ALBANIAN DISABILITY RIGHTS FOUNDATION

SMALL STEPS

FORMATIVE EVALUATION OF THE IMPLEMENTATION OF THE STANDARDS OF SOCIAL SERVICES FOR INDIVIDUALS WITH DISABILITIES IN THE RESIDENTIAL AND DAY CARE CENTERS AND RELATED PROTECTION AND FULFILLMENT OF HUMAN RIGHTS

Cordaid

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OF THE STANDARDS OF SOCIAL SERVICES FOR INDIVIDUALS WITH DISABILITIES
IN THE RESIDENTIAL AND DAY CARE CENTERS
AND RELATED PROTECTION AND FULFILLMENT OF HUMAN RIGHTS

Albanian Disability Rights Foundation

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EXECUTIVE SUMMARY

The Standards of Social Services for Individuals with Disabilities in the Residential and Day Care Centers were approved with the Decision of the Council of Ministers nr. 822, date 12/06/06. Their purpose is: (a) to guarantee the exercise and fulfillment of the fundamental rights and freedoms of the individuals with disabilities as provided in the Albanian constitution, domestic legislation and relevant United Nations and Council of Europe conventions; (b) to improve the quality of services in public and non-public centers by establishing criteria for their evaluation; (c) to be of assistance for the local government in their monitoring role; and (d) to encourage the involvement and the responsibility of the community at large. The legal document contains five standards of services for the following areas: (a) participation of people with disabilities in the decision-making process at the local government; (b) assessment and individual support plans; (c) promotion of independence, inclusion and self-determination; (d) service procedures; and (e) fair treatment and the grievance process.

The purpose of this formative evaluation conducted 15 months after the Standards were approved was to examine the steps taken for and the current results of their implementation in the residential and day care centers that provide services to clients with intellectual disabilities and the fulfillment of the human rights related to those standards.

Data were collected from February-April 2008, in 26 residential and day care centers that provide services for 564 persons with intellectual disabilities. Clients of all ages (n=68, 54% females) participated in 16 focus groups; 34 family members of the clients of day care development centers (65% females) participated in ten focus group meetings and 152 parents (74% females) participated in the written survey. A total of 136 staff members (90% females) participated in the written survey. Additionally, 26 center directors were interviewed and 25 completed the written survey.

The main findings of this evaluation are the following:

- The center directors and staff are knowledgeable about the Standards, but they have not yet started work on their implementation.
- The current situation in the development centers (which serve primarily clients with intellectual disabilities of various ages) as compared to the Standards criteria is **"marginally satisfactory"** for the following standards:
  - *assessment and individual supports plan;*
  - *promotion of independence, inclusion and self-determination; and*
  - *fair treatment and the grievance process.*
- The situation was deemed "**unsatisfactory"** in the area of *service procedures.*
- The involvement of the local government in supervising the residential and day care centers has just

begun, and as such the area of *participation of people with disabilities in the decision-making process at the local government* was not covered in this evaluation.

- The development centers need support in formulating a reliable multidisciplinary assessment and individual planning process that is client-centered, and promotes client independence, community inclusion and self-determination.
- All services procedures for the development centers must be rewritten to reflect the criteria of the Standards. The new service procedures need to include the process of service monitoring.
- The clients' voice is seldom heard. More needs to be done to turn parents into "active participants" in the evaluation and individual planning process.
- The centers are segregated and more efforts need to be made for the meaningful inclusion of the clients in the activities of non-disabled peers.
- Although there are no flagrant violations of human rights of the individuals with intellectual disabilities in day and residential care centers that put them in harm's way, the study revealed some concerns that leave these individuals with a significant disadvantage to the rest of the Albanian society.
- Much more needs to be done to secure that all of them enjoy all the civil, political, social, economic, and cultural rights to which they are as entitled to as their non-disabled peers and are preemptively protected from any form of abuse and exploitation.
- The individuals with intellectual disabilities in inclusive settings in general, and those in the homes for children and seniors in particular, are deprived of any disability-related services.
- The following are the recommendations for change:
- The **State Social Service (SSS)** needs to take the leadership role in the process by providing more guidance through models, studying and disseminating best practices, providing clear inspection guidelines that are related to the Standards and offering hands-on training for the development of written policies and operational procedures that ensure the implementation of the Standards. Additionally, the SSS must include the homes for children and seniors that provide services for people with intellectual disabilities in the process of the development of new policies and procedures that are in compliance with the Standards and in the inspection for their implementation.
- On the other hand, **the agencies that run the development residential and day care centers** do not need to wait for the leadership of the SSS. They can start the work by creating a task force with representatives from clients, parents, staff and administration to develop new policies for each center based on the Standards. They need to make sure that they include the protection and the fulfillment of the relevant civil, political, economic, social and cultural rights of their clients in the new policies and practices.
- It is recommended that **the homes for children and seniors, which serve clients with intellectual disabilities**, make sure that they provide the necessary services to these individuals by networking and/or contracting with other organizations that primarily serve individuals with intellectual disabilities. Additionally, they need to change their policies and operational procedures to become compliant with these Standards by networking with other organizations that primarily serve individuals with intellectual disabilities.

INTRODUCTION

In the fall of 1993 the awful condition of the clients with intellectual disabilities in state residential institutions was exposed to the world through the repeated broadcasting in the headline news programs of CNN. A naked young man, covered in feces, shocked the conscience of many people in the world who wondered how the Albanian society had come to accept this total lack of respect for human dignity. Odom, Horner, Snell and Blacher (2007) explain that developmental and intellectual disabilities are socially constructed, and the societal response depends on how the society views the causes and the people affected. In 1993, an intellectual disability in one of the members of a family was seen by many Albanians as a misfortune, a shame and a curse.

A sociologist that studied the situation of people with intellectual and developmental disabilities in the region of Mirdita was shocked to hear the mother of a 12 year-old son describe her situation in this haunting sentence, "having a sick[1] child is like having an open grave, it does not let you live, it does not let you die" (Personal communication, 1993). Faced with the societal stigma and a total lack of community services, many parents chose to put their children in the institutions and "forget" about them in their efforts to lead "normal" lives. Unfortunately, the state, which became the ward for these individuals, did the same: put them in a house and "forgot" about them. The human rights of many children and young people were violated daily by those who were paid to take care of them. They were exploited further by those who filmed them without getting permission and showed them to the world as a journalistic "scoop."

LEGISLATION

As Albanian society is transitioning towards democracy, thanks to the efforts of disability advocates in the country the ineffective medical intervention model for people with intellectual and developmental disabilities is being slowly replaced by a community-based social approach. This change is being reflected in the newly created legislation[2] that covers various areas of life of people with disabilities as well as services for them which focus on integration and normalization (ADRF, 2006 a, b). Of special interest for this study are:

The newly created legislation that covers various areas of life of people with disabilities as well as services for them focuses on integration and normalization.

[1] This term was and is often used as a euphemistic term to refer to people with intellectual and developmental disabilities.
[2] For a full coverage of the legislation that covers the rights of people with intellectual disabilities see: ADRF (2006). Overview of the Rights of People with Intellectual Disabilities in the Areas of Social Services, Health Care, Education, Employment and Vocational Training as well as ADRF (2006). Study and Assessment of Disability Legislation in Albania.

- *Public Law "On Social Assistance and Social Services" nr. 9355, date 03/10/05*[3], which has replaced the Public Law nr. 7710, date 05/18/93, "*On the Social Assistance and Social Welfare;"*
- *Strategy of Social Services (2005 - 2010),* approved with Decision of the Council of Ministers (DCM) nr. 265, date 04/28/05;
- *Social Service Standards and the Standards of Services for Children in Institutions,* approved with the DCM nr. 658, date 12/17/05;
- *National Strategy on People with Disabilities (2005-2015),* approved with DCM nr. 8, date 01/07/2005;
- *Standards of Social Services for Individuals with Disabilities in the Residential and Day Care Centers*, approved with the DCM nr. 822, date 12/06/06.

THE STANDARDS OF SOCIAL SERVICES FOR INDIVIDUALS WITH DISABILITIES IN THE RESIDENTIAL AND DAY CARE CENTERS

The Standards of Social Services for Individuals with Disabilities in the Residential and Day Care Centers[4] were formulated with the assistance of the British Council experts through an extensive process that included all stakeholders: representatives of all national disability advocacy and service organizations, many of whom were people with disabilities or parents; Albanian experts in the field, including experts from the Ministry of Labor, Social Affairs and Equal Opportunities, and State Social Service. The Standards were discussed and reviewed in multiple sessions in six major cities in the country in meetings of local stakeholders. The Standards for Residential and Day Care are based on *the Social Service Standards* and the *Standards of Services for Children in Institutions* which must also be implemented by the residential and day care services for people with disabilities, but the former provide specifications that are related to the clientele. The DCM (2006) states that, Standards (a) guarantee the exercise and fulfillment of the fundamental rights and freedoms of the individuals with disabilities as provided in the Albanian constitution, domestic legislation and relevant United Nations and Council of Europe conventions; (b) will improve the quality of services in public and non-public centers by establishing criteria for their evaluation; (c) will be of assistance for the local government in their monitoring role; and (d) will encourage the involvement and the responsibility of the community at large.

The Standards of Social Services for Individuals with Disabilities in the Residential and Day Care Centers cover the following areas:

Participation of people with disabilities in the decision-making process at the local government.

Assessment and individual supports plan.

Promotion of independence, inclusion and self-determination.

Service procedures.

Fair treatment and the grievance process.

The legal document contains five standards of services for the following areas: (a) participation of people with disabilities in the decision-making process at the local government; (b) assessment and individual supports plan; (c) promotion of independence, inclusion and self-determination; (d) service procedures; and (e) fair treatment and the grievance process. The expected outcomes accompanies each standard together with the criteria for the fulfillment and the required evidence.

[3] The dates are written according to the American standard: month, date, year.
[4] From this point forward the Standards of Social Services for People with Disabilities in the Residential and Day Care Centers will be referred to as the Standards.

Although a packet of minimum requirements, the goal of the Standards is to regulate the residential and day care services in Albania with an approach of client-centeredness and introduce and consolidate the social paradigm of services for people with disabilities. By focusing on the clients' rights and the work towards their independence and social inclusion, the Standards challenge traditional beliefs and attitudes towards people with intellectual disabilities in Albania, and link the work in residential and day care centers with the fulfillment of human rights for people with intellectual disabilities.

INTERNATIONAL CONVENTIONS RATIFIED BY THE ALBANIAN GOVERNMENT

The Albanian government has ratified all major human rights conventions. It has not yet ratified the United Nations Convention on the Rights of the Persons with Disabilities.

The Albanian Parliament has ratified the following international conventions which are directly or indirectly linked to the rights of people with intellectual disabilities:

- International Covent on Civil and Political Rights (1991)
- International Covent on Economic, Social, and Cultural Rights (1991)
- International Convention on Elimination of All Forms of Racial Discrimination (1994)
- Convention on the Elimination of All Forms of Discriminations against Women (1994)
- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1994)
- Convention on the Rights of the Child (1992)
- Convention for Protection of Human Rights and Fundamental Freedoms (1996)
- European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (ratified on 01/02/96 and carried into effect on 01/01/97)
- European Social Charter (revised in 1998). Article 15 has not yet been ratified. Albania has not signed the United Nations Convention on the Rights of the Persons with Disabilities adopted by the United Nations on 13 December 2006.

HUMAN RIGHTS RELEVANT TO CLIENTS OF RESIDENTIAL AND DAY CARE CENTERS

The clients of the residential and day care centers are entitled to all civil, political, economic, social and cultural human rights established by the documents ratified by the Republic of Albania. However, for the purpose of this study, only the following rights which are relevant to the settings of residential and day care will be investigated:

- The right to life, especially in regard to situations of risk.
- The right to equality and non-discrimination.
- Freedom from cruel, inhuman or degrading treatment or punishment.
- Freedom from exploitation, violence and abuse protecting the integrity of the person.
- Freedom of expression and opinion, and access to information.
- Respect for privacy.
- Participation in political and public life.
- The right to an adequate standard of living.
- The right to accessibility and personal mobility.
- The right to good health.

- The right to participate in cultural life, recreation, leisure and sport
- The right to habilitation and rehabilitation.
- Age specific rights: children, the right to education.
- Age specific rights: adults, the right to work and employment.

Although not all these rights have been explicitly mentioned in the Standards, they are in their spirit as specified in the DCM. Moreover, it is the duty of the local and central administration, which are responsible for the accreditation, supervision and monitoring of centers, to make sure that people with intellectual disabilities have these rights respected and fulfilled while they receive services in those centers.

PREVIOUS STUDIES

Previous studies of the development residential and day care centers for people with intellectual disabilities have pointed out that while there was an increased interest in improving the quality of services and meeting the government standards, still many issues persisted that had an impact on the quality of life of the clients served and the fulfillment of their human rights. (ADRF, 2006; ADRF, 2007). First, the services did not meet the demand both in regards to numbers of clients served and the geographic distribution. The number of people with severe and profound disabilities served was very small and restricted to residential care, where they were confined in their beds. Then, the physical conditions of the buildings were far from satisfactory in some centers and adaptive and rehabilitative equipment was missing in all of them.

While there was a high ratio of direct service staff to the clients served, there was no mandatory training for the staff, and many professions needed for habilitation were missing. Although efforts were being made to strengthen the contacts with families in residential care centers, they were weak and the families were rarely involved. The work with clients was mostly limited within the environment of the centers, with half of them organizing occasional activities in the community. ADRF (2007) also reported that both the parents and the staff had limited knowledge of the legislation related to the functioning of the residential and day care centers, with 75 % of the center directors reporting partial knowledge and 53.9% of the parents interviewed reporting no knowledge at all.

THE PURPOSE AND RATIONALE FOR THE STUDY

This study will evaluate the impact of the implementation of the Standards of Social Services for Residential and Day Care Services on the quality of life of their clients and the protection and fulfillment of their human rights.

The implementation of the Standards started in January 2007. The purpose of this formative evaluation conducted after 15 months is to examine the steps taken and the current results of the implementation of the Standards by the residential and day care centers that provide services to clients with intellectual disabilities and the fulfillment of the human rights related to those standards.

This formative evaluation study is needed for several reasons. First, although the Standards have been in place for more than a year, no evaluation has yet been done to study their degree of implementation as well as their impact on the work with the clients and their quality of life. The DCM of 12/06/06 stated specifically that the standards would be piloted for a year before being revisited for necessary changes. Also, the states that ratify international human rights documents are under the obligation to respect, protect and fulfill the human rights of the citizen through effective regulations and by facilitating access to rights, especially to the

marginalized groups who have a history of human rights violations. As the Standards are stated to be grounded in the human rights paradigm, an analysis of the fulfillment of clients' human rights will reveal the effect of the Standards on them and will indicate areas where intervention is needed.

Permission to conduct the study was given by the Executive Director of the SSS through a Memorandum of Collaboration between the said agency and ADRF signed on 02.15.2008. The memorandum contained the rights and obligations of both parties and had a special section on the confidentiality of data obtained.

STUDY QUESTIONS

This study will provide responses to the following questions:

1. How are the Standards of Social Services for Individuals with Disabilities in the Residential and Day Care Centers in regards to individual assessment and support plan; independence, inclusion and self-determination, service procedures, and fair treatment and grievance procedures being implemented in the residential and day care centers attended by people with intellectual disabilities?
2. What is the status of the protection and fulfillment of the fundamental civil, political, economic, social and cultural human rights relevant to persons with intellectual disabilities attending residential and day care centers?

THE STUDY TEAM

The evaluative study was undertaken by ADRF, a national organization with a broad range of activities, such as advocacy, training, legal aid, rehabilitation camps, a production line of assistive equipment for people with disabilities which employs people with disabilities, inclusive community services, publications, and so on. Since its inception, ADRF has lead and coordinated major initiatives in the country for the rights of people with disabilities, such as the formulation of the National Strategy for People with Disabilities, the implementation of which it monitors through annual reports. The principal investigator is a parent of an adult with intellectual disabilities who has attended both residential and day care centers. Three other members of the team are ADRF staff and one works for the SSS. The study was funded by CORDAID, through the Grant no. 432/10033A.

METHODOLOGY

SITE VISITS

The study was conducted in 26 centers of various types that provide services to a total of 564 individuals with intellectual disabilities of all age groups (see Table 1). The centers are located in 12 cities in northern, central and southern Albania and they may be divided into the following categories:

a) Centers that provide residential services mainly for children and adults with intellectual disabilities, called Residential Development Centers (RDC). Although the operation budget for these centers comes mainly from the central government, they are now being supervised by the local government. These centers were created during communism and were originally run by the Ministry of Health. In 1993, they passed under the administration of the Ministry of Labor and Social Protection and soon, with few exceptions, will be run by the local government of the municipality where they are located. All six centers were included in the study. One of them provides residential services during the weekdays only. Another one also provides day care services. These six centers provide services to 203 clients.

b) Centers that provide day services for children and adults mainly with intellectual disabilities. These nine centers have been created in the last 13 years and five of them are funded and run by government agencies. One of them is run by a non-profit organization but funded by the government through a World Bank Project. Another one is mainly parent funded through pay for service, and the other two centers are run by non-profit organizations and funded through various grants. These centers serve 249 clients.

c) Eleven centers that provide day and/or residential care services mainly to mainstream populations and who also provide services to individuals with intellectual disabilities (n=11). Four of these centers are homes for children 0-14 years of age and three are homes for the elderly. People

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Family members of the clients of day care development centers (n=34, 65% females) participated in ten focus group meetings.

152 parents (74% females).participated in the written survey.

136 staff members (90% females) participated in the written survey.

26 center directors were interviewed and 25 completed the written survey.

Data were collected in February-April 2008.

with intellectual disabilities have been placed in these centers due to lack of space in other centers. Another two centers serve mainly people who have been abandoned or have economic hardships, and they have chosen to also serve people with intellectual disabilities. The last two centers mainly provide services to people with physical disabilities and hearing impairment and they have chosen to also serve clients with intellectual disabilities. These inclusive centers provide services to 112 clients with intellectual disabilities.

Table 1: **List of Participant Centers**

Center's Name	Category of Services	Location	Number of Clients with ID	Main Source of Funding
Clients with ID only				
RDC* Shkoder	Residential	Shkoder	43	Government
Valet e Detit	Residential	Durres	32	Government
RDC Vlore	Residential	Vlore	22	Government
Pellumbat	Residential	Tirane	30	Government
Une Jam Si Ju	Residential	Berat	28	Government
RDC Korce	Residential	Korce	48	Government
DDC**Shkoder	Day	Shkoder	44	Government
Valet e Detit	Day	Durres	12	Government
DDC Lezhe	Day	Lezhe	27	Government
DDC Atelie	Day	Korce	23	Government
Lira	Day	Berat	30	Government
Te Qendrojme Se Bashku	Day	Tirane	30	Government/ World Bank
Shtepia e Kuqe	Day	Tirane	30	Parents/donors
Ndihmoni Jeten	Day	Tirane	28	Donors
Dora e Ngrohte	Day	Tepelene	25	Donors
		Total	452	
Clients with Various Disabilities				
Balashe (physical)	Day	Elbasan	25	Government
SHESHI (hearing impairments)	Day	Shkoder	12	Donors
		Total	37	
Inclusive Centers				
Gjirokastra Senior Home	Residential	Gjirokaster	9	Government
Kavaja Senior Home	Residential	Kavaje	10	Government
Shkodra Senior Home	Residential	Shkoder	7	Government
Tirana Children's Home, 0-6	Residential	Tirane	3	Government
Tirana Children's Home 6-14	Residential	Tirane	10	Government
Shkodra Children's Home, 6-14	Residential	Shkoder	5	Government
Saranda Children's Home, 6-14	Residential	Sarande	5	government
Madonina Del Grappa	Residential	Shkoder	18	Donors
Fshati i Paqes	Residential	Shkoder	8	Donors
		Total	75	
	Grand Total	564		

Notes: * RDC is Residential Development Center
** DDC is Day Development Center

The site visits in these 26 centers consisted of structured observations and study of documents. The observations included the conditions and furnishings of the sites, the safety of clients and the relationship of the staff with the clients. The team also studied all the center documents that described the service procedures, eligibility criteria and the grievance process. A minimum of four client files were selected randomly for the study. The team read the assessment, the individual plan and the progress notes for these clients and took careful notes.

