

1. What should be the roles and responsibilities of different parts of society in supporting individuals who have a developmental disability?

EVERY MEMBER OF SOCIETY HAS A RESPONSIBILITY TO ACCEPT EVERY INDIVIDUAL REGARDLESS OF ANY DIFFERENCES. EVERY INDIVIDUAL HAS A RIGHT TO BE ACCEPTED. SOCIETY NEEDS TO VALUE ALL CITIZENS BY RESPECTING THE GIFTS AND STRENGTHS OF ALL PERSONS. PARTICIPATION IS THE VEHICLE FOR THE EXPRESSION OF CITIZENSHIP. EVERY INDIVIDUAL HAS THE ABILITY TO MAKE DECISIONS AFFECTING THEIR LIVES; THEY MAY JUST DO IT DIFFERENTLY AND MAY NEED SUPPORT TO DO SO. THEREFORE, EVERY INDIVIDUAL HAS THE RIGHT TO DECIDE HOW THEY WISH TO LIVE THEIR LIFE. ACCORDINGLY THE MOST FUNDAMENTAL PRINCIPLE MUST BE:

NOTHING ABOUT ME WITHOUT ME!

THIS THEME IS SUPPORTED BY THE FOLLOWING COMMENTS FROM OUR RESPONDENTS

Individual

- has a right to income & disability supports according to needs
- has a right to self determination, respect for human worth and dignity
- has a right to quality of life
- has a right to be provided with accurate information to enable them to make informed decisions and be given the opportunity to do so
- has a right to be provided with accurate information regarding their disability
- has a right to expect the same rights as other members of society
- has a responsibility to identify needs truthfully, honestly, and responsibly
- has a right and responsibility to insist that others accept the fundamental principle as identified above
- has a right and responsibility to take their rightful place in society

- has a right to anticipate the same levels of informal, natural support as anyone else and should be expected to provide the same to others
- has a right to expect to be treated with dignity and respect
- should be an active participant in their community doing meaningful and productive things, the same as anyone else according to their unique lifestyle and system of support
- be responsible to participate in personal planning, identifying strengths, needs, interests, dreams, anticipated outcomes, and financial supports required which specifically reflect individual circumstance
- has a right to have stability in their lives
- has a right to exercise their rights as citizens, and along with these rights comes the responsibility to fulfill their citizenship duty
- has a right to entitlement and equity in funding for a broad range of options best suiting their individual needs and lifestyle choice
- has a right to disability supports that are adequate, appropriate, and accessible and of their choice
- has a right to be recognized as a person, funded as an individual not simply as part of a group
- has the right to be a stakeholder in decisions affecting his/her life i.e. choice in type of support and/or workers

Family / Support Network

Responsibilities:

- to identify needs truthfully, honestly, and responsibly
- to assist the individual to determine their own life
- to help ensure that the dreams of the individual are center
- to respect the wishes of the individual
- to recognize the need to let go, accepting the natural progression of life
- to assist the individual to advocate for themselves
- to advocate solely in the best interest of the individual when necessary to advocate on their behalf
- to assist in the development of a circle of friends for the individual
- to provide guidance, love, emotional support
- to be accountable to the family member with the disability; ensuring funding is spent wisely, in the best interest of the individual, promoting community inclusion and as independent a lifestyle as is possible

Rights:

- to control adequate funding
- not to be intimidated by the 'experts' as they truly are the experts when it comes to their loved ones
- not to be subjected to the pressures of service providers wanting to keep status quo (segregated, congregated programs & services) that detracts from true citizenship, value, respect and from being seen as individuals
- to a fair and equitable process for funding and portability of funding
- to be equal stakeholders in the entire decision making process including policy discussions and decisions which affect their lives and the lives of their loved one

Government

Rights

- to expect an honest, truthful and responsible identification of needs from the individual / family/ support network
- to expect an honest, truthful and responsible accounting of any funding directed to the individual/family/support network

Responsibility

- to provide equitable and secure funding
- to ensure an acceptable level of disability income supports which take into consideration the unique needs of the individual and family as well as the increased costs of being disabled (present level of ODSP too low)
- to legislate disability supports (SSAH, I.F.)
 - having NO support entitlement is tantamount to a death sentence (an adult without care cannot survive; lack of such care leads to death; without funding they cannot obtain necessary care)
- develop legislation for social reform
 - establishing rights of disabled
 - establishing formal appeals mechanism
 - mandating that families are included in policy discussions & decisions
- to continue providing supports to facilitate full participation in society as has been the norm for children within the education system

- essential that individualized funding be developed to provide financial supports for full participation in community (day care, education, employment, transition periods, affordable housing, transportation, quality medical care, infrastructure for innovative delivery of supports)
 - establish independent facilitators / planners networks
 - establish citizen's advocacy networks
 - establish individual / family networks
 - making individualized funding available to all who want it
 - enabling individuals/families/support networks to self administer funding
 - establish better partnerships with other sectors of society
 - learn to trust individuals/families/support networks
 - including individuals/families/support networks in all aspects of policy discussions and decisions as they have to live with the decisions
 - recognize that they are supporting 'people' not 'things'
 - recognize that this is the 'our life'
 - recognize that needs are unique and ever changing
 - recognize individuals/families/support networks are the experts on the needs of the individual
 - look to other jurisdictions that are successfully making individualized funding work
 - look to other jurisdictions to answer questions like how best to determine adequate funding

- to be accountable to the individual
- to recognize the needs not just of the individual but of the family supporting that individual
- ensure seamless supports
- establish a 'one stop shopping' community resource to facilitate access to various supports
- ensure realistic wages for workers which includes benefits etc to enable hiring of trained, experienced, educated, dedicated support workers, thus reducing the high turn over rate
- fund supports not programs; allocating funds directly for an individual rather than an agency's program
- develop policies allowing for flexible, portable funding within the traditional supports model
- streamline service delivery to enable more direct service dollars
- mandate team meetings as part of I.E.P. to ensure that transition plans are meeting needs of individual, not just generalized plans
- ensure accountability on the part of the service providers and individuals/families/support networks

- ensure that large amounts of money are not spent on meetings with management of agencies struggling with issues centered around protecting their turