Ollanta Humala (2010-2011) or the administration of former President Alan García⁷; secondly, through relatives or neighbours who mentioned the programme to them; and thirdly, they were enrolled directly by surveyors who visited the households.

⁷ In fact, this was the Solidarity Assistance Pilot Programme (Programa Piloto de Asistencia Solidaria), which was created in August 2010 and provided a monthly grant of 100 soles for adults over 75.

'Let's say that the television said that the Government, Mr. Ollanta, was going to give the pension [...] he offered to give a pension of 250 [soles] per month, but as it turned out it was 250 every two months. And so it is that when it came to the provinces [...] I went to the municipality, and I signed up.' (Older person 3)

'A friend points out to us that they're giving Pensión 65 [...] that they'll give me money [...] So, I took the motorcycle taxi, went over there to the administration [...] People were in line, they're lining up, and so I did too, and I jumped in line [...] And for that, a lady like you put my name down.' (Older person 7)

Older adults also mentioned a committee in the district during the government of former president Alan García which took responsibility for enrolling seniors in the city of Piura and requested a fee of between 2 and 5 soles per month. Apparently, enrolment never took place and the committee subsequently disappeared.

When asked if their enrolment in the programme was linked to their impairments some members of Pensión 65 replied that they did not know and others assumed that their disabilities were taken into account⁸. Participants were mostly aware that the programme was for older people in poverty, but many still considered their enrolment to be a matter of luck or 'the grace of God'.

'They told me the government was giving away a pension of 250 to help the elderly, the most needy, and as I found out, I went over there, and I said to myself, 'it's true' so then from there we continued on receiving, receiving thank God that we have received it and are receiving it.' (Older person 4)

'It was by luck, then, what else what it be? Or they would see my age, and take sympathy on me. Sometimes God gets involved, if one needs it. It's luck that they chose me. That's my luck, if you want, that favoured me for something.' (Older person 10)

The local coordinator of Pensión 65 confirmed that the programme does not target persons with disabilities specifically, although he stated that they have recently started to identify beneficiaries with disabilities during monitoring and to give them priority. In contrast, the OMAPED representative believed that no specific attention had been given to older persons with disabilities by the programme and felt that all social protection programmes ought to be in closer communication with OMAPED on this issue.

In terms of registration, most difficulties encountered were related to the lack of a national ID as well as delays in processing applications. As with Juntos some participants mentioned presenting documents in addition to their national ID, such as copies of the electricity bill or water bill. The local coordinator of Pensión 65 noted that seniors who have limited ability to remember face particular challenges, especially when it comes to the procedure for acquiring IDs.

'At their age, many times older persons don't remember where they were born or, not even, if they had a birth certificate. Thus, we issue a new birth certificate.' (Public official 5)

Relatives and the head of the OMAPED also expressed concern that some older persons with visual, hearing and physical impairments may face problems in accessing information on the programme and rely on family members or neighbours to inform them about it. However, despite this, the majority of interviewees stated that the enrolment process was almost automatic, often recalling only that they signed a form. Further, older persons with disabilities themselves did not report any problems specifically related to their limitations during the enrolment process.

⁸ It should be noted that many older persons interviewed did not consider themselves 'disabled' as they perceived their limitations as appropriate to their age.

4.2 Conditionalities

4.2.1 Knowledge of conditionalities

Juntos calls for ‘shared responsibility’ between enrolled households, whose members must use specified health and education services, and the state institutions that provide such services. Specifically, the members of enrolled households must fulfill the following ‘co-responsibilities’:

- Pregnant women: to attend monthly prenatal checkups;
- Boys/Girls 0-36 months: to go to the health centre for growth and development checkups, protocols outlined in primary health care;
- Boys/girls from 3 to 6 years: to attend early education schools or PRONOEI (non-school programme on early education);
- Boys/girls/teens/young people from 6 to 19 years or until they graduate from secondary school, whichever occurs first.

As mentioned above, these obligations were amended in November 2014 to provide guidance for the case of children or adolescents with disabilities:

- Households with a single target member with severe impairments will have their responsibilities (conditionalities) verified at the health facility.

It should be emphasized that the directive only refers to children with severe impairments who have no siblings. It does not specify what should happen in the case of children with severe impairment who are not the only child in the household, nor in the case of those children currently exempted from conditionalities, whose impairment is mild, who do not attend school regularly, and who rarely use health services in the area because they require specialized care that is not provided in Morropón.

In general, all Juntos participants interviewed understood the conditionalities required by the programme. Ensuring that children attend school was mentioned as the primary obligation by beneficiaries

of the programme. For many, this requirement also implied compliance with all payments required by the educational institution, such as tuition and parents’ association contributions, although in fact this is not regulated by the programme.⁹

‘We must [...] not owe money to the schools. So that money is to pay the schools. Because if we owe the school money, the teacher goes and tells the engineer [Juntos local coordinator] ‘that mom has not paid.’ (Enrolled Caregiver 4)

‘[Children] have to go to school, to pay school fees on time, to attend with the proper uniform, clean, all that.’ (Enrolled caregiver 6)

Parents and caregivers were aware of the need to undergo regular health checks. They were also aware that this requirement only applies for younger children (0 to 5 years old). However, a teacher who was interviewed said that she always told caregivers this was an obligation to be fulfilled even in the case of children older than 5 years.

4.2.2 Compliance with conditionalities

Within Morropón, children with disabilities were either enrolled in one of four regular schools or in the Basic Especial Education Centre – CEBE. Juntos caregivers of non-exempted children with disabilities all reported that they attended school regularly as did the three mothers with disabilities interviewed in relation to their children.

‘Q: Does your son always go to school?’

A: Yes, he goes at night.

Q: Always? Doesn’t he have any difficulty going?’

A: What do you mean? No, he goes every day.

Q: So, he is going.

A: Yes, every day my son goes to school. He has to go because if not they suspend you from the programme.’ (Caregiver with disabilities 2)’

⁹ The impact of costs for schooling on the poorest households has been raised in a number of reports by the Ombudsman Office: Ombudsman Office. Reports 127 (2007), 131 (2008), 147 (2009) and 155 (2011).

While some interviewees made the link between attendance and receipt of the allowance, not all interviewees identified Juntos as a primary reason for sending their children to school as they have always required their children to attend school.

'I am ignorant. I cannot read, but I do not like [that for] my children. I have never made them miss [classes]. There are some mothers who make them skip it so that they can help them with housework, I do not. It's the same with the girl [with disabilities], I have never made her miss the school. Or being late. Why is she going to miss school? She does nothing here, she has to go to school.' (Enrolled Caregiver 3)

However, the opinions of teachers and officials interviewed differed from the beneficiaries' statements in this regard. Two of them noted that the intervention of Juntos in the area has made children with disabilities attend schools more regularly and they perceived the fear of losing benefits from the programme to be a key factor in this regard. One interviewee also recognized that some mothers feel that the school 'does not help' children with disabilities and hence stop sending them to school, but that Juntos enables action to be taken in such cases.

'Here in Morropón all children are enrolled in Juntos, disabled or not. Yes, all children. [...] In a way there is a little more pressure. If they don't come to school there is no JUNTOS programme. So then there is a little pressure there and the children attend more frequently, sure.' (Official 1)

'Mothers have to bring their children to school every day. That is something that is being done, albeit when children get sick and bring a justification, there is no punishing for them. However, there are mothers who think that sending their children to the school does not help them, and stop sending them. That's when you give notice to the [Juntos] responsible and there have been cases of mothers who have been sanctioned [for that reason].' (Official 3)

Although children with disabilities who are exempted are not required to comply with the regu-

lar school attendance requirement, participants are clear that other children within the household do have to attend. For example, a mother whose daughter was declared exempted and who has another daughter and two grandchildren enrolled in the programme, explained that her daughter with disabilities was removed from the checklist of conditionalities but not the other children.

An exceptional case among the beneficiaries interviewed was a caregiver with disabilities, who herself has a daughter with intellectual impairments, who has not been exempted from the conditionalities. According to the mother, the adolescent daughter has speech, learning and walking difficulties, and attends an alternative school irregularly because she 'does not learn anything' and needs to be escorted by one of her sisters.

'At night school, she studies. Because she is disabled [...] we took her twice, every two weeks, like that.' (Caregiver with disabilities 1)

Similarly, some caregivers mentioned that regular school attendance ceased to be compulsory when Juntos programme officials realize the situation of the children.

'There is no such thing as mandatory compliance because the school principal and the teacher talked to the Juntos coordinator; then, he is aware of my son's situation.' (Enrolled caregiver 11)

Another interviewee mentioned hearing from a Juntos programme officer that:

'It is enough if they (children with disabilities) attend, out of all of the 20 days a month, at least 12, that is ok.'

As this suggests, there is clearly some flexibility in the enforcement of conditions regarding children with disabilities. Nevertheless, from the perspective of prioritising the development and inclusion of children with disabilities in the educational system, this flexibility has potential longer-term impacts as regular attendance ceases to be a priority for both the parents and the school.

Table 5: School attendance of children with disabilities not excused from conditionalities

Child	Impairment	Age	Level of education	School attendance	Difficulty to attend school
1	Blindness in the right eye. A lot of trouble seeing with the left eye.	6	1st grade Primary school	Regular	Transportation costs: three soles per day
2	Comprehension and communication difficulties. Heart murmur.	7	1st grade Primary school	Regular	Absences at school when she feels sick.
3	Serious learning difficulties. No medical diagnosis.	8	2nd grade Primary school	Regular	Feeling sleepy in classes. She does not like going to school.
4	Vision impairment. Frequent severe headaches. No medical diagnosis.	7	1st grade Primary school	Regular	Absences for headaches and body pains.
5	Partial blindness because of retinal detachment and maculopathy. Low school performance.	12	1st grade Secondary school	Regular	His mother wants him to drop school because of his severe headaches.
6	A lot of difficulty to hear, pronounced in the left ear.	13	2nd grade Secondary school	Regular	Having a hard time understanding classes. Classmates are bullying her.

Source: SODIS/CRONICAS.

Table 6: School attendance of children with disabilities excused from conditionalities

Child	Impairment/limitation	Age	Level of education	School attendance	Difficulty to attend school
7	Hydrocephalus. Difficulties to see, walk and talk.	7	Without reference	Irregular	Expensive transportation costs. Lives half an hour away from Morropón, has to go by motorcycle.
8	Cerebral palsy. Using wheelchair.	8	3rd grade Primary school	Regular	None.
9	A lot of difficulty to listen and to talk. A lot of difficulty to learn. Migraines.	13	5th grade Primary school	Regular	Child needs a lot of support and care, leaves classes. Child has two siblings with disabilities not attending CEBE (special education) because of the cost of transportation.
10	Mild intellectual impairment. A lot of difficulty to learn. Epilepsy.	15	3rd grade Primary school	Not registered	Child is not learning at school. She needs much care and support, and also needs an overseer at school because she is aggressive with other kids. Transportation costs.
11	Cerebral palsy.	11	No reference	Registered but not attending.	Teacher is not prepared to treat children who have seizures.
12	Mild intellectual impairment.	13	No reference	Not registered	Child is not learning at school. Transportation costs.
13	Mild intellectual impairment. Difficulty to talk and understand. Low school performance.	18	4th grade Secondary school	Regular	None

Source: SODIS/CRONICAS.

4.2.3 Challenges with compliance

The health problems of some children with disabilities associated with their impairments, such as pain and excessive sleep, were reported as one of the principle barriers to their regular attendance at school by both enrolled caregivers and public officials.

‘These children are quite susceptible to illness. For example in the case of one child, he cut his foot with a nail or piece of glass, and his foot immediately swelled and became infected, and for that he missed one week. [When] there is a strong wind, they catch cold; it gives them the flu. I have children who get seizures the night before to the morning, and it makes it difficult for them to be able to come, right?’ (Public official 1)

‘My son has headaches, he cannot see well. Sometimes at night the headache wakes him up because the pain he feels. I have to get up to warm him some water for his brain, because he tells me that his brain hurts, and in the morning at dawn everything hurts, his little body hurts. He tells me ‘Mommy, all my bones hurt, I can’t walk! He’s crying every morning. Sometimes he doesn’t want to go to school because he says ‘it hurts, Mommy.’ (Enrolled caregiver 4)

A similar challenge represents the cost of the daily transportation of children with mobility impairments. This aspect also affects children living far away from educational institutions. The cost of a motorcycle taxi is 1.50 soles per person (approximately 0.50 US Dollars) within the urban area Morropón. While one interviewee who lives in a village located half an hour from Morropón said that she spends 10 soles per day in sending her daughter to school which consumes much of the JUNTOS grant.

During interviews, it was mentioned that previously the local government authorities had paid for the transport of children with disabilities to the special school, but this service stopped when the council changed. The interviewees indicated that children attended school more frequently when they were able to rely on that benefit, both because of the direct costs and the time involved in escorting them home.

‘Many years ago, people say the Municipality paid the mobility, hired motorbikes taxis to pick up children from their homes. Then, they had more assistance [...] and yes it was quite regular. [...] A motorcycle charges 1.50 soles each trip. Go and back, it’s three soles. People will no longer have anything left to eat.’ (Official 1)

‘The Council send them transportation, but because another [mayor] came in, he wouldn’t send it [...] so now they are by their own, [...] you had to take care of them, looking for them, searching them, sometimes they come home at night, sometimes they’re still on the street and I have to go getting them. I have to be for them, sometimes things can happen. It’s very natural, as you see, people can take them.’ (Enrolled caregiver 12)

‘I don’t have the time to bring her, to carry her, because the special [school] is far and I have no transportation, I have no financial resources [to do that] every day; to pay for her transportation and to bring her back. And that’s the problem.’ (Enrolled caregiver 10)

Some parents also mentioned the lack of appropriate educational services for their children which meant that they were unlikely to benefit from attendance. While in one case, the school refused to allow the child to attend because of his seizures.

‘Every parent had to assume the responsibility to bring the child to school, but in my case, as my child began to have seizures and the teacher was no specialist for children like that [...] the teacher got scared, that was three years ago, she got scared and didn’t want me to bring my son because he seized and she was afraid.’ (Enrolled caregiver 11)

The following tables detail the attendance of children with disabilities reported by beneficiaries interviewed, divided according to the requirements of programme conditionalities (exempted and non-exempted) including the type of impairment, level of study and attendance, and difficulties attending classes.

Table 5 suggests that while non-exempted children all attend classes regularly, physical ailments associated with their impairment, such as headaches or pain, negatively affect the experience of many. Regarding children with disabilities who are exempted from conditionalities (Table 6), some regularly attend school in any case, but two children were not enrolled at all because of the costs of transport and the perception of parents that the child would learn nothing. However, it is noteworthy that in some cases of more severe impairments, the children attend on at least an occasional basis, suggesting that it is not necessarily the type of impairment of the child that determines their attendance, but that other factors such as transport, support and family perceptions are involved.

As mentioned above, where children with disabilities are exempted from conditionalities, the Juntos representative interviewed mentioned that supervision is accomplished by measuring their attendance at health checkups.¹⁰

'They are not enrolled in school because due to their impairment they cannot go every day. But, they are controlled in their health [because] they will need to go for health checkups.' (Public official 2)

This matches the testimony of a caregiver of a girl with disabilities, who is exempted and whose school attendance is irregular. She mentioned taking her for health checkups and knowing that her health checkups are being registered.

'Because they are children who cannot be obliged to go school, the teacher talked to the [Juntos] coordinator. So, I take her to the medical centre because they also visit the medical centre to verify if we are taking them there. If she accessed health care or not is not a problem, they registered attendance.' (Enrolled caregiver 4)

This approach is also reflected in the new Enrolment Process Directive mentioned above. However, at present it is not applied in all cases as some participants reported that they only take their children to the health centre when they are sick, not because of health checkups.

4.2.4 Sanctions for non-compliance

Breaching of conditionalities leads to discontinuation of the allowance until non-observance is justified or rectified and this is something all of the caregivers were aware of. Interviews revealed that six of the caregivers were suspended at least once, including one of the caregivers with disabilities. Nonetheless, in only one case did the caregiver consider the sanction imposed unfair.

'I don't know why I got suspended once. They suspended me for over two months, and then I asked the engineer: 'why am I suspended if I comply with my daughter's health checkups?' [who was pregnant]. He said, 'They suspended you at the medical centre.' He went to the medical centre to get an answer and I was complying with all my responsibilities, at school too [...] 'I don't know why they suspended you,' he said, because there was no reason, they should check better.' (Enrolled caregiver 4)

When a child with disabilities is absent from school, caregivers had to report it to teachers or Juntos staff, pointing out the reasons for the absence. Generally, teachers were responsive to parents' justifications because they are aware of the condition of their students and the difficulties they face. Teachers usually grant justification for absences, although in some cases they requested a medical note.

'Well, I go [to the school] and talk to the principal, or talk to his teacher. I told them he is not coming because he is not feeling good. Then, the teacher asks me to send him tomorrow, and if they still feel sick, let me know.' (Enrolled caregiver 1)

None of the caregivers interviewed said they had been visited at their homes by Juntos officials in order to monitor or support the accomplishment of conditionalities. Instead, lead mothers are in charge

¹⁰ According to MINSA, the growth and development control of children from five to nine years is made once a year. More information at: http://www.minsa.gob.pe/transparencia/dge_normas.asp.

of follow-up with families and organising orientation meetings for caregivers in which Juntos officials may also participate. The topics of these meeting are how to spend the money and avoid sanctions. They also discuss cases of non-compliance with conditionalities and sanctions for caregivers at fault.

‘Q: Has anybody from Juntos visited you? Have you ever talked to a Juntos official?’

A: No, we just have meetings with the lead mothers in my neighbourhood. We have our own lead mother and she calls us for meetings every month.’ (Enrolled caregiver 11)

‘The lead mother always convene meetings for us and we talk [about the programme]. She tells us to keep children’s school attendance, and if there is any absence we should justify it... They ask us for not to stop taking children for health checkups, and required vaccinations.’ (Enrolled caregiver 5)

Caregivers also mentioned the potential for sanctions if they are thought to be misusing the allowance by spending it on something other than their children’s needs. For example, although it was not a widespread practice some mothers were reported for using the grant to buy alcohol instead of buying food for their children. Lead mothers report these cases to Juntos local managers for follow-up purposes, including social sanctions.

‘We are looking for a mother who used to get drunk with the money from the allowance, when it is supposed to be used for children’s necessities. Because of this, we have meetings and discuss this; so if we know somebody is not respecting the agreement to use the money for the children, I have to report this to the ‘engineer’. You report the case to the lead mother, she talks to the engineer, and the next month the accused person would be asking: ‘why am I not getting the allowance?’’ (Enrolled caregiver 1)

‘We all had to attend the meetings [...] ‘We don’t want you to buy home appliances, but food for the babies’, they told us during the meetings. Some-

times they penalize us; for example, they didn’t give me the allowance of 200 [soles]. Then, they told me to write down: ‘I am being punished for laziness. Laziness overcame me and I couldn’t go.’ They wrote big papers like that, we wrote that on the board.’ (Enrolled caregiver 9)

When asked about this issue, some Juntos officials interviewed proposed to establish a direct supervision strategy for the way parents use the allowance received from the programme; and to conduct periodic households visits to assess *in situ* living conditions of the users and verify if they really need to be programme beneficiaries.

4.2.5 Conditions for Pensión 65 beneficiaries

Pensión 65 programme has no conditionalities. Collecting the allowance every two months was the primary responsibility seniors reported as necessary to maintain their enrolment, although in reality the programme does not require users to cash the allowance on a specific date, they can do it at any time. Nonetheless, there is widespread perception that members have to go to the bank according to the schedule Pensión 65 establishes.