To ensure inter-rater reliability, the members of the study team were trained and given specific instructions for the procedure of the observations for each section. They took notes through a semi-structured questionnaire that covered the following aspects of the observation: (a) information on the location of the center and its primary services; (b) physical and sanitary conditions of the center; (c) safety and privacy of the clients; (d) transportation; (e) procedures and documentation; and (f) individual assessment, and support and development plans. Most of the items were developed as multiple-choice items. The observers were also encouraged to write their impressions in open-ended segments.

To avoid subjectivity, the team worked in groups of two for their site visits. Prior approval for the site visit was given by the director of the center. The directors and the staff of all centers collaborated with the research team without hesitation and provided the necessary support for the data collection process.

FOCUS GROUPS WITH CLIENTS

Individuals of different ages, with different levels of support needs and of both genders (54% females) participated in 16 focus groups (n=68). The focus groups were organized in the centers without the presence of staff. Two members of the research team participated in all focus groups. Clients generally responded in very brief sentences, which may be due to either the severity of the disability or lack of experience with this process.

The client focus group questionnaire consisted of six open-ended questions formulated in simple language on the following topics: (a) what they liked the most about the center; (b) the changes they would like to see; (c) the recent activities in the center; (d) whether their opinion was asked; and (e) whether they had witnessed any cases of abuse or harassment by their peers and staff.

FOCUS GROUPS WITH PARENTS

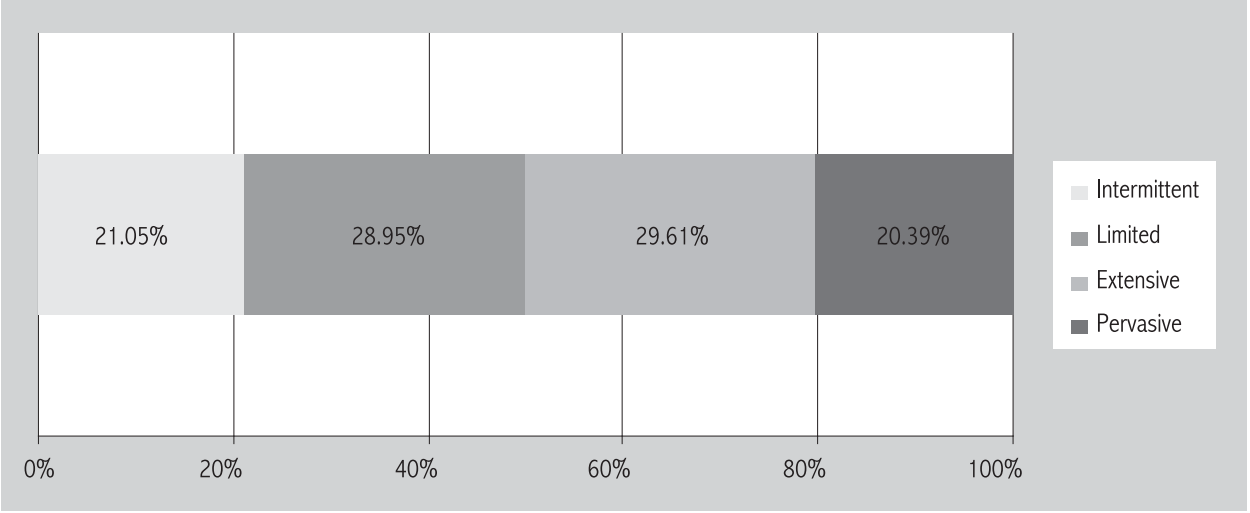
Parents of clients in day care centers and one residential day care center who lived in the same city were approached by the research team to participate in the focus groups. In order to accommodate their times, small focus groups were organized. The parents were encouraged to express their thoughts by promising confidentiality of the information. At the beginning of the meeting the parents were given an explanation of the purpose of the study, and the rules of the focus group: they were free not to respond and could leave when they wanted. No notes regarding their identity were taken. A total of 34 parents participated in ten focus groups.

The parent focus group questionnaire consisted of seven questions on the following topics: (a) what they liked about the center; (b) what changes they would like to see; (c) the activities the child had participated in; (d) whether their opinion was taken in regards to activities of the center; (e) whether they have participated in their child's individual planning process; (f) whether they had expresses any complaints and the response they had received; and (g) whether their children were treated with due respect.

PARENTS' SURVEY

A structured questionnaire was mailed to the parents/family members of clients in residential development centers who kept the contacts with their children (in a pre-addressed return envelopes). The parents/family members of day center clients picked up the questionnaire when they dropped their children and returned them at the center in sealed envelopes. Although strongly encouraged to complete the questionnaire, parents/family members were told that the participation was voluntary. With a response rate of 84.4%, the number of parents/family members that participated in the survey was 152; the majority of whom 66% (n=101) were from day care centers. The gender distribution of the children/family members of the respondents was almost evenly distributed (52% were females, n=79). The age range of family members/children was from 4-45, with the majority being of school age. The perceived level of support[5] of family members (Figure 1) was also almost evenly spread. However, the parents/family members from residential centers reported a higher incidence of higher levels of support-extensive and pervasive- (62%) than the day care parents/family members (43.6%).

Figure 1: **Perceived needed level of support of children/family members**



The parents' questionnaire was structured and consisted of three sections: (a) evaluation of the center's effectiveness in working with the client and their satisfaction with the condition in the center with a grade 4-10 (this is the Albanian school grade system); (b) their participation in the Individual Planning process and their knowledge of the grievance process (yes/no alternatives); and (c) a section on the demographics of the family member (age, gender, level of supports) and clients demographics (gender). The questionnaire had content validity but was not tested for reliability. Prior to being mailed to the parents/family members, it was piloted with five parents who made suggestions for changes for clarity.

STAFF SURVEY

The professional staff (caregivers, social workers, psychologists and others) who worked with individuals with intellectual disabilities (n=200) were given questionnaires to complete during their working hours. They were

[5] To measure the perceived need for supports the following scale was used: (a) *intermittent:* supports are provided as needed and may be episodic; (b) *limited:* supports are characterized by consistency, time may be limited but is not intermittent; (c) *extensive:* supports are characterized by regular involvement (such as daily) in some environments, but are not time-limited; and (d) *pervasive:* supports are characterized by constancy and high intensity across all environments, may be potentially life-sustaining in nature.

advised that their participation in the survey was voluntary. The response rate was 68%. Of the 136 respondents, three-fourths (74.2%, n=101) were working in centers that offered services primarily to clients with intellectual disabilities.

The questionnaire for the staff consisted of seven open-ended question and seven multiple-choice questions (yes/no/do not know). The open-ended questions tested the knowledge about the mission of the center, the individual plan, and the grievance and complaint process, and asked for examples that illustrated previous responses in regard to the parents' and clients' participation in the center's decision-making process, illustrations of complaints and trainings received. Gender, level of education and the job title were included for demographic characteristics. The questionnaire had content validity as all questions were related to the Standards or human rights.

DIRECTORS' SURVEY

All but one of the directors (n=25) completed a structured questionnaire, which included official information that covered the following areas: (a) services offered by the center; (b) staff number, education level and the job evaluation process; (c) the number of clients and eligibility criteria; (d) budget information; (e) the grievance process; and (f) religious services attended by clients. All the information requested was official and public.

THE IMPLEMENTATION OF THE STANDARDS OF SERVICES FOR PEOPLE WITH DISABILITIES IN RESIDENTAIL AND DAY CARE CENTERS

STANDARD ONE: PARTICIPATION IN THE DECISION-MAKING PROCESS AT THE LOCAL LEVEL

Description

Standard One states that based on the principle of inclusion and non-discrimination, the persons with disabilities are included as partners in all interest groups that involve the welfare of people with disabilities. The evidence for the fulfillment of this standard includes (a) the number of persons with disabilities who are members of relevant commissions; and (b) the accessibility of the local government decision-making process to wheelchair users, people with visual impairments (by having documents printed in Braille) and people with hearing impairment (by providing interpreters at the meetings). In addition, the local administration needs to provide regular updates on the issues relevant to persons with disabilities and the coordination of services for them.

Outcomes

This standard was not included in the study, because at this stage there are no case management services at the local government (municipality and/ or commune) level which make this standard relevant to the welfare of the beneficiary of services in residential and day care centers.

STANDARD TWO: ASSESSMENT, EVALUATION AND INDIVIDUAL PLAN

Description

Standard Two requires that social services have clear assessment procedures, which include a multidisciplinary approach and active participation of parents/guardians. Conducted annually, and, whenever possible in the natural environment, assessment is strengths-based, and reflects the personal, physiological, psychological and social needs for support to live in the community and enjoy age-appropriate functions; and takes into account the community resources as well. The individual supports plan (IP) is updated annually

Rating:

Marginally Satisfactory.

Achievements

Clients are assessed at intake and evaluated consistently.

Assessment/evaluation is multidisciplinary.

All clients have individual plans.

Most parents are involved in the individual planning

based on the assessment through a multidisciplinary team approach with the active participation of clients, parents/guardians in every step. The evidence that this standard has been met includes proof for both aspects: the assessment and the individual plan. As regards assessment and evaluation, the following is the required evidence: (a) written procedures that describes the assessment/evaluation and the functioning of multi-disciplinary assessment teams; (b) forms used for assessment/evaluation; (c) examples of multidisciplinary assessment signed by the members of the team and the client and/or family member; (d) staff knowledge of the assessment/evaluation process; (e) clients'/family members' acknowledgment that their opinion has been actively sought; and (f) the assessment has been age-appropriate and conducted in the natural environment. The evidence that the standard has been met in regards to the IP includes, (a) the existence of the plan; (b) evaluation of the progress made; (c) the client/family member participates in the IP meting and signs the document and (d) receives a copy of the IP.

and get a copy of the individual plan.

Most of the staff have good knowledge of the process of individual planning.

Issues

Assessment is frequently not strengths-based.

Clients are rarely involved and parents are not active participants in the assessment and the individual planning process.

The experts of the multidisciplinary teams do not collaborate all the time.

The quality of individual plans varies, based on the model adopted. Often they do not meet the requirements of the standards.

Issues (cont.)

The individual plan of clients in centers that do not serve primarily people with disabilities does not take into account their intellectual disabilities.

The centers that do not primarily serve clients with disabilities do not have expertise in the field of intellectual disabilities.

