

### Insights from Moldova:

Role of Peer-to-Peer Support in Advocacy, Influence, and Fostering Independence

#### CHANGING THE WAY WE CARE MOLDOVA

Changing the Way We Care is a global care reform initiative that promotes safe, nurturing family care for children reunifying from institutions or at risk of family separation.

Caregivers are at the heart of familycentered care reform efforts. They are the critical link to ensuring that those who need care get it in a way that allows them to thrive. To do this, caregivers often have to navigate a maze of services and service providers to identify and manage the needs of the child under their care. While service providers are focused on specific issues related to care (e.g., education or health), the caregiver tends to have a more holistic view of the child's needs. For a caregiver who has a child with special needs or disability, accessing and managing the services that the child and family needs can be confusing, time-consuming, physically and mentally exhausting, and isolating.

Changing the Way We Care partner, **AudiViz**, recognizes that caregivers have a
wealth of experience that could be
harnessed and shared among each other
and the larger community. In August 2022,
AudiViz launched a Peer-to-Peer Family
Support initiative focused on caregivers and
children with hearing deficiencies to **advocate** for improved services at the local
level, **influence** decision-making of local
government, and **foster** independence of
children and young adults by building skills
around communication, decision-making,
and career guidance.

#### What is Care?

The World Health Organization defines care as:

All activities undertaken by
others to ensure those who
cannot fulfill such activities
independently maintain a
standard of living and of
functioning that allows them to
reach their full potential, to fulfill
their human rights and to
maintain human dignity.

#### Who are the Caregivers?

Research from the World
Economic Forum found that
globally, women and girls
contribute more than 70 percent
of total global caregiving hours
(paid and unpaid) and perform
more than 75 percent of unpaid
care work.

A study by <u>EuroCarers</u> found that because of caregiving responsibilities, women unwillingly reduce their working hours or drop out of employment. On average, working women spend 22 hours per week in unpaid work.

#### INSIGHT 1: WALKING THE PATH

The path of a family with a child with disability is filled with the wisdom and **insight** that comes from overcoming hurdles both personal and societal. It can also be an isolating experience. Peer-to-Peer Family Support Groups allow those on similar paths to **share** experiences, break down barriers of isolation, and advocate for improved access to services.

#### Walking the path

In a pivotal scene in the movie *The Matrix*, the character Morpheus tells Neo "...there is a difference between knowing the path and walking the path."

Many professionals in care reform 'know the path', but it is caregivers/parents and children with disabilities that have 'walked the path.'

It is this difference that is at the root of AudiViz's establishment of a Peer-to-Peer Family Support Group for parents and caregivers of children and young people with hearing impairment. In this group, parents and caregivers act as "guides/mentors" offering direct counseling to families who have just learned about their child's hearing condition or who have older children and need the unique support and wisdom that comes from someone else who has walked this path.

It is not just parents and caregivers, young people with lived experience, some of whom recently left residential institutions, have insights and wisdom to share and benefit from interacting with others on the same path.

The Family Support Group (FSG) meets monthly to discuss, strategize, and attend skill-building workshops with a focus on honing advocacy and communication skills. Parents and caregivers then develop individual action plans to advocate for the services they need.

[Participation in the Support Group] **makes me stronger**, it makes me move forward. For me, it makes me know more, not for someone else, but for myself.

#### **Spotlight: AudiViz**

Founded by a group of volunteers in 2018, AudiViz works with children and young people with hearing and sight impairments and their families to overcome barriers they face in the social, medical, and educational fields.

#### **AudiViz Mission**

- Promote the importance of early intervention, in order to improve the quality of life of children with hearing and vision impairments.
- Expand the National hearing screening program.
- Provide methodological and technical support to medical staff and teachers in order to consolidate and improve the medical and educational services addressed to children with hearing and sight impairments.
- Increase the level of information and awareness on the issue of hearing and sight impairments at the community level, promoting an inclusive society in which the rights of people with disabilities are recognized and respected.

#### AudiViz Team

The AudiViz team is made up of professionals with experience in the field of sensory impairments: psychologists, psychopedagogues, speech therapists, and medical workers.