‘Honestly, they don’t say a thing. We just go to collect the allowance, and that’s it. They don’t say: lady you should be informed of... They just give us money, they give us a paper, and they tell us to come back in on a specific date and that’s it. This is how it is.’ (older person 5)

Some members of the programme (and the head of OMAPED) also reported that they have to attend a medical consultation. In addition, some older persons said that they were required to enrol in the Integral Health Insurance – SIS (*Seguro Integral de Salud*).

‘The only thing we’ve been said is we have to go to the medical centre to ask for social health insurance, to access health care services. The doctor said that, because of Pensión 65, you could access to hospitals in Piura,’ (Older person 7)

However, rather than a requirement, accessing SIS is actually a benefit and not a condition of being enrolled in Pensión 65. Enrolment is supposed to be automatic.

4.3 Payment

4.3.1 Payment for Juntos beneficiaries

The allowance given by Juntos is 200 soles (approximately 66 US Dollars). This amount is paid every two months, and the enrolled caregivers need to go to the National Bank office or to a National Bank ATM machine to collect the allowance.

Table 7: Options to collect the allowance provided by Pensión 65

Code	Method of travel	Person accompanying	Cost (Soles)	Time	Difficulties
1	Motorcycle taxi	Son	3.00	4 minutes	Mobility impairment; helped by her son.
2	Walking	Niece	0.00	5 minutes	Niece helps because he has difficulties walking (uses crutches).
3	Motorcycle taxi	Son or daughter	0.00	10 minutes	No difficulties. Son runs a motorcycle taxi so she does not pay.
6	Walking and motorcycle taxi	None	1.50	20 minutes walking 5 minutes motorcycle taxi	Goes by holding onto walls, or some people help him on his way.
7	Walking and motorcycle taxi	Husband	3.00	15 minutes walking 5 minutes motorcycle taxi	Her husband helps because she has difficulties walking. They take a chair with them to allow her to rest.
8	Walking	Daughter	0.00	20 minutes	Her daughter helps her because she has difficulties walking.
9	Motorcycle taxi	Daughter	2.00	10 minutes	Her daughter helps her because she suffers from dizziness and she can fall down.
10	Walking	None	0.00	20 minutes	He has visual impairments. He goes walking slowly, clinging on to the walls, until reaching the bank.
11	Motorcycle taxi	Daughter	3.00	10 minutes	Her daughter helps her to go because she has significant difficulties walking.
12	Motorcycle taxi	Wife	3.00	10 minutes	His wife helps him to go because he has significant difficulties walking.
13	Motorcycle taxi	Son	3.00	10 minutes	Her son helps her to go because he has difficulties seeing.
14	Motorcycle taxi	None	3.00	5 minutes	He has difficulties seeing, but the motorcycle taxi leaves him just in the front of bank.

According to caregivers interviewed, the lead mothers are in charge of informing them of the date of payment, following a specific schedule established by the Juntos programme, and it should be respected to avoid being suspended.

'You can't go before that date, because if you go before, they suspend you... You can go on the day after, but not before. She [the lead mother] lets us know when to go. She says you can go to the ATM machine with your debit card, and we go, but only if our lead mother said we could go. She helps the programme.' (Enrolled caregiver 5)

'Now we are using ATM machines with our debit card, and the lead mother is always watching, and the engineer is also watching. If we go to collect the allowance late, they also suspend us, because we are not proceeding as requested.' (Enrolled caregiver 4)

Caregivers of children with disabilities and caregivers with disabilities did not mention having problems accessing the bank. The only difficulty mentioned by some of them was in using the debit cards as it was the first time that they had used this technology. Moreover, caregivers mentioned that they received priority treatment in consideration of their children's disability. This normally happens without the need for a request from caregivers, except for one case in which a caregiver said she had had to argue with security staff at the bank.

Furthermore, three caregivers with disabilities interviewed mentioned that they receive priority attention and support by the bank staff when cashing the allowance. In only one case does someone other than the caregiver collect the allowance, in this instance the caregiver's daughter who collects the money on behalf of her mother.

'I go with my debit card. I go with him [a family member] and a young lady at the bank with a little machine presses the buttons - because I don't see. She says: 'take this, this is your money'. She rolled up the bills and gives it to me.' (Caregiver with a disability 3)

'I go by motorcycle. They get me in, I wait for a while and then I get out... The janitor who is at the entrance helps me to get into the front.' (Caregiver with a disability 4)

'Well, look I don't know how to read. I go with my national ID, a copy; I gave it to the bank agent, and he made me put my fingerprint. And then he gives me the money.' (Caregiver with a disability 2)

4.3.2 Payment for Pensión 65 beneficiaries

In the case of Pensión 65, the allowance given is 250 soles (approximately 83 US Dollars) per person, also on a bimonthly basis. To collect the allowance, participants also have to go to the National Bank office or to a National Bank ATM machine. At the counter of the bank, they must show their national ID (original and copy), and a receipt for the last payment.

All of the older persons interviewed mentioned that they go personally to cash the allowance. However, the Pensión 65 programme coordinator mentioned that in cases when seniors are unable to collect the money, family members may represent older persons to collect the allowance. In this situation, the participant can grant a letter of attorney authenticated by a notary or, when there is no notary in the district, by a local judge (*'juez de paz'*).¹¹ The letter of attorney is only valid for three months to reduce the scope for fraud.

'Now, regarding persons with disabilities, if they can't move from home to the bank for payment, you can write a letter of attorney. Or, if the user tries and manages to come, then we give him the facilities for getting paid quickly. Everybody is important, but there are some people in a more urgent condition than others [...] We are trying to give facilities to judges so they can send a letter of attorney to the bank.' (Public official 6)

¹¹ Information available at: <http://www.bn.com.pe/gobierno/programas-sociales/pension-65.asp>

‘Letters of attorney are valid for three months. Why? Let’s supposed you got a letter of attorney for one year. What could happen? There is a phrase I’ve always paid attention to: Where there’s a law, there’s a loophole.’ (Public official 6)

In general, members of Pensión 65 go to the National Bank by motorcycle taxi, although a smaller number reported walking despite their seeing, walking or remembering limitations. Many older people go to the bank with a family member rather than on their own. Motorcycle taxis cost 1.50 soles; consequently, they usually spend three soles and it takes them between five and twenty minutes depending on the area in which they live.

In general, older people reported that the bank provides a good service and they experienced very little inconvenience. The few complaints were related to staff behaving in a rude manner when they queuing.

‘No one. Thanks God, so far no one, because everybody is kind to me.’ (Older person 5)

‘Those in charge of paying are a bit rude; sometimes the security person is rude too. This short guy who is in service now, he is very kind to us. But the others are not so friendly. The problem is that my mom cannot sit down for so long. If mom would have better health conditions, things would be different. Though my mom is 87 years old now, almost 88.’ (Caregiver family member)

It is important to note that, despite the generally positive perception of the service they receive, older people mentioned they usually have to wait in line between two and five hours. Many users have difficulties walking and are not able to stand up for so long which is why they bring chairs with them or they sit in the streets waiting for to be served. As such, the lack of complaints may be partly explained by the users’ low expectations in terms of the receipt of services.

‘They start paying the cripples. When there are no cripples left, they pay everybody else.’ (Older person 10)

‘I am obliged to line up and, sometimes, I can’t stay standing up on my feet.’ (Older person 5)

‘Sometimes I go, but I cannot stay standing up on the line. I go to sit on the street.’ (Older person 12)

Most of the users of Pensión 65 go to the bank on the first day of payment and after the second day the number of users reduces significantly. According to the Pensión 65 programme manager, seniors can cash the allowance at any time and at any place in Peru. Nonetheless, most still believe that if they do not go to the bank on the first day, they will not be able to claim the payment.

‘They’ve been informed that they can cash the allowance any day during the week, in any place in Peru, at the National Bank. However, seniors always think if they don’t cash the first day they will lose the money.’ (Regional Coordinator)

A public official also mentioned that the bank has just one counter for preferential attention, which is attended by the manager of the office. However, because the manager has many responsibilities, he is not permanently at the counter and as a result older persons with disabilities often have to wait for a long time. This is compounded by the size of the bank office which has only three counters.

‘Yes in Morropón we have inconveniences because the bank is very small. The bank just has 3 staff people.’ (Public official 6)

Overall, older persons with disabilities enrolled in Pensión 65 face more difficulties than Juntos caregivers in collecting the allowance, in particular when they have mobility or visual impairments. They often have to go to the bank escorted by a family member, and most have to pay a motorcycle taxi even though the district is small. In addition, they face long waits at the bank itself even if they are able to join the line for preferential treatment. However, despite this, the perception of the users is generally positive with very few specific complaints and no-one reporting being unable to claim the payments.

4.4 Using the allowance

All of the Juntos caregivers stated that they spend the allowance mainly on food and education for the children under their care, which accords with the guidance of Juntos officials. As such, most mothers reported that immediately after collecting the allowance they buy food and essential supplies for their children. If there is any money left over, it is generally used for buying school uniforms, registration fees and other school expenses.¹²

‘They told us in a meeting that the money given was meant to be used for food, medicine, but nothing else.’ (Enrolled caregiver 8)

‘Before they said that money given was meant to be used for supporting [the children] and for paying school.’ (Enrolled caregiver 9)

‘This is the kid’s money. No, we don’t take it for ourselves; all of this is for the kid. For example, if the kid needs new shoes, we buy them. The same if he needs a notebook. Everything is for him [...] Well, I can take some money as a loan and as soon as I get the money, I put it back. That is what was being said by an official, we cannot take the money because this is for the kid.’ (Enrolled caregiver with disabilities 2)

A caregiver of a child with a visual impairment also mentioned that, apart from general school expenses, she has to buy silicone on a weekly basis because it is used by the teacher to delineate the contours of the words for her child.

‘The teacher puts silicone on the numbers, words, and she says to my daughter to ‘touch it’. Then my daughter goes through from side to side, and she recognizes it. She does this every day, so we have to buy silicon every week... It costs six soles, a big bottle of silicon. We have to buy silicone [every week] because without it she couldn’t work.’ (Enrolled caregiver 1)

When asking caregivers if the 200 soles allowance given by Juntos is enough to meet the needs of the children under their care, all agreed that it is not. It is particularly insufficient in cases in which the child’s impairment obliges families to spend more money on a regular basis, for example diapers or medicine.

‘A: I collect the money from the allowance provided by Juntos, I go out at 4pm from my job, I go to buy milk, a big package of diapers, costing 48 soles, 25 pounds of sugar and a bag of rice.

Q: How many days do those diapers last?

A: 17 days for both of them, they share. Milk sometimes lasts 16 or 15 days [...]

Q: Only for diapers and milk?

A: Yes, only for this.’ (Enrolled caregiver 9)

‘A: I use one hundred soles to buy rice, sugar and essential supplies. I use fifty soles for them, diapers, medicine and the other fifty for school, lunchbox, fruit.

Q: Is this how you distribute it?

A: Yes.

Q: Is it enough?

A: To be honest, it is not enough.

Q: What are you usually unable to buy?

A: Mainly, I use it for diapers and medicine. Sometimes I have and sometimes I haven’t, sometimes I spend my money and I don’t have more to buy stuff for him.’ (Enrolled caregiver 8)

Interestingly, none of the interviewees specifically mentioned the transportation expenses for attending school, even in the case of children living outside the centre of Morropón, despite the high cost that this represents for the household. In only one case, the caregiver mentioned being able to put aside savings as a consequence of being enrolled in Juntos, enabling her to purchase more expensive items.

‘From the 200 soles, sometimes I kept some, and the rest I invested in purchases. For example, I bought a dresser for each one of my children, they didn’t have one before. I could buy this for each of them with the allowance I received. Because they had new dressers, then they needed better mattresses.

¹² Students in the area received food made at school but the cost of this meal is covered by parents.

Well, these are more expensive, right? I also bought them new mattresses.’ (Enrolled caregiver 6)

In the case of Pensión 65, most older persons with disabilities managed the allowance directly. There were only two examples in which this was not case, both male beneficiaries who passed the money to their wives because they felt that they better understood the needs of the household and were in charge of the distribution of resources.

Most interviewees said that they spend the majority of the money received from Pensión 65 on food. Some of them buy food in bulk on the day of payment because they can get access to wholesale prices, while others use the money to buy items day by day. All interviewees said that they mostly buy essential products, such as rice, sugar, milk, pasta, oil, eggs, meat, fruits and vegetables. Where Pensión 65 recipients lived with their adult children, they also mentioned contributing to buying household products or food as well as electricity and water bills, and, in a couple of cases, even investing in home repairs.

As with Juntos, the money received from Pensión 65 is generally insufficient to cover all of the needs of

older persons with disabilities. Because of this, interviewees reported that most of the time their adult children had to provide extra money to help cover their subsistence costs.

‘Sometimes when I am short of money my children help me out, I don’t buy a thing here, I only buy what I will eat. (Older person 7)

Regarding health care, many respondents mentioned that they spent money buying medicine and paying for medical consultations in private or public health facilities. They reported purchasing medication for vision problems, arthritis, pain and high blood pressure, among other things. However, many also reported interrupting or improperly following treatment due to lack of resources and, in some cases, adult children helped to pay for the treatment needs of their parents.

‘These days because there is no [public medical] care, it costs 6 soles buying medicine in the drug-store [...] If we need a [medical] exam, they charge 30 soles. In addition, they charge 20 soles for medical care, only for medical care. So, they charge 50 soles, without medicine.’ (Older person 7)

Table 8: Economic activities of household’s heads

Participant	Household head	Marital status	Nº underage dependents	Other dependents	Household head occupation
1	Grandmother	Separated	6	0	Merchant
2	Mother	Separated	1	0	Temporary merchant
3	Father	Separated	1	2	Temporary labourer
4	Father	Married	3	0	Temporary labourer
5	Father	Concubine	4	0	Merchant
6	Father	Concubine	4	0	Temporary labourer
7	Father	Married	1	0	Temporary labourer
8	Father	Married	4	1	Temporary labourer
9	Father	Concubine	5	0	Temporary labourer
10	Mother	Widowed	4	0	Farmer
11	Mother	Separated	2	0	Merchant
12	Aunt	Single	2	4	Merchant
13	Mother	Separated	3	1	Merchant

Source: SODIS/CRONICAS.

'I have been motionless for five years; five years static. Because of that, my daughter gives me that, no matter what, 400 soles. She bought bone-building pills for me.' (Older person 11)

In general, older persons with disabilities reported not be able to meet the expenses of accessing health care services with the money from the allowance, especially when they needed regular medicines due to their impairments or specific services or devices, such as crutches, a support cane, eye drops or glasses.

4.5 Impact

4.5.1 Economic impacts

Although the amount of the allowance families receive from Juntos is considered insufficient for all their needs, there is nonetheless a positive perception of the programme amongst most caregivers.

'Who gives money during these days? In this crisis time? Even if allowance would be only 50 soles, it would a kind of help. Government helped us.' (Enrolled caregiver 5)

'Juntos programme is a great help to me. Sometimes it is more money than the money earned by the father of the children. It is not enough and sometimes, during the weeks he is not working, we don't even have anything to eat. Fortunately, during those days we got the notice that payment is ready, and we have to go to collect the allowance. Then we have for our children. To us it is a great help.' (Enrolled caregiver 4)

The capacity to plan economic expenses based on the security of a fixed income to be received over a fixed period is another important benefit, while some women reported being empowered within the household economy by the receipt of the allowance.

'[Juntos] changed my life [...] because before, I didn't manage money, but now this is money for my children, so I manage 200 soles for them. Their dad cannot spend this money, because this is money for my children. I know what to buy for my children, food, breakfast, lunch. Before, his dad controlled how much I spent on food; he used to ask how much does the fruit cost? But now, nobody controls how I spend the money for my children. In this facet, my life has changed a lot.' (Enrolled caregiver 15)

Even though the allowance given by Juntos helps with the household economy, the amount is insufficient for large families and even more when heads of households are unemployed or in temporary employment (as is common with the agricultural labour market in Morropón). Table 8 illustrates the high number of dependents and unstable economic livelihoods of many of the households interviewed.

'I wouldn't have a concrete answer regarding improvement. Money is very little; 200 soles every two months is very little. I don't think that amount would change their lives, or improve household economies [...] Here families are large; they have six, seven, four, three.' (Public official 1)

'They spend the money in food and school, because they have to pay registration and buy school materials for children. I wonder how these mothers manage having five or seven children, because Juntos provides only one allowance per family.' (Public official 3)

Nonetheless, Juntos can represent the most important income source in households with a lack of family support. This was the case for a widow with severe impairments who also has a daughter with mild impairments. Both face difficulties in their ability to work and as such, without Juntos the widow would be totally reliant on money provided by her other children. Another mother, a caregiver of a child with disabilities who has three other children and whose partner sells bread products in the street, also reported a similar situation.

'Q: Who helps you the most financially?

A: Juntos programme. [...] At least I can have money for one month, at least for food'. (Enrolled caregiver with disabilities)

In a context of economic precariousness, most of the parents of children with disabilities reported spending their resources supporting all of the members of the family, without particularly prioritising the needs of children with disabilities. For instance, the mother of a child with a hearing impairment said that her children's life has improved because they are more comfortable at home, but she was not able to repair the hearing aid her son uses. As such, even though caregivers interviewed recognized the benefits Juntos brought to them, some of them expressed a preference for a social programme specifically oriented to persons with disabilities. This reflects the limitations of the programme described above in terms of covering the additional costs of disability and enabling children with disabilities to access specialized health and education services.

In the opinion of the officials interviewed, the conditions of children with disabilities enrolled in Juntos have improved since the programme began. However, most also believed that it was not sufficient to assist households to escape from poverty or exclusion, partly because of their precarious economic situation and partly because of other factors, such as the lack of teachers with adequate training on inclusive education.

'It has been observed a change [because] now children are going to school. They are also better nourished. The difference is noticeable, but this is not happening in all cases [...] There are still some cases of children with poor school performance. In these cases, changes or improvements aren't noticed because they should have a preferential treatment for their problem, which is not happening.' (Public official 3)

'A high percentage of persons with disabilities in the area is poor [...] There is a general kind of poverty [in Morropón], but this is aggravated for fami-

lies having members with disabilities. Here, for instance, I know there is a family in which four of his members have disabilities. If we imagine how they live, their conditions [of poverty] are even more heightened. (Public official 2)

In the case of Pensión 65, older persons with disabilities also felt positively about the programme at a general level. This includes the symbolic benefit of inclusion in the programme as many felt that this was the first time that the State had cared about them and provided them with assistance, which implied a recognition of their rights as well as the of time they had worked. Most mentioned that now they can at least pay for basic food and medicine and some even said that the regular income was sufficient for them to stop working. However, as with Juntos, although in general beneficiaries reported that their situation had improved, the majority said that they still do not have enough resources to address the specific needs related to their impairment.

4.5.2 Educational impacts

Since school attendance is one of the main responsibilities of the beneficiaries, inclusive education for children with disabilities is a necessity if the longer-term impacts of the programme are to be achieved with respect to these children. However, the information compiled from the interviews with caregivers suggests that schools in Morropón do not adequately accommodate the needs of children with disabilities. In general, the caregivers interviewed felt that teachers at the regular schools treated children with disabilities well, sometimes giving them more time and attention than other children. For example, one caregiver even mentioned that the teacher awaits her granddaughter's arrival and goes with her to the restroom when she needs it. However, there were also a number of complaints about the poor treatment of children with disabilities at school.