Outcomes

Assessment and Evaluation

The site visits revelead that all centers (with the exception of the Kavaja Senior Home) had a process of assessing and evaluating the client, although in all but two centers there were no written procedures that described the process. Assessments and evaluations were done periodically, annually at a minimum, and in ten of them (38.4%) two-four times per year. In the centers for people primarily with intellectual disabilities, all clients have evaluations as part of their files: They are generally age-appropriate, cover various areas of the person's development and are conducted by center specialists (psychologists, social workers, speech therapists and physical therapists, when part of the staff).

Despite the tendency to focus on the client's needs for support, attempts are made to identify clients' strengths as well. The evaluation includes data on the family, but no efforts are made to acknowledge family and community resources that may be available. All national residential care centers report that the ties with most clients' families are not very strong, and they see a lack of interest by the parents who live in other districts to be involved in the process. The situation is somewhat different in day care centers, especially in the ones run by non-profit organizations funded by international donors. However, 40 % (n=12) of day care parents who participated in focus groups disclosed that, even in the day care centers (where parents are much more involved), the evaluation/assessment was done by the expert of the center without the parents' presence, and clients and family members are not included in the evaluation/ assessment process: In the best cases they are given information only when it is over.

From the information we received, it is difficult to judge the involvement of clients in the evaluation; however staff responses in their survey indicate that the clients are at best passive in the process- positioned as recipients rather than participants in the process, in a traditional medical model. The evaluations/assessments in the clients' files had neither clients' nor family members' signatures.

The centers that do not serve primarily individuals with intellectual disabilities, such as the government-run senior and children's homes, did not have a process that took into account the special needs of the clients with disabilities and did not have the necessary expertise on site to implement this Standard. Instead, the general process for non-disabled clients is used, which does not take into account the developmental needs arising from their intellectual disabilities. Assessment by experts who are not trained to work with people with disabilities may miss important aspects germane to clients with intellectual disabilities.

The process for assessment/evaluation was different in different centers. While it was typically done for each client individually, in one center, it was done for two clients together. Although the day care center parents reported that they were multidisciplinary (with three experts of different fields), the files reviewed brought to light that each specialist had a separate evaluation that was not shared with the other center staff in many cases, as it was in the expert's client file and not in the general client file. All government run center directors who were interviewed were interested in having a good assessment/evaluation process but felt that, due to lack of expertise, the guidelines and the necessary forms needed to come from the SSS.

The Individual Plan

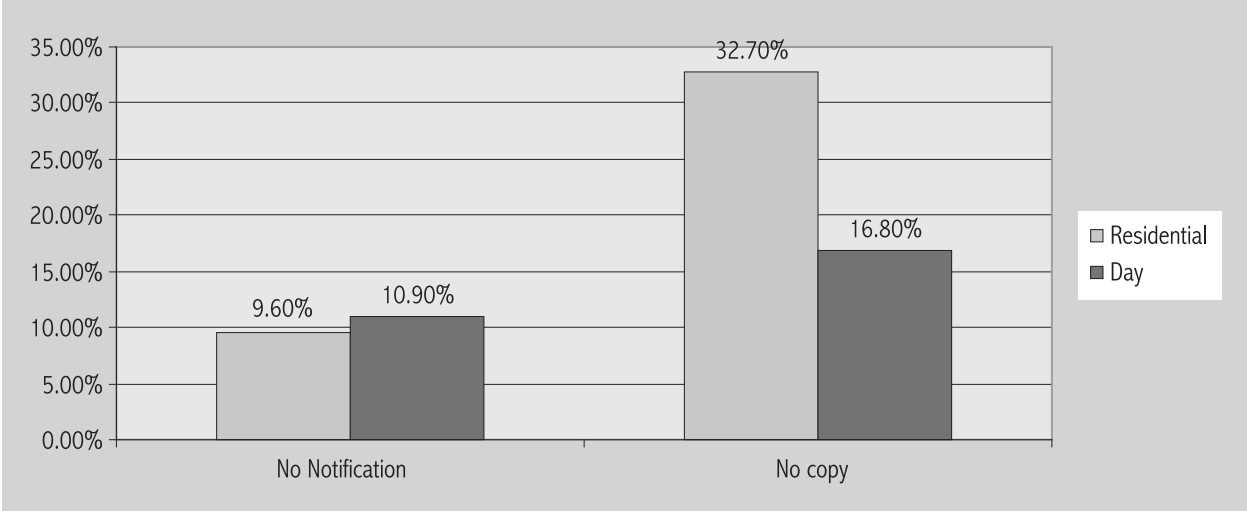
All centers visited (with the exception of Kavaja senior home) had individual support plans for all clients which were built on the prior assessment/evaluation. In one center, however, the plans were made for a two-client unit, rather than individually. From the description of the process by the staff in their survey, it becomes clear that all individual plans have goals in various areas as well as indicators that show the realization of the goal. The plan seems to be based more on the needs than the strengths of the individuals and is often described by the staff in their survey as, "the plan that is formulated on the basis of client's specific needs.

The plan shows how the staff will work with the client." Another indicator is that only 20% of the respondents in the staff survey mentioned clients' abilities while describing the IP. As a rule, parents are notified of the individual plan meeting: 89% of surveyed parents (n=136) reported they had received notification) and 60% (n=18) of the day care parents who participated in the focus groups said that they had participated in the IP meetings. There are no rules and regulations on the development of the individual planning meeting in any of the centers and only 34.3% of the respondents in the staff survey mentioned that the process is multidisciplinary. In seven of the centers, parents participate in the meetings and in two of them they sign a copy of the IP. Many of the staff comments (from their questionnaires) described the parental involvement mostly as that of a "silent" partner, who are asked if they agree with the decision made by the expert for their child. Client involvement in the process is very rare. They are described in the staff comments as people who cannot make any decisions due to their intellectual disabilities. Only the staff of one center (run by a nonprofit and funded by international donors) has mentioned the clients as partners in the process and whose requests and opinions are honored.

The site visits, the review of client files, and the staff survey responses revealed a process similar to the assessment/evaluation: the expert writes the plan (sometimes together with the educator who works directly with the client) and then informs the client/family of it. In most of the centers, the expert keeps the client's individual plan in his/her file and only shares the information with the client's educator, but not other staff. In one of the centers, a more holistic approach was used and a weekly plan was created for each client with all areas of work. Parents/family members are generally supposed to receive a copy, but the parents' survey indicated that this is not always

the case: Almost one in four have not received copies of the Individual Plan (n=35, 22.8%). The phenomenon is noticed both in the residential (where it may be expected) and the day care centers. Figure 2 illustrates the distribution of notifications by residential and day care centers.

Figure 2: **Percentage of Parents Who Reported Not Having Received Notification for the Meeting and Not Receiveing a Copy of the IP. Source: parents' survey.**



At the time when the data were collected (March-May 2008) UNICEF in collaboration with the Ministry of Labor, Social Affairs and Equal Opportunities was conducting staff training for the IP and the SSS was preparing an official document that would standardize the IP for all centers.

Recommendations:

The SSS needs to prepare and distribute without delay clear instructions on the process of assessment, evaluation and individual planning and provide standardized model forms for assessment, evaluation and individual planning that reflect the requirements of the standards.

Train the parents to understand the process of assessment, evaluation and individual planning and their role in them.

Find ways to involve the client in the process.

Make sure that the Standards of Services for People with Disabilities are implemented in the residential and day care centers that do not primarily serve people with disabilities by providing the necessary expertise through contracting and existing staff training.

STANDARD THREE: INDEPENDENCE AND INCLUSION, TIMELY AND GOOD QUALITY SERVICES

Description

Standard Three requires that social services promote the independence, inclusion and self-determination of the individuals with disabilities by offering timely, high quality and age-appropriate services which meet the physical, psychological and social needs of the clients. The evidence for the fulfillment of this standard is required in two

spheres: (a) community planning (for the distribution of various services for people of all ages and various types of disabilities in the all communities in the country); and (b) the residential and day care centers. The evidence that this standard has been met for the latter requires: (a) documentation that the mission and service philosophy include the enhancement of the clients' independence according to their abilities and community resources, inclusion, self-determination and close collaboration with families; (b) acknowledgement by parents/clients that the latter receive the necessary support to enhance their independence and the former and/or the latter make the decisions on the services received and the staff who work with the clients; (c) common work practices which are inclusive and encourage clients' participation in the community; and (d) parent/family satisfaction with the support received. To prove that services are timely, the agency keeps documentation with dates of requests for services and dates when services are offered.

Outcomes

Independence

Only 65.7% (n=69) of the staff from day and residential care centers that work primarily with people with intellectual disabilities included the notion of the development of clients' independence as part of the center's mission or the IP. Also, in the way it is expressed, in most of the cases it is related to "acquiring the skills to meet their own basic needs, i.e., personal hygiene and feeding, on their own." However, one of the adult day care centers also focuses on skills that enhance independence, such as cooking and cleaning. But none of the centers visited has embraced the philosophy of independent living and the clients are primarily seen as consumers of habilitative and social services rather than citizens who make decisions for their lives.

Parents are generally happy with the work done on the development of client independence, and they have evaluated the work done by the staff with a mean of 8.87[6] out of 10. However, one in ten, (9.8%) gave it a grade lower than 7. Parents are less satisfied with the work done for the development in general. Although the mean grade is high (8.63), about one in six of the parents (17.8%) have rated their satisfaction with a grade lower than 7.

Inclusion

Rating:

Marginally Satisfactory

Achievements:

All development centers have included development of independence and community integration in their mission.

Work focuses in the development of skills that enhance independence.

Clients participate in events that occur in the community.

Some centers are working towards deinstitutionalization.

Parents are satisfied with services.

Parents favor day care services over the residential ones.

Issues

Very few clients participate in inclusive activities.

The centers have not embraced the philosophy of independent living.

Transportation is not always available for community activities.

Issues (cont.)

There are very few available slots for children and adults with disabilities in the centers.

The centers have limited geographic and administrative distribution. They operate in11 cities only.

Day care centers are only found in 8 cities.

The existing centers do not keep a waiting list.

Efforts are made in most of the centers to integrate their clients in the community where they live in various forms. This is made possible due to their location. With only one exception, all residential and day care centers visited were

[6] It is difficult to interpret parents' satisfaction index, as it is as subjective indicator largely based on their expectations. From the dialogue in focus groups, however, there is reason to believe that parents define "development" and "independence" in the same way the staff do: "the ability of the individual with intellectual disabilities to take care of his/her basic needs" and the data should be read with this operational definition in mind.

in the residential areas and not isolated. Until the early 1990's, the current clients of residential and day care centers, people with moderate and severe intellectual disabilities, were either institutionalized and "forgotten" or considered a shame to the family and kept behind locked doors, but the situation is slowly changing. More than half of the staff that participated in the survey have mentioned clients' inclusion or integration as a part of the center's mission, philosophy or as a goal of the client's IP (63.8%, n=67). However, inclusion seems to be interpreted by most of the staff, parents and clients as *living in the community and participating in activities that occur outside the premises of the center, in the community*, rather than being educated, or working or participating in activities with non-disabled peers in the least restrictive environment with the appropriate supports. One of the day care centers is an exception: Five of its clients attend school in inclusive settings with the support of the center's staff.

Community participation activities are a favorite of both the clients and parents, who ranked them first both in what the clients like to do and what they wished the clients had more opportunities to do. Although site observations revealed a very good predisposition for community participation events in all of the centers, four of them (which serve about 100 clients, both children and adults) had not secured reliable transportation yet, which was mentioned by center directors as a valid obstacle.

The integration of children and adults from residential and day care centers for people with intellectual disabilities in activities and events with non-disabled peers is low as Table 2 indicates, but it signifies a step in the right direction. The few work opportunities for adults with intellectual disabilities are in sheltered workshops, and none of the day care centers for adults which provides vocational training and work opportunities has a supported employment program for work-related activities in the community.

Table 2: **Participation of Clients in Inclusive Activities**

Center's Name	Category of Services	Location	# of clients	Number of Clients in Inclusive Environments			
				School	Sports	Arts	Work
RDC* Shkoder	Resid.	Shkoder	43		3	3	5
Valet e Detit	Resid.	Durres	32				
RDC Vlore	Resid.	Vlore	22				
Pellumbat	Resid.	Tirane	30				2
Une Jam Si Ju	Resid.	Berat	28				
RDC Korce	Resid.	Korce	48				2
DDC**Shkoder	Day*	Shkoder	44		5	8	
Valet e Detit	Day	Durres	12				
DDC Lezhe	Day	Lezhe	27		7	12	
DDC Atelie	Day	Korce	23				
Lira	Day	Berat	30				
Te Qendrojme Se Bashku	Day	Tirane	30		10	10	
Shtepia e Kuqe	Day	Tirane	30	5	1	15	4
Ndihmoni Jeten	Day	Tirane	28				3
Dora e ngohte	Day	Tepelene	25		15	15	
Balashe	Day	Elbasan	25				
		Total	**477**				
		Total in inclusive env.		**5**	**41**	**63**	**16**
		Percentage in incl. env.		**1.0%**	**8.6%**	**13.2%**	**3.3%**

As the mission for many of the centers is "*rehabilitation and development for community integration,"* we calculated the correlation between these two concepts in the staff responses. It proved to be moderate (r=0.33). This shows that staff have not yet internalized the association of both aspects and the work to enhance the clients' skills is not yet seen as closely related to their community inclusion.

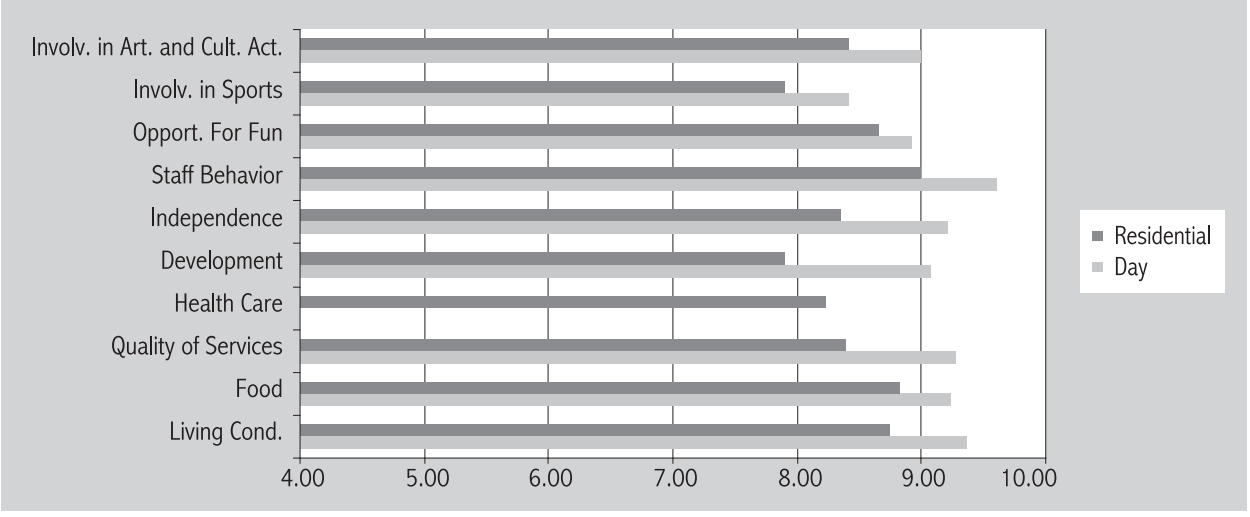
Deinstitutionalization and Prevention of Institutionalization

Each residential care center has a social worker, whose main function is establishing and maintaining relationships with families. In some of the centers, work is focusing on returning some of the clients to their biological families. However, a number of clients in centers (n= 44) are considered "abandoned" by their families. These families refuse to have any contacts with the center staff and do not visit their children/family members.

Another major obstacle is the lack of day care centers, special education or any option of services for people with intellectual disabilities in most of the country. The existing centers cover only nine cities in nine districts; there is nothing at all in other 27 districts and/or 356 municipalities and communes[7]. One residential care center functions only during the week, which gives the clients the opportunity to spend their weekends in integrated environments. Five of the day care centers provide training and some support for the parents, which may qualify as a measure of preventing institutionalization in the area where the day care center operates. Three of the day-care centers also provide home service for home-bound clients or in the context of early childhood intervention. The home services, though, are part of the range of other services these agencies offer.

Parents seem to favor the day care services over the residential ones. The indicators of satisfaction are all higher for day care than they are for residential canters, as demonstrated by Figure 3. Most of the differences are statistically significant, with the exception of "opportunities for fun" "involvement in sports," as illustrated in Table 3.

Figure 3: **Satisfaction of parents with various aspects of residential and day care services**
Note: The day care centers do not offer health care services.



[7] There are 365 communes and municipalities in Albania.

Table 3: **Data on Parents' Satisfaction Divided by Type of Service**

Aspect	Mean for DC	SD	Mean for RC	SD	P Value
Living Conditions	9.37	0.96	8.74	0.90	0.000*
Food	9.24	1.06	8.82	0.97	0.019*
Quality of Services	9.28	1.20	8.39	1.10	0.000*
Health care			8.23	1.18	
Skill development	9.08	1.26	7.90	1.46	0.000*
Independence	9.21	1.14	8.35	1.21	0.000*
Staff behavior	9.60	0.72	9.00	0.92	0.000*
Opportunities for fun	8.91	1.29	8.65	0.96	0.160
Involvement in sports	8.42	1.69	7.90	1.45	0.055
Involvement in artistic and cultural activities.	9.00	1.33	8.41	1.31	0.011*

Note: DC: day care centers, RC: residential care centers

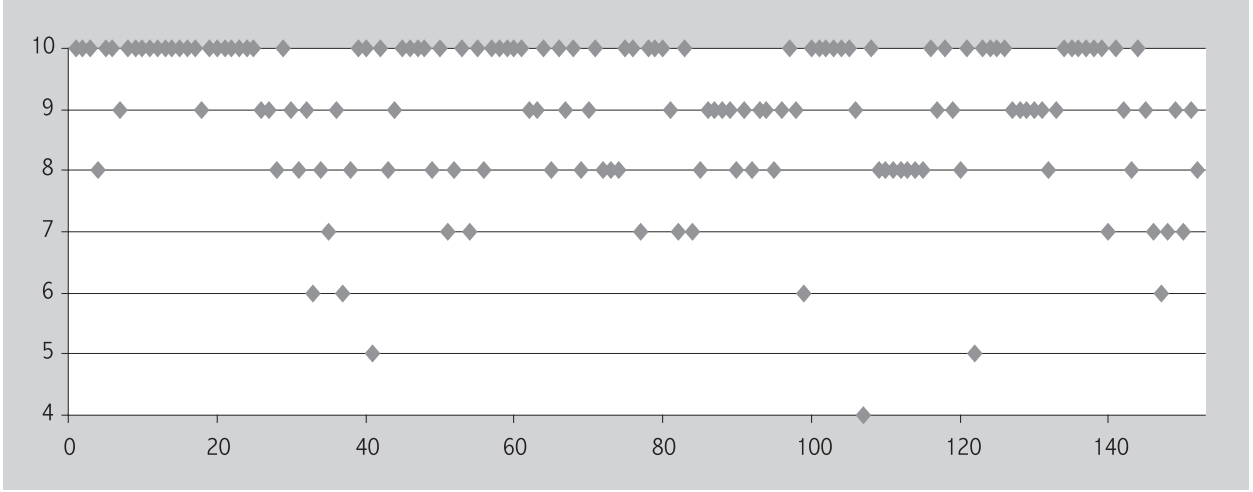
* indicates that the difference is statistically significant. Two-tailed t-tests were conducted.

Timely and Good Quality Service

The process of enrollment in a state–run residential and day care center is almost closed, due to lack of space. The eligibility rules for government run residential and day care centers have been established with a Decision of the Council of Ministers. The day care centers run by non-profit organizations have their own eligibility criteria. As most of them function based on the availability of donor funding (which limits their staff and space prospects), it is likely that parents who need services may not access them at the time needed. None of the centers keeps a waiting list, so the evaluation team was unable to evaluate this aspect.

Both clients and parents expressed satisfaction with the quality of services in the focus groups and the same level of satisfaction was also expressed in the parent survey. When asked to give it a grade from 4 (failing) to 10 (excellent), they have given it a mean grade of 8.94. Since it is a relief to be receiving any services at all that (as expressed by parents in the daily conversations), it is difficult to judge whether the high grade given by most of the parents (n=71, 46.7%) really reflects the level of satisfaction with the quality of services, or the fact that the services exist. Also, it is noteworthy that one in six parents (n=26, 17.1%) thinks that the services could be improved. The grade for services from each completed parent questionnaire is presented in Figure 4.