INSIGHT 2: BECOMING AN AGENT OF CHANGE

Parents,
caregivers,
young people
with lived
experience who
have 'walked
the path' are
often the best
advocates for
their families'
needs as well
as for larger
societal
changes.

Their power is in their experience.

With the right tools and training, they can become a formidable agent for change.

#### **Agents of Change**

Global Citizen, a global advocacy organization, describes being an advocate as an 'act of service." Advocacy encourages people to use their power to become agents of change influencing decisionmakers and demanding changes that benefit humanity.

For those 'walking the path' with a child with a disability, their power is in their experience. It is in the personal stories they have to share, the obstacles they have had to overcome, and the lessons they have learned along the way.

Audiviz is harnessing this power through the active participation of parents of children with hearing impairments and young people with hearing impairments to influence the decision-making processes of local public authorities, educational institutions, and the health sector.

AudiViz's advocacy agenda includes:

**Face-to-Face Meetings:** Holding direct meetings with decisionmakers to put forward recommendations to improve services for children with hearing impairments.

**Partnerships:** Establishing sustainable partnerships with local public authorities to improve services that meet the needs of children with hearing impairments and their families.

These advocacy activities...all the ideas came from the parents...they want to be empowered and trained in advocacy so that they know how best to ask for help, to request services in a way that is both unique and well-informed.

Angela Moiseeva, Director, AudiViz

#### What is Participation?

The CTWWC People with Live Experience (PWLE) participation strategy is underpinned by a set of principles adopted from The Committee on the Rights of the Child's General Comment No. 12 (2009) and broadened to include young people and adults with lived experience.

Participation principles include:

• Transparent and informative

- Voluntary
- Respectful
- Relevant
- Inclusive
- PWLE-Friendly Environments and Working Methods
- Supported by Training

#### What is Advocacy?

Advocacy is taking **action to create change** in your life or in your community.
It encompasses a broad range of activities including:

**Self-advocacy**: Speaking up for your own needs and interests.

**Individual Advocacy:** Speaking out in support of a vulnerable individual needs and rights.

**Systems Advocacy:** Changing policies, laws, and rules to positively impact people's lives.

INSIGHT 2: BECOMING AN AGENT OF CHANGE

By sharing their experiences, parents, caregivers, and young people can help illuminate the gaps between policies on paper and real-life practices and advocate for changes that address their needs and help bring about a more inclusive society.

#### Agents of Change cont.

**Training:** Providing hands-on, practical advocacy training to parents and caregivers on how to advocate for services for their families, including how to write compelling letters to local authorities, how to conduct in-person meetings, and the importance of follow-up and accountability of their representatives.

**Action Plans:** Developing action plans that include individualized education plans for each child, as well as overall policy action plans that impact the wider community. The action plan is shared with local public authorities and its implementation monitored by the Family Support Group.

Policy change: Petitioning the Republican Center of Audiology to adapt the strategy of the National Cochlear Implant Program.
Petitioning to secure access to communication and information for children who use sign language at school.

**Policy recommendations:** Harnessing the experience of the FSP to develop policy recommendations aimed at local public authorities, schools, and health providers to improve and/or develop services focused on community needs.

**Monitoring:** Monitoring the implementation of policies and services to ensure they meet the needs of children with hearing impairments and their families.

Let's go, let's insist, let's talk, let's open our mouths. We are advocating for the future of our children. Let's be constantly alert...this is what we live for, to see our children in the future happy, fulfilled, and healthy.

Luiza, Parent Advocate

# Policies vs. Practice: Breaking down Barriers to Inclusive Education

Though in theory children in Moldova have access to inclusive education, in practice this has often meant that a child with a disability sits in the classroom with their peers but is not engaged in classroom activities. It can lead to a child feeling isolated, discouraged, and becoming withdrawn.

"My teacher came to class, but he didn't use sign language at all, he only spoke verbally. I didn't understand anything, even when I tried my best to lip read, but I wasn't getting it. I wanted it explained to me in a clearer way so that I could understand the topic myself."

Mihai, 18 years old

AudiViz is working to break down the barriers to education in schools by advocating for the provision of communication support to children and young people with hearing impairments to ensure they are able to learn and achieve alongside their hearing peers and gain the qualifications needed for employment or further education.