'Other children were standing up front and he [my son] was at the back, then I said: teacher please place him at the front, not at the back [...] Sometimes he needed to go to bathroom and they didn't

allow him to go. He urinated his pants. After that, I had to get him out and put him back in a new school. Thanks God I made friendship with all of the teachers, and they treat him well.’ (Enrolled caregiver 13)

‘Once, she came with bruises on her body. She told me that teacher had hit her. We went on an assembly and I complained about the teacher’s bad treatment to my daughter. Other parents backed me up. The teacher told me that I should have talked to her privately. I apologized but I was angry because she knows my daughter has a disability.’ (Enrolled caregiver 10)

In the opinion of an official interviewed, this issue is related to the lack of training for teachers at regular schools and the lack of support from the Support and Advisory Service to Special Educational Needs (*Servicio de Apoyo y Asesoramiento a las Necesidades Educativas Especiales* or SAANEE)¹³ of Morropón.

‘Although it is true that children are sent to regular schools, they are being discriminated against at school. They are not being attended to according to their needs. I am on the side of teachers; they are not prepared for teaching children with disabilities. This is hard work for someone in charge of another 20 or 30 children. This is a professional challenge for them, and they are not well-trained. The CEBE do not have a SAANEE to provide logistical support.’ (Public official 1)

It is significant that some parents described teachers as ‘good’ because they gave their children a passing grade in courses in consideration of their disabilities, even when they were aware of the low levels of achievement of their children.

‘Now she is at school, at fifth grade of elementary school [...] She is passing every year; she has never

failed a course. However, she misspells the words, for instance instead of ‘mamá’ [mother], she wrote ‘amama.’ (Enrolled caregiver 9)

‘He is registered at the OMAPED; he has a disability card, and he gave a copy to every teacher. They help him, his grades are low but he passes.’ (Enrolled caregiver 5)

Regarding the school environment for children with disabilities, four mothers reported that their children had suffered bullying or discrimination from schoolmates and teachers. In some cases, teachers or school authorities intervened, although this did not adequately address the issue.

‘They give him nicknames [...] He says: ‘mom, they don’t want me there. If we need to work together they leave me alone, they told me ear-something’. I felt sorry, they insult him and he told me ‘mom, why did they ask me if I am sick? I don’t have a contagious illness, why are they this way with me?’. He comes home angry saying: ‘I resent I cannot listen, they laughed at me because I can’t hear and I get angry’. He comes and argues with his brothers, he wanted to fight with them. This [situation] affects us, because I know he suffers because he has to use a hearing aid and it’s sad.’ (Enrolled caregiver 6)

Although Juntos officials are not mandated to intervene in these cases, one mother mentioned that the local coordinator of the programme informed the school about the care required by children with disabilities leading to a positive change. However, this was the only case reported of an intervention by Juntos official in this manner.

Regarding the CEBE ‘Fray Martín de Porres’, many of those interviewed reported serious limitations and deficiencies. Even though this is the only special education centre for children with disabilities in the entire province of Morropón, they can only provide education to eight students because they only have one teacher. Indeed, according to one public official interviewed, last year the CEBE had just six students attending regularly. Further, the centre’s teacher is

¹³ The SAANEE is part of the CEBE. It is composed of teaching professionals and other personal trained to provide support and advisory services to regular schools, students with special education needs related to disability enrolled in basic regular education and technical productive education, and also parents or guardians. More information at: <http://basicaespecial.minedu.gob.pe/saaneer>

also in charge of administrative tasks, such as running the school as a principal, and is not in fact a special education specialist. She has training in early childhood education and has been reassigned to this position. Many of the caregivers interviewed were aware of these issues and also highlighted the inadequate infrastructure of the centre.

'Before this school was taken by UGEL and used as a storage. Until now it is being used as a storage [...] Now, the teacher is in charge, because there is no director until now. She was supposed to be the only teacher to attend just eight children, but they need much more. For example, they need a psychologist, a neurologist, a nutritionist because children need to take consultations with them. They need well-trained personnel to work with students with disabilities.' (Enrolled caregiver 11)

In this context, parents prefer to register their children with disabilities at regular schools or in some cases do not register their children at school at all. Further, many caregivers were aware that the centre is reserved for children with severe or multiple impairments only, which is consistent with the Regulations for Basic Special Education.¹⁴ Thus, caregivers of children with other disabilities refrain from registering them even where they could not access regular schools because of the lack of support. For example, two caregivers of children with disabilities who could not find adequate conditions in regular schools decided not to register their children at the CEBE because they considered this centre to be for children who were 'more disabled'.¹⁵

4.5.3 Health impacts

The inadequate condition of health care services in the area hinders the development and inclusion of children with disabilities. Interviews with caregivers of children with disabilities enrolled in Juntos showed that children who took part in this study

attended health checkups at the medical centre of Morropón, but that these were intended to measure children's growth rates or to treat common illnesses rather than to address health issues related to their impairments. This reflects the lack of specialists, including paediatricians, neurologists, and oculists, available to serve children with disabilities at the medical centre of Morropón.

'I took her to the medical centre here. But, you know, we don't even have a paediatrician for our children here, they are only general practitioners.' (Enrolled caregiver 10)

As a result, most caregivers had to go to other better-equipped health care centres at the regional level or to pay private specialists to diagnose or treat their children's impairments, even though it costs more than they can afford. This in turn affects the ability of families to pay for continuity of treatment, regardless of the type of medical facility they went to.

'The doctor in Lima diagnosed brain paralysis. [...] I took her to therapy. I took her two or three years ago to the Clinic San Juan de Dios in Lima for foot surgery because she couldn't stand up very well. After the surgery she can stand on her feet, but she cannot walk very well. [...] The doctor told me she needed to be in continuous treatment, but sometimes I don't have the money to take her to therapy.' (Enrolled caregiver 8)

'He told me they will do a tomography with contrast, or something like that, though I couldn't pay for what it costs [700 soles]. Where I could get that money? I don't have any support. [...] I needed 100 soles for the neurologist, 20 soles for transportation, and another amount of money for medicine [...] thus, a 200 soles allowance is very little.' (Enrolled caregiver 13)

In some cases, as caregivers do not have enough financial resources to take children with disabilities to specialists, they give them medicine prescribed previously whenever they present similar symptoms or even self-medicate.

¹⁴ More information at: www.minedu.gob.pe/normatividad/reglamentos/RegEducacionBasicaEspecial.php

¹⁵ Interviews with enrolled caregivers 10 and 12.

*‘Sometimes, because my neighbour has epilepsy too, I ask her to give me medication, I don’t know the name of the pills, but it helps to control her.’
(Enrolled caregiver 9)*

In the case of beneficiaries of Pensión 65, most of them considered that their health had improved after being enrolled in the programme, because they can now buy medicine and food that they could not afford before. However, when asked if the allowance permits them to treat their impairments, the general response was negative. For instance, according to one interviewee, rehabilitation therapy costs him more than 800 soles per month, and glasses 120 soles. This is in addition to other health issues common among older persons in general, such as high blood pressure, bone and spinal pain and high cholesterol.