Figure 4: **Grade for services by each parent**



Recommendations:

Introduce the staff to the independent living paradigm and inclusive practices by organizing training workshops for all of them.

Increase the contacts of the clients with non-disabled peers by organizing joint activities.

STANDARD FOUR: SERVICE PROCEDURES

Description

Standard Four requires the agencies involved in the services for people with disabilities to have a written referral, evaluation and service provision procedures which include among others the multidisciplinary approach and the role of the client and/or family member. Measures need to be taken to make sure that all staff and clients/families are familiar with these procedures. The criteria and evidence that prove the fulfillment of this standard, besides the written procedures, are the involvement of the multidisciplinary team in the evaluation of clients and the formulation of the IP, the expertise of the professionals staff on site, contracts with professionals not working for the center, staff's knowledge of these procedures and client/family access to them.

Outcomes

Written Service Procedures

All of the agencies visited had operational procedures. These included the list of services offered, and in some cases the conditions in which these services were offered, parents' obligations and rights and minimum job descriptions for staff. No reference was made in these service procedures on the system of service monitoring and service evaluation. Only one of the centers (run by a non-profit) had detailed procedures on the assessment and evaluation of clients, and the selection and functioning of the multidisciplinary teams. None of the packets of documents studied for this purpose met the requirements of the standard. Many sections were missing and the service procedures were not client centered at all. The standards of services were not described and the client's or family's role was not detailed.

The System to Monitor the Implementation of Operational Procedures

Each agency visited seemed to have a system that monitored the implementation of operational procedure, through the administrative hierarchy. A careful review of the job descriptions reveals this administrative hierarchy, although the system is not well-explained in the agency documents and only one of the agencies has an organizational chart that explains the lines of responsibilities.

Rating: *Unsatisfactory.*

Achievements:

All of the agencies have operational procedures; which include, as a rule, the list of services offered, and in some cases the conditions in which these services were offered, parents' obligations and rights and minimum job descriptions for staff.

In most cases procedures include the multidisciplinary approach.

The development centers have the professional resources to work with multidisciplinary teams.

Staff are knowledgeable of the operational procedures.

Most parents have received copies of rules and regulations.

Issues:

More than a year after the approval of the Standards, the existing operational procedures/ rules and regulations have not been revised to reflect the new requirements.

Issues (cont.)

There are no written referral procedures.

There are no written evaluation procedures.

There are no written service provision procedures.

Staff Knowledge of the Operational Procedures

Almost all staff that participated in the survey were able to explain the basic operational procedures of their agency in their own words, although there were differences in the quality of the responses. They had a good idea of the mission and philosophy of services (9 out of 10), the procedure for the IP (14 out of 15), and the eligibility requirements (3 out of 4).

Clients and Families' Knowledge of Procedures and Standards of Services

Most of the parents who participated in the survey (n= 114, 75%) reported to have received copies of written operational procedures. However, as these operational procedures do not describe the standards of services, it may be concluded that clients and parents are not aware of what to expect and require from the staff in regards to the quality of services, as there are no indicators in this regard.

There is no written description of the system to monitor the implementation of operational procedures.

There are no written procedures o n the collaboration of the multidisciplinary teams.

The existing procedures are not client-centered.

Most of the therapists (esp. speech, physical and occupational) do not have degrees in the field of practice.

Multidisciplinary Teams

All the centers have the professional resources to work with multidisciplinary teams as indicated in Table 5. However, due to a medical approach often used (as explained previously) not all centers work with multidisciplinary teams, although various professionals are involved in the life of clients and work with them. Most of the professional staff who work in the centers have appropriate college degrees in compliance with their job title. This is not true, however, of speech and physical therapists, whose original degrees do not include training in the field of practice. This due to lack of degrees in these areas in the country. Some of the centers have hired the first graduates in specialized pedagogy, the very first college degree to work with people with special needs. Most of the staff have had training in working with people with disabilities. Five of the centers have also contracted services from professionals outside the center, and one of them is collaborating with another agency to provide physical therapy services.

Table 4: **Professional Staff**

Center's Name	Services	Location	# of Clients	SW	PS	ST	PT	M	T/E
RDC* Shkoder	RC	Shkoder	43	1		1	1		20
Valet e Detit	RC/DC	Durres	44	1		1	1	5	11
RDC Vlore	RC	Vlore	22	1			1	1	8
Pellumbat	RC	Tirane	30	1	1	1	1		12
Une Jam Si Ju	RC	Berat	28	1	1	1	1	1	14
RDC Korce	RC	Korce	48	1		1	1		10
DDC**Shkoder	DC*	Shkoder	44	1		1	1	1	20
DDC Lezhe	DC	Lezhe	27	1		1	1		5
DDC Atelie	DC	Korce	23	1					4
Lira	DC	Berat	30				1	4	7
Te Qendrojme Se Bashku	DC	Tirane	30	2	2			1	6
Shtepia e Kuqe	DC	Tirane	30	1		2			5
Ndihmoni Jeten	DC	Tirane	28	3	2	1		1	2
Dora e Ngrohte	DC	Tepelene	25					1	2
Balashe	DC	Elbasan	25	1			3	1	5
		Total	477	16	6	10	12	16	131

Note: SW: social worker, PS: psychologist, ST: Speech Therapist, PT: physical therapists, M: medical doctors or nurses, T/E: teachers and educators.

Recommendations:

The State Social Service needs to provide further guidelines on the formulation of the written referral, evaluation and service procedures and policies and formulate a model to be followed by all centers that provide services for people with intellectual disabilities.

Each agency needs to rewrite all policies and procedures to reflect the requirements of the Standards.

Each agency needs to create a system for evaluating the effectiveness of services with client-centered measurable indicators.

Each agency needs to start a process for assessing client and family satisfaction.

STANDARD FIVE: FAIR TREATMENT, AND COMPLAINTS AND GRIEVANCES

Description

Standard Five demands that all service beneficiaries (clients and family members) are treated fairly and are not discriminated against in the eligibility rules and service provision. In addition, the clients and/or their families enjoy the right to air their complaints and grievances which are documented and addressed according to the written procedures. All those interested get a copy of the eligibility criteria; all clients/family members get copies of the complaint and grievance procedure.

The organization has a procedure for the monitoring of services, which involves the clients/family members. The center staff are required to have good knowledge of the eligibility rules and the grievance process.

Outcomes

Eligibility Criteria

As described by the directors and the staff members, the eligibility criteria for the state-run development centers are based on the DCM nr 196, date 05/09/2002. They include medical documentation of the client's intellectual disability, documentation of family's economic status, and a parents' written request.

The placement in the national centers is decided by a commission at the SSS. These criteria have not yet changed, even for the centers which are currently supervised by the local social services. The staff and the center directors have commented that they are totally powerless in the process and although there was an initial age eligibility criterion to divide the centers according to age groups, the residential centers continue to serve all ages up to 55 years of age in one of the centers. In all fairness, as very few children or adults leave the residential care centers, there are very few available slots

Rating:

Marginally satisfactory.

Achievements:

There is a system in place that secures fairness for service eligibility in the national residential care centers.

All centers have a complaints and grievances process.

Staff know the complaints and grievance process.

Clients and their family members are informed of the complaints and grievance process.

Most centers have addressed the complaints and grievances of their clients in a timely manner.

Issues:

Centers run by non-profit groups do not submit their eligibility criteria for services to the accreditation body.

New eligibility criteria are required for centers that are no longer national.

Eligibility criteria of many day care centers discriminate against people with severe needs.

The other centers, mainly day care, have several criteria besides the medical proof of an intellectual disability: toilet training and being able to feed himself/ herself top the list (see Table 5 for more information). The preference is to work with children and adults with mild and moderate intellectual disabilities because, as one staff member writes, "they may achieve results."

The self-feeding and toilet-trained criteria are discriminatory towards children and adults with severe and profound intellectual disabilities, for whom the services have yet to be developed. The process of determining eligibility for services in the center run by the non-profit organization is not described in the operational procedures and is not reviewed by the accreditation body (the SSS). This situation makes it difficult to judge its fairness.

Issues (cont.):

Clients and families are not involved in the monitoring of services.

Staff do not have good knowledge of the eligibility criteria.

There is no system to secure fairness during service delivery.

The complaints and grievance process has not been revised to reflect the new requirements of the Standards.

The staff are not very familiar with the eligibility rules and only about one in four has a good understanding of them (23.5%, n=32) and another quarter (25%, n=35) has either no understanding or very poor knowledge.

Table 5: **Eligibility Criteria as Described by the Center Directors**

Name	Services	Location	Age	PP	R	TT	EBH	V	NB
RDC* Shkoder	RC	Shkoder							
Valet e Detit	RC.	Durres							
Valet e Detit	DC	Durres	18+		x	x	x		
RDC Vlore	RC	Vlore	6-25						
Pellumbat	RC	Tirane	18+		x				
Une Jam Si Ju	RC	Berat	18-		x				
RDC Korce	RC	Korce				x	x	x	
DDC**Shkoder	DC	Shkoder	6-18						
DDC Lezhe	DC	Lezhe				x			x
DDC Atelie	DC	Korce	15-35	x	x	x	x		
Lira	DC	Berat			x	x			
Te Qendrojme Se Bashku	DC	Tirane			x	x			
Shtepia e Kuqe	DC	Tirane		x					
Ndihmoni Jeten	DC	Tirane	12-25		x	x	x		
Dora e Ngrohte	DC	Tepelene			x	x	x		x
Balashe	DC	Elbasan	14+		x	x	x		

PP: parent pay; R: family's place of residence; TT: toilet trained; EBH: eats by himself/herself; V: verbal; NB: no behaviors.

Service Monitoring

As described in the previous section, there are no written procedures on service monitoring except the one linked to administrative hierarchy. Under the current process, the clients and families are not included in the process of service monitoring, unless it is a concern that relates to the client himself/herself or the child/family member.

Complaints and Grievances

All the agencies have a complaints and grievance process that is included in the operational procedures. Most of the agencies have a complaint box, which is put in a prominent place and is opened by a committee every month. Some other agencies have a complaints notebook, where staff write oral complaints and report them to the director. The clients/family members are also given the right to go to court if they feel that their rights have been violated. In addition, there is a parent representative in the Advisory Board of every center, who is supposed to voice the parents' concerns. There are no timelines or procedures for the response and action. The process has not been revised after the approval of the Standards.

