



Current Trends in Community Care

LECTURE

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Disabled Persons

&

Community Care



Disabled Persons & Community Care —

Overview of lecture

- Terminology
- The international perspective
- The local situation
- Provisions for disabled people



The international perspective

- Trend to **de-institutionalise**;
- Abandon medical-institution approach;
- **Care in the community** became focal point;
- Move from institutional models to **rehabilitative models**;
- The promotion of '**independent living**' as a concept;
- '**Rehabilitation**' and '**independent living**' often meant the movement of disabled people along a **linear residential continuum**.



The international perspective

Linear Residential Continuum:

- accepted conceptual framework in residential services during the 1980s;
- under this paradigm, disabled persons were placed in residences that best met their needs at that point;
- would move to less restricted settings as they became rehabilitated;
- ultimate goal was that of moving out of continuum to independent living.

The international perspective

Disabled Activist Movement:

- Focused on:
 - community-based care;
 - user involvement in decision-making;
 - choice of services.
- Brought with it new approaches to housing for disabled people;
- Outcome ⇒ PARADIGM SHIFT:
 - From reliance on residential services continuum to emphasis on what has become known as Supported Living.

The international perspective

Supported Living:

- Community support and integration means:
 - Being *a valued part* of the community – not just being *in* the community;
 - Having opportunity to participate in decision-making;
 - An emphasis on choice and decision-making by disabled person;
 - This emphasis is reflected in programmes that use the concept of **empowerment-community integration approach**.



The international perspective

Critical elements of Supported Living:

- Use of generic housing dispersed in the community;
- Flexible, portable, individualised supports;
- Consumer choice;
- Services are 'de-linked' – not tied to a particular location but made available regardless of where the individual lives;
- Assistance in locating & maintaining housing outside family when necessary.

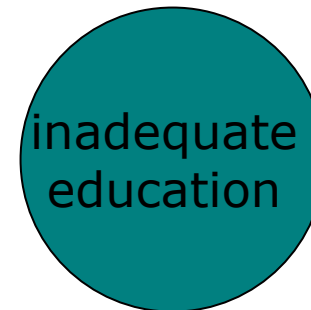
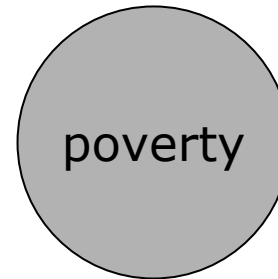
The international perspective

Criticisms of previous rehabilitation approaches:

1. Imbalance of power between professionals and service-users:
 - Insufficient knowledge is paid to desires, needs and experiential knowledge of person and family;
2. Focus on deficits rather than potential of service-users:
 - Contributes to stigma that disabled persons need professionally delivered services;
 - Encourages dependency;
 - Ignores informal community supports.

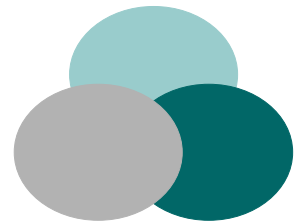
The international perspective

3. Locating the source of the problem with the individual:
- Ignores social conditions that individuals face such as:
 - poverty;
 - poor quality housing;
 - lack of adequate education.



The international perspective

- **The new perspective based on concepts of Supported Living, has been used internationally in designing programmes depending on:**
 - specific needs of the community;
 - available funding;
 - prevalent service culture.



Local Situation

- In Malta & Gozo there is no visible homelessness:
 - because of strong family ties;
 - because every person is provided or somehow or other;
- Change over last 50 years in our perception of:
 - who people in need are;
 - how best to address these needs.





Local Situation

- Before 1960s, disabled people lived:
 - at home – at times in an inadequate manner;
 - in institutions such as MCH or SVPR.
- Early 1960:
 - Mons Mikiel Azzopardi advocated for disabled persons' right to adequate housing away from the natural family when needed;
 - 'Dar tal-Providenza' was born;
 - In a brief span of time, institution became saturated – long waiting list developed.



Local Situation

- **How did Mons Azzopardi contribute?**
 - Exposed stigma that existed around disabled persons and their families;
 - Rejected the false belief that disability was God's punishment for family's sinful ways;
 - Unveiled the reality of disabled persons who were kept hidden, some of whom lived in atrocious conditions;
 - Emphasised issue that disabled persons should not be housed in hospitals.

Local Situation

- Dar tal-Providenza full ⇒ parents directly or through support groups / activists started to lobby for alternative housing arrangements;
- This gave rise to the famous question:

**'What is going to happen to
our disabled children
once we have gone home
or unable to care for them?'**



Local Situation

- **Status quo for the next 15 years;**
- **Late 70s or early 80s Jean Vanier visited Malta:**
 - Lectured on concept of 'Arche Communities':
 - Idea of group homes where disabled and non-disabled shared the home;
 - Sparked a ray of hope but, for some time, no one took initiative to embark on such a venture.

Local Situation

- **1989** ⇒ **1st initiative** ⇒ **DAR IL-WENS:**
 - Housing 10 persons and supported by staff;
- **1990** ⇒ **Foundation for Respite Care Services set up:**
 - A joint initiative of the National Parents' Society for Person with Disability and the National Commission Persons with Disability;
 - Acquired 'Dar il-Kaptan' in Mtarfa where the first respite centre was set up;
 - Concept of respite developed to address parents' needs for regular breaks to regenerate energies and be able to look after their disabled children longer.