Interviewees also mentioned recent difficulties accessing health care services because hospital staff were on strike. Due to the strike, medical centres would only deal with emergency cases and were even charging for some consultations where they would not normally have done so. As a result, some interviewees went to private practitioners or directly to the drugstore.

‘Well, there is almost six months the medical centre is not open to care. As said, we go for private health care services, to the drugstore ‘Buena Salud’ or ‘Arcangel’.’ (Older person 7)

Pensión 65 participants had diverse opinions regarding the quality of the health care services received, from acceptable to inadequate. However, the majority expressed their concern about the excessive time it takes to be attended, reporting that they have to wait the entire morning or even come back in the afternoon or the next day to access medical care.

In common with Juntos beneficiaries, older persons with disabilities and public officials also mentioned that the health care system only provides generic and basic medicine, such as painkillers, and anti-inflammatories, and that specialized treatments are not available free of charge. Laboratory examinations and medicine were also described as costly,

even though they were enrolled in SIS, while medicine prescribed at the medical centre is only available at the drugstore which charges high prices.

‘Well, we have to buy medicine, they don’t provide medicine, you have to buy it at the drugstore, they just give you the prescription. Since Pensión 65 is not enough, you have to wait for your son to get money to buy the medicine.’ (Older person 13)

Further, according to older persons and the head of the OMAPED, priority attention is not given to persons with disabilities as the facilities work on a ‘first come first serve’ basis.

‘Yes, we have to wait. If there are more than 20 patients waiting, they ask you to come back in the afternoon or the day after.’ (Older person 7)

As well as the health facilities themselves, OMAPED also attracted criticism from some interviewees who felt that it had not been responsive to the needs of persons with disabilities, especially in relation to the provision of healthcare services.

‘There is an office at the municipality, working for persons with disabilities since 2011. It was mentioned they will help persons with disabilities to access rehabilitation, medicine and money; but, so far, there are no results shown.’ (Official 3)

Indeed, while most children with disabilities were registered at the office, the majority of older persons were not familiar with it or received only minimal support.

‘Well [...] the municipality, what can I say? Sometimes they call persons with disabilities for a meeting; they give us essential goods for Mother’s Day. But, how did they manage that? They give tickets on a first-served basis. So because of our need we go at 1 am to get some food and essential goods.’ (Older person 7)

5 Conclusions

Female nurse with patient conducting eye tests in a public building



Neither Juntos nor Pensión 65 have a specific focus on disability and – until the recent changes to the Juntos rules – both do not actively target persons with disabilities. However, if individuals and households meet the programmes' core requirements, some consideration is given to their needs at various stages of the enrolment process as well as in providing benefits and monitoring compliance. This means that barriers to accessing the programme for persons with disabilities are relatively minimal, but limitations in the financial benefits provided by the programmes and the poor quality of public health and education services constrain their positive impacts.

Concerns that Juntos' conditionalities would exclude many households containing children with disabilities were found to be largely addressed by the existing practice of exempting certain children with disabilities from complying with the conditions along with a degree of flexibility in enforcing compliance for those children with disabilities who are required to attend school on a regular basis. Caregivers were adequately informed about the monitoring system of conditionalities at schools and health centres and, as a result, were concerned to justify any absences to avoid suspension of the allowance. Nonetheless, households containing children with disabilities face many difficulties in fulfilling these responsibilities, including the cost of the daily journey to school, the need for additional support and supervision, the limitations of the regular and special education system, and negative perceptions of children with disabilities, especially among other students.

In some cases these issues were sufficient to prevent students from enrolling or to cause them to drop out entirely, although only among those exempted from the condition to regularly attend school. Importantly, the type or severity of the impairment of the children did not necessarily determine their access to education. Other factors appeared to play a bigger role, such as parents' lack of economic resources or the perception they have of the school's ability to take care of their children or provide a meaningful education. No differences related to the gender of children with disabilities were found with respect to compliance with conditionalities.

Juntos officials determine whether children with disabilities will be exempted or not from conditionalities and, while this exemption may favour a family, it may not benefit the child as it left to the caregivers the decision whether to send them to school or not. In practice, exempted children were found to be less likely to be enrolled in school and this practice is likely to be enhanced by the new Juntos Enrolment Process Directive, in which it is established that the health centres will be in charge of supervising compliance with conditions for children with severe impairments.

Members of neither Juntos nor Pensión 65 reported significant difficulties during payment. All of the caregivers in charge of children with disabilities collect the allowance without inconvenience and they are given priority when they take their children to the bank. Priority treatment is also given to caregivers with disabilities, who normally go on their own to collect the allowance. However, Pensión 65 participants faced some challenges related to the cost of transport, the need for support during the journey and long queues at the bank.

Participants of both programmes mentioned that although the allowance given by Juntos and Pensión 65 is small, it has allowed them to partially cover some of the basic costs for food, school expenses and medicines. However, in most cases the situation of children with disabilities has not been dramatically improved because priority is given to covering the expenses of the whole family. Caregivers were aware that the allowance is intended to be used to assist all children enrolled, and not exclusively children with disabilities. As such, the costs of specialized health services and assistive devices were often seen to be too great to cover, even with the additional income from Juntos. Similarly, in the case of older persons with disabilities enrolled in Pensión 65, although the allowance has helped them to improve their health status and nutrition, it does not allow them to access more costly specialized treatment or to buy assistive devices.

These findings suggest that the mere inclusion of persons with disabilities into programmes does not

necessarily determine a positive impact. The lack of adequate services for persons with disabilities (education, health, rehabilitation) limits or reduces the impact of social protection programmes. Therefore, including children with disabilities as target members of the Juntos programme is insufficient for them to achieve real inclusion until education and health services are improved. In the case of Morropón, improving services at schools requires that they have:

- Teachers adequately trained to teach and assist children with disabilities;
- Specialists on special education that support inclusion in regular schools;
- Accessible, adequate and safe infrastructure for children with disabilities; and
- School environments free from discrimination.

Furthermore, health centres in the district need to hire specialists to assist with the health issues of persons with disabilities. This is crucial to avoid unnecessary travel to other cities to see specialists, with associated higher costs.

Finally, the lack of transport and support for mobility also hinders access to services and may have a significant impact on the household income. Juntos and Pensión 65 are unable to cover these and other disability-associated costs and, as such, some interviewees mentioned the need for complementary services and benefits specifically for persons with disabilities and their households. As such, beyond the need to consider disability within the targeting criteria and service package of mainstream social protection programmes, the possibility of following a twin-track approach and establishing additional specific programmes should be evaluated.

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