The staff of the centers know the grievance and complaints process (93% gave accurate responses). Most of the parents (84.8%, n=130) also report to have received a copy that describes the process. The site visit team was not given any official record of complaints made, although seven centers reported several complaints that were addressed in the questionnaires completed.

The nature of complaints vary: in two centers the complaints have been about verbal abuse by other clients, in two other centers about the attitude of staff, in one residential center the clients requested more time in the community, and a client requested a room by him/herself. The parents in a day care center requested transportation and a meal at the center and in another one longer hours of service. The staff and the center directors reported that all these complaints/requests were given due attention and many of these issues were resolved.

In one of the centers, however, the conflict between parents who complained about the attitude and behavior of the staff and the director was not resolved without the intervention of the local government, after some of the parents withdrew the children from the center. The two staff members were fired and changes were made in the center.

Recommendations:

The SSS needs to provide guidelines on the acceptable eligibility criteria for various services provided by non-profit organizations and monitor their implementation, making sure that the clients are not discriminated on the basis of needs for support.

All agencies need to formulate the process of monitoring the implementation of services and involve clients and family members in it.

All agencies need to write up the process of complaints and grievances, and add timelines and responsibilities.

Agencies need to keep record of clients' complaints and the response to them.

PROTECTION AND FULFILLMENT OF HUMAN RIGHTS

THE RIGHT TO LIFE

The site visits, and the focus groups with parents and clients provided evidence for a pattern of good care for the clients in residential and day care centers that did not put the clients in harm's way. The buildings are safe, efforts are made to supervise the clients all the time and the entrance and exit is secure and guarded by center security. The staff are responsible for the safety of the clients at all times and the clients are always accompanied by staff to their community events.

The centers do not have written evacuation procedures for emergency cases, and no fire drills have ever taken place in any of the centers.
The safety concerns are not part of the clients' evaluation and the individual supports plan.

However, the site visits and the study of center documentation raise some valid concerns in regards to the protection of the right to life. The centers do not have written evacuation procedures for emergency cases, and no fire drills have ever taken place in any of the centers. Also, the day care centers do not have regulations in place for the pick-up of clients by individuals formally authorized by parents, when they are not available. The safety concerns (like fire and water safety, manipulating sharp tools like scissors, playing with electric outlets, etc.) are not part of the clients' evaluation and the type of supervision care needs are not part of the IP.

FREEDOM FROM TORTURE OR CRUEL, INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT

None of the parents or clients reported any cases of degrading treatment or punishment of the clients. Also, none of the complaints reported was related to mistreatment or punishment. The observations in the centers showed that the staff are generally caring and respectful of clients.

None of the centers has restraint procedures for cases of violent behaviors and staff do not receive any training on how to deal with these cases.

However, of concern is the fact that none of the centers has restraint procedures for cases of violent behaviors and staff do not receive any training on how to deal with these cases. This situation may leave open the possibility of use of undue force or coercion, which would be a violation of the client's human rights.

EQUALITY AND NON-DISCRIMINATION

The day care centers for adults do not accept individuals who are not toilet trained and cannot feed themselves.

No discrimination was found on the basis of gender, ethnicity or socio-economic status in enrollment or the provision of services. However, the centers openly favor the clients who need intermittent and limited support (qualified in medical terms as mild and moderate mental retardation) and many of them (especially the day care centers) deny services to clients who need extensive and pervasive support. Three day care centers for adults include the requirement for high functioning in their eligibility rules, and one residential care center who provides services for children and adults writes in its mid- and long-term objectives, " Make efforts to return to the parents individuals over 18 years of age who do not respond to our level of rehabilitation programs." In another case, the director, while reporting the status of the clients, divides them into two groups: those who can be habilitated and those who may not, and consequently do not participative in any habilitation program. In addition, all day care centers require toilet training and ability to feed oneself for service eligibility

Accessibility and Personal Mobility

Most of the buildings are two-three stories, but only three of the centers are wheelchair accessible.

Most of the buildings of the residential and day care centers are two or even three storied, but of the 26 centers visited, only three were judged and reported to be wheelchair accessible with two of them on only one level. Only one of the centers, which was recently renovated, had an elevator. In one day care center, the clients who are immobile are carried by staff or parents to the second floor. In a senior center, one person is totally confined to his/her room due to lack of any supportive equipment, while another one crawls over the stairs. The other centers do not accept clients who are wheelchair users.

None of the centers has any assistive technology, even low- or mid-tech such as adapted furniture and utensils, manual communication boards, or pencil grips or adapted toys. Sign language is not used with or taught to non-verbal clients.

FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE, PROTECTING THE INTEGRITY OF THE PERSON

The centers do not have written specifications on what constitutes exploitation and abuse of clients.

Care is shown in the centers to provide protection from violence, abuse and exploitation both by staff or other clients, although most of the centers do not have written rules and regulations. Only in one center, the rules state that staff are prohibited from abusing other individuals (staff or clients) verbally and physically and they are not allowed to enter the kitchen and eat from the clients' food (which would be a case of exploitation).

Not specifying what constitutes exploitation (for example there are no rules on not receiving gifts and presents from clients and their families) and what constitutes verbal, physical, and sexual abuse leaves the door open for interpretation and violation of clients' human rights. In one of the senior centers, for example, the evaluation team noticed that the staff were cold and abrasive towards the seniors with disabilities as they required extra care and the staff felt they did not have the training to work with these individuals. Such an attitude, if not addressed by rules and regulations, may precipitate human rights violations of these clients.

The parents are generally vigilant to protect their children from exploitation and abuse. A focus group with parents reported a case of persistent verbal abuse accompanied with sexual innuendos in one of the day care centers by two of the center staff. The case was first reported to the director, who did not take any measures to address the situation. Frustrated, the parents turned to the local social services that supervise the center, and as a result of their intervention the allegations were investigated and the responsible staff were fired. The case demonstrates the urgent need for written procedures for these cases.

Three of the centers reported cases of slanders and verbal abuse of clients towards each other, which were addressed when they were reported by the affected clients. Although action was taken in these three cases, the staff did not consider these cases as human rights violation. Some of them made light of the cases when they describe the complaints as "only gossip and verbal abuse amongst clients." This reinforces the need for including the measures for protection of the integrity of the person in the rules and regulations of the center.

FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

None of the centers reported having regular meetings with clients and/or parents on the center's work and services. No client and family satisfaction surveys are conducted to get feedback for the quality of the services.

Efforts made to protect and fulfill these human rights can be seen in several instances. First, all agencies have a process for the expression and response to the complaints and grievances of clients and/or their legal guardians, and 85% of the parents report that they have received written documentation that describes the grievance process. Second, as a rule, information from the assessment and the progress of work with the IP is shared with clients and their legal guardians. The parents have given the efforts of the agencies in this regard a high mark (9.3/10). Third, most of the parents (75%) report that the agencies have made their operational rules accessible to them.

But there are some concerns. The clients' voice is rarely heard in the process of evaluation and individual planning as the approach is professional-rather than client-centered. Although clients' and/or parents' opinion is sometimes taken on the activities organized in the center, the clients and or parents are seldom involved in any other way in the agency. All examples provided by staff on parental involvement in the center concerned parents' information about different aspects of the IP. None of the centers reported having regular meetings with clients and/or parents on the center's work and services. No client and family satisfaction surveys are ever conducted to get feedback for the quality of the services.

Each center has an administrative board/council, which as a rule has one parent representative. This may create a good opportunity for parents to express their opinion. But, the members of the administrative board/council are selected by the director of the center and they operate under him/her, which may subdue the parents' voice (especially in the conditions of service scarcity).

RESPECT FOR PRIVACY

There is no legal protection for the clients' information. Most clients in residential care centers do not have personal space for personal belongings.

This is an issue which receives very little attention in the residential and day care centers. There are no written rules for staff, 3-5 clients in residential centers share the same room, only five of the 14 residential care centers have individual nightstands or wardrobes for clients, which they can control. In addition, there is no legal protection for the clients' information, which is shared freely without the clients' or parents' consent.

GOOD HEALTH AND HEALTH CARE

Physical examinations are not required periodically. Vaccination records are not required. Clients are not tested for TB.

All clients in residential care receive free health care (which includes medication) and those in day care receive low cost care and reduced drug prices (unless parents choose to go to private clinics). A comprehensive health examination is requested for all clients prior to being enrolled in a program (residential or day). Almost all the residential care centers (with the exception of one) have staff with medical training, mostly nurses. The ones that do not have a doctor on staff, report to have contracted with medical practitioners in their area. Parents seem to be generally satisfied with the care shown for the health of their children in residential development centers, and gave it a mean of 8.21 out 10 (mode=9).

However, there are some areas that need improvement. The physical examinations are not required periodically (for example annually) for clients in day care. Also, in most of the cases no vaccination records are demanded and no tuberculosis (TB) testing is expected.

HABILITATION AND REHABILITATION

Only a few therapists are professionally trained. There are no training requirements for the staff.

All the development centers report they provide several habilitation and habilitation services such as physical therapy, occupational therapy, speech therapy and art therapy, and counseling by psychologist and social workers. With the exception of psychologists and social workers who have college degrees in their area of expertise, the professionals who are involved in providing the therapeutic interventions are not trained or licensed as such. The first college graduates in physical therapy in the country graduated in 2007 and only on of them works in a center. For the other professions, such as occupational, speech, art, and music therapy there are no degree programs. In most of the cases, the people who work as physical therapists in the centers are physical education teachers, those who work as speech therapists are teachers of Albanian language, and those who work as art therapists are art teachers. However, most of them are very dedicated people who have learned on the job.

One of the major problems that most of the development centers report is lack of the necessary equipment for physical therapy, teaching aids for speech and art therapy and assistive technology or devices in general. Another problem reported by parents is the low number of staff, usually called special or development educators who work directly with the clients for the implementation of the IP[8].

Staff training is not systematic and it does not include required topics. None of the centers has a training curriculum, and they depend on the training offered by the local advocacy organizations or international groups. The SSS does not have training requirements for the center staff. None of the training sessions that the staff reported to have attended in the previous year included any habilitation/rehabilitation topics.