Local Situation

- **In mid-1990s ⇒ Dar Nazareth opened:**
 - Rev Angelo Seychell offered his own residence to open this community group home for disabled persons built on the 'Arche' model;
 - Recently opened 2nd home 'Dar I-Arcipriet Degabriele' for the same purpose;
 - Rev Seychell also dedicates a lot of his time in the running of these homes.



Local Situation

International influence towards independent and supported living:

- Focusing of building services around the needs of the individual rather than that of the service provider:
- Main concepts of new line of thought are:
 - **Community-based services;**
 - **Dignity and Respect;**
 - **Privacy and Confidentiality;**
 - **Empowerment;**



Local Situation

- More concepts of the new line of thought:
 - **Choice and Control;**
 - **Community Presence;**
 - **Community Participation;**
 - **Equal Opportunities;**
 - **Person-Centred Approach;**
 - **Maximising inter-dependence;**
 - **Support as against caring.**



Local Situation

- These key factors necessitated that an **educative process** be put in motion with the aim of:
 - minimising overprotection and/or neglect of disabled person;
 - eradicating lack of sensitivity among professionals;
 - working towards physical and social accessibility;
 - encouraging acquisition of knowledge and information.

Services of Agenzija SAPPOR

Within this scenario:

- **Agenzija SAPPOR was established in 2001:**
 - Set up by the Foundation for Social Welfare Services within the Ministry for Social Policy;
 - To provide residential services practicing latest concepts of Supported Living;
- **Agency on its own will not meet existent and future demand but will:**
 - Start to bridge the gap between demand and supply;
 - Set standards that are acceptable to the persons who make use of the services.

Local Situation

In the meantime:

- **public awareness campaigns highlighted disability issues:**
 - foremost, the right of disabled persons to be accepted as full members of society;
 - exposed the difficulties faced by disabled people in society;
- **medical advances meant that disabled people were living longer.**



Services of Aġenzija SAPPORT

Aġenzija SAPPORT gives priority to:

- Persons who manifest severe challenging behaviour, which behaviour may be of continuous stress to their primary care givers;
- Persons in the community who are at serious risk of ending up in an institution;
- Young disabled men and women who have been placed in institutions due to a lack of adequate alternative accommodation.

Services of Agenzija SAPPOR

Service offered by Agenzija SAPPOR:

- **Social Work and Resource Services:**
 - Co-ordinate service through assessment, short-term and long-term interventions to meet desired objectives of disabled person and his/her significant others;
 - In adherence with agency's holistic & person-centred approach, strive to provide individualised support service that would empower the disabled person to realise their dreams to enhance their quality of life;

Services of Agenzija SAPPOR

More services offered by the Agency:

- **Community Services:**

- empower disabled persons and their family/carers through support at home;
- promote their right to live in the natural family ambiance and to be participant citizens in their community;
- an option that is carefully considered before a request for residential services is entertained.

Residential Services only offered if all else fails and alternative accommodation is deemed essential for well-being of the disabled person

Services of Aġenzija SAPPOR

Different Models of residential services adopted by Aġenzija SAPPOR:

1. Housing Estates:

- 2 3-bedroom apartments in housing estates of Fgura & Kirkop provided by Housing Authority;
 - Fgura – 3 persons living together since November 2002;
 - Kirkop – 4 residents living in this flat, 3 since February 2003 & another joined them recently.
- Supported round the clock and in accordance with their needs.

Services of Agenzija SAPPOR

More Models :

2. Detached Bungalow:

- 'Villino Maria' – a 5-bedroomed bungalow purposely built in Mtarfa for clients who, due to their impairments, have suffered severe hardship:
 - 6 residents living together;
 - all service users at this property are in the age bracket of 19 – 25 years;
 - some have been rehabilitated from MCH;
 - some necessitated a transition period of over 1 year due to their challenging adjustment requirement.

Services of Agenzija SAPPOR

More Models :

3. **Residenza Vajrita – M'Scala:**

- Previously a tourist complex, restructured to house 12 independent flatlets:
 - every flatlet comprises one twin bedded bedroom, kitchenet & living/dining room;
 - 6 flatlets on 2 floors;
 - 1st floor inaugurated February 2003:
 - at present houses 12 residents and another 1 is in transition;
 - 2nd floor inaugurated December 2003
 - 10 persons living there already, and another 4 are in transition.

Services of Agenzija SAPPOR

More Models :

4. Dar I-Arka – Gozo:

- Agency entered into a contract with 'Fondazzjoni Arka' through Ministry for Social Policy and Ministry for Gozo:
 - Acquired the possibility of providing residential services for 6 persons in Dar I-Arka;
 - 5 of these 6 residential placements have already been filled;
 - A 6th person is being considered.

Services of Agenzija SAPPOR

Agenzija SAPPOR – Summary:

- In 2½ years of operation we have:
 - Provided Residential Services as follows:
 - put 5 properties on the market;
 - with 40 persons already in residence;
 - & 6 others in transition.
 - Provided Community Services as follows:
 - 55 persons receiving community services;
 - different requirements are entertained and different methods utilised according to the needs and wishes of the person;
 - 390 hours of community services / week.