# INSIGHT 3: ADDRESSING SOCIAL ISOLATION AND LONELINESS THROUGH COMMUNICATION AND ADVOCACY

Children with hearing deficiencies and their families often struggle with social isolation and loneliness. Engaging the community family members, social workers, teachers, health staff to learn sign language can help break down barriers and build social connections.

#### **Social Isolation and Loneliness**

In early 2023, AudiViz conducted a series of focus group discussions with children and young people, as well as parents and caregivers, to identify barriers to education, medical services, and community integration. The discussions provided important insight into the struggles faced by the children and their caregivers.

In interview after interview, a common theme emerged - children with hearing deficiencies and their caregivers often felt isolated from their community and broader society. Social isolation and loneliness are increasingly recognized as having high personal and societal costs and have been linked to significant health issues including heart disease, stroke, depression, anxiety, addiction, and early death.

#### **Access to Communication**

AudiViz is working to tackle this issue by increasing access to communication and building sign language skills within the community including teaching children, parents, family members, social workers, and teachers sign language to communicate. The use of sign language has been shown to break down barriers that are contributing to isolation of children and families.

AudiViz is advocating along with the Family Support Group for children for the **right to a sign language interpreter** at school to help them access information necessary for a child's education and development.

Sign language is the language that would help the child to be like others, to integrate into society.

Caregiver,
Focus Group Discussion

## Social Isolation and Loneliness:

Focus Group Discussions with children with hearing deficiencies and their caregivers

"I feel very lonely, I have no friends, I can't communicate with anyone..."

"If you don't have communication, it's like living in darkness..."

"Children don't really accept him because he doesn't talk, they don't call him into their circle of games"

"I want to have friends."

"I want it to be a place where we would meet with friends who don't hear, to play chess, to watch TV, to be together"

# INSIGHT 4: FOSTERING INDEPENDENCE AND FINDING THEIR VOICE FOR INFLUENCE

Young people with Lived Experience voices can be elevated to influence decisionmakers and policy to impact positive change in the community. In focus groups, young people with Lived Experience took a rightsbased approach and raised important issues around inequality and access.

#### **Voices for Influence**

For young people, especially those with disabilities, life in a residential institution can erode their confidence and their ability to do things for themselves. As they make the transition from a residential institution to their home communities, they need to gain self confidence in their ability to tackle challenges and barriers.

AudiViz recognizes the need to engage young people early on to foster independence by working directly with them to build both hard skills (e.g., university and vocational training) and soft skills (e.g., interpersonal skills, leadership, problem solving, time management, and teamwork). They take an individual approach and hold counseling sessions and workshops that build life skills to prepare them for the future. In the process, they help them find their voice and become architects in building their own future.

Not surprisingly, these young people not only have a lot to say and want to be heard. In AudiViz-led focus groups, young people discussed issues around inequality and the need for a rightsbased approach. They spoke about the discrimination they faced in a hearingfocused world and what could be done to overcome the obstacles. AudiViz engages them on ways to harness their experiences to influence decisionmakers and decision-making processes. They are coached on how to raise their voices for influence and keep decisionmakers accountable to their commitments.

"There's a lot of stigma around hearing impaired people, but we're just like everyone else – we're equal."

Young Person with Lived Experience, Focus Group Discussion

#### **Voices for Influence:**

Recommendations from Young People with lived experience to local authorities to promote positive change.

- Provide communication support to children and young people with hearing impairments at school to ensure they are able to learn and achieve alongside their hearing peers and gain the qualifications needed for employment or further education.
- Teach children and young people with hearing deficiencies skills that will help them live independently in a hearing environment: entrepreneurship skills, money management, communication with hearing people and know the rights of people with disabilities.
- Train employers on disability rights, accessibility, communication skills and hearing impairment awareness.
- Support young people with hearing deficiencies in the school-employment transition process.
- Support young people with hearing impairments to form groups and social networks to share learning and support to increase their aspirations and confidence.
- Provide high-quality information and training for families and communities so they understand the lives of people with hearing impairments, their rights and needs, and can adequately support them.



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Need to know more? Contact Changing the Way We Care at, info@ctwwc.org or visit changingthewaywecare.org.

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