The children with intellectual disabilities and emotional disorders in the children's homes do not receive any habilitative services as these centers do not have professional staff, nor do they contract with professionals in their area, even though in one children's home ten children have been determined to have intellectual

[8] A ratio of direct support staff to clients is difficult to calculate. There are no required ratios for either residential or day care centers.

and developmental disabilities. The same is true in the senior homes, where no work is done with the seniors with intellectual disabilities. The directors complain that they do not have the resources to meet the needs of the clients with intellectual disabilities and want them transferred to other institutions. Unfortunately, due to lack of available space this has proven to be impossible. In the meantime, the clients caught in this administrative deadlock, are denied their basic right for habilitation and rehabilitation.

ADEQUATE STANDARD OF LIVING

Only five centers have central heating and air conditioning.
Only three of the residential care centers, which have been built recently by international donors, look like homes.
The furnishings live much to be desired in 70% of the visited centers.
Some of the buildings are not well-maintained.

The 26 residential and day care centers that were visited provide a range of differences in the standard of living for the clients from excellent to poor. Most of them are located in the community (with the exception of one senior home) in two-three story buildings. One of the day care centers is on the second floor of a former dormitory of a boarding school and another one is in an apartment in a multi-story building.

Five of the buildings are newly renovated or built, seven need repairs, two have been renovated several times but are not well maintained (some window panes were broken and not repaired). With the exception of two centers (both of them day care), all the others have courtyards, most of which have playgrounds. The sanitary conditions are generally good, with running water, sufficient number of toilets (generally kept clean) and showers. But there are some issues. For example, in one senior center the ladies' showers for third floor residents (some with them with intellectual disabilities) were on the first floor. In another one, the water deposit did not work, so the clients did not have running water during the day, when the water supply was interrupted. Very few buildings (n=5) have working central heating and air conditioning.

The living arrangements are like a family home in only three of the residential care centers, the others have the traditional institutional design with large rooms and narrow halls. The furnishings are very good in only eight of the centers (30%), and leave much to be desired in the others. The clients are sensitive to this need. In the focus group they expressed the desire to live in a family-like home which is well-furnished.

Food is provided in almost all day care centers (with one exception) either for free or low cost and prepared by trained cooks. There are nutrition standards which are generally followed. Some centers reported client complaints about food, which have been addressed. The parents' satisfaction index with the living conditions and food is high, 9.15/10 and 9.09/10, respectively. The indicators are lower for the residential centers, 8.74/10 and 8.82/10, respectively.

It was impossible to calculate the cost per client as some donor-funded centers did not provide figures on their budget. The budget for the 2007-2008 for the state run residential development centers (n=6) and day care centers (n=2) was 162.6 million lek (2.06 million US dollars with the exchange rate of June 2008). This budget did not include the investment fund.

PARTICIPATION IN POLITICAL AND PUBLIC LIFE

The individuals over 18 years old in the development residential centers have not been registered to vote.
The clients do not have a voice in how centers are run.
There are no organizations that bring together people with intellectual disabilities in day or residential care centers.

The clients with intellectual disabilities in either residential or day care centers are not encouraged to participate in either political or public life. None of the centers has a program that prepares the clients for the political process. The clients from the development centers who can understand the voting process with assistance have never voted and have not even been registered to vote. There are no organizations that bring together and represent the people with intellectual disabilities in general and those from the residential and day care centers in particular.

The clients do not have a voice in how the centers are run and the services are delivered and none of them is a member of the administrative board/council. Their feedback is taken occasionally only in regards to the type of activities that might be organized and when complaints are expressed. Very few centers have written clients' rights, which in most cases consist in receiving good care and having their basic needs met.

PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORTS

Six development centers report than none of their clients participate in cultural, artistic or sports activities.
In the other centers only 10-30% of the clients do.

Not all centers create conditions for the clients' participation in the cultural life, recreation and sports and three residential development centers and three day care centers have reported that none of their clients is involved in these events as an active participant. For the other centers, the numbers are generally small varying from 10% - 30% of the clients. However, the centers organize various activities of a recreational nature which sometimes involve sports and artistic and cultural aspects. In addition, some centers have arts and crafts programs for the clients, which they enjoy. Based on the latter, the parents have expressed satisfaction. Recreation opportunities have been rated with 8.8/10, opportunities for sports 8.2/10, and artistic and cultural activities 8.8/10. According to reports from the focus groups with parents and clients, the centers also organize many leisure activities such as birthday parties for clients, walks in the city, picnics in parks, visits to touristic attractions, etc., and they would like to organize more but are limited by budgetary constraints or transport availability.

EDUCATION

Most of the school-age children in residential and day care centers do not go to school at all.

Very few children from the residential development centers attend school. Only 17 of them from three centers attend segregated special education schools in the community. Most of the residential development centers (n=4, 67%) however have certified teachers on staff and all of them have a considerable number of staff called "special" or "development" educators, who work for the implementation of the IP.

About 120 children receive education in compliance with their IP in six of the day care centers. Some of these children have extensive support needs and as such they are not accepted in the special education schools. The other part live in the cities where there are no special education opportunities at all, and the day care center has taken over that function.

Table 6: **Educational Opportunities for Children**

	Center's Name	Location	Clients*	Attending School	Teachers**	Educators***
1.	RDC Shkoder	Shkoder	43		1	20
2.	Valet e Detit	Durres	32	3		11
3.	RDC Vlore	Vlore	22	7	3	5
4.	Pellumbat	Tirane	30		1	11
5.	Une Jam Si Ju	Berat	28		4	3
6.	RDC Korce	Korce	48	7		10

Note: *This number includes children and adults.

**Teachers have a college degree in teaching.

***Educators have completed high school. Some of them have received training on working with clients with special needs.

The practice of providing education in the residential and day care centers has two problems, one philosophical and the other one is administrative. Philosophically, this practice fosters segregation and isolation. Administratively, the residential and day care centers are supervised and managed by social services authorities rather that those of education. This means that that they do not belong to the educational system in Albania and as such are not part of the professional educational training and supervisory system.

VOCATIONAL TRAINING, WORK AND EMPLOYMENT

There are very few work opportunities.
All the work opportunities are in sheltered employment.

Three of the day care centers provide primarily vocational training and work opportunities for adults with intellectual disabilities. The site observations showed that the working conditions are safe and healthy and the clients worked under the guidance and supervision of trained staff. The products are primarily local arts and crafts, some of them of very good quality. The clients enjoy the work and the work environment and they learn from good local arts and crafts experts. The centers divide the clients into groups based on their abilities, and preferences and the training is on the job. The clients are not paid for the work done, but they receive a free meal.

Some of the products have been sold, but the workshops are encountering difficulty in two areas, getting funding to purchase raw materials, and legislative obstacles in paying the clients for the products sold.

All the work settings can be characterized as forms of sheltered employment. The clients are not trained to work in supported employment, as it still does not exist in the country.

Conclusions:

Although there are no flagrant violations of human rights of the individuals in day and residential care centers that put them in harm's way, the study revealed some concerns that leave these individuals with significant disadvantage to the rest of the Albanian society.

Much more needs to be done to secure that all of them enjoy the same civil, political, social, economic, and cultural rights as their non-disabled peers and are preemptively protected from any form of abuse and exploitation.

Recommendations:

Each center needs to include the protection of relevant, civil, political, social, economic, and cultural human rights in the centers' written policies and operational procedures. The protection and fulfillment of human rights needs to be monitored consistently according to written procedures.

Studies need to be done on how to best include the clients in the decision-making process in the centers and the recommendations need to become part of the written policies and operational procedures for each enter.

DISCUSSION, GENERAL CONCLUSIONS AND RECOMMENDATIONS

The goal of this formative program evaluation was to measure the initial implementation of the Standards of Social Services for Individuals with Disabilities in Residential and Day Care centers in relation to the impact on the lives of people with intellectual disabilities and the protection and the fulfillment of their human rights. From the very first site visit, the evaluation team was confronted with the unexpected. Although the directors and the staff of the centers were aware of the existence of the Standards and had participated in training workshops, none of the centers had started the process of the implementation of the Standards, as they were waiting for official policies and guidelines from the SSS. This is in full violation of the DCM that passed the Standards with the expectation that their implementation would start immediately. In this context, this evaluative study may be better defined as a partial baseline study, which if repeated, will measure the impact of the Standards.

The implementation of the Standards has been very slow for two reasons. The first may be related to lack of professional and administrative competence and capacity in the residential and day care centers, especially the ones run by the government. The second may be related to the attitude of the SSS, which has yet to connect the process of accreditation and inspection to the new Standards. Such an attitude has left the center directors perplexed, taking it as a message of "business as usual, forget the Standards."

This study showed the need for the immediate implementation of the Standards in order to enhance the quality of services and bring their philosophy and practice in line with the contemporary paradigms of independent living, inclusion (or, at least, the least restrictive environment), and self-determination.

The following are the main recommendations for the **State Social Service:**

- Take the leadership role in the process by:
  - Providing more guidance through models;
  - Studying and disseminating best practices;
  - Providing clear inspection guidelines that are related to the Standards; and
  - Offering hands-on training for the development of written policies and operational procedures that ensure the implementation of the Standards.
- Start the process immediately. Every day lost has a negative impact on the quality of life of people with intellectual disabilities.
- Include the homes for children and seniors that provide services for people with intellectual disabilities in the process of developing new policies and procedures that are in compliance with the Standards and in the inspection for their implementation.

The recommendations for **the agencies that run the development residential and day care centers** are as follows:

- Do not wait for the leadership of the SSS. You are responsible before the law for the immediate implementation of the Standards.
  - Create a task force with representatives from the clients, parents, staff and administration and start the work to develop new policies for your own center based on the Standards. This can be done in five meetings if you take one Standard per meeting.
  - Make sure that you include the protection and the fulfillment of the relevant civil, political, economic, social and cultural rights in the new policy and practice. You may use this document as guidance.
  - Submit the newly created policies and operational procedures to all stakeholders: clients, family members, staff of all levels and the Administrative Board. Organize meetings to get their feedback officially.
  - Have the Administrative Board approve the new policies and operational procedures with the changes.
  - Start the implementation.
  - Make sure to evaluate the progress and address the issues after the first six months.

For the homes for children and seniors, which serve clients with intellectual disabilities the following recommendations apply:

- Make sure that you provide the necessary services to these individuals by networking and/or contracting with other organizations that primarily serve individuals with intellectual disabilities.
- Change your policies and operational procedures to become compliant with these Standards by networking with other organizations that primarily serve individuals with intellectual disabilities. You may integrate their new policies and operational procedures into because they are compatible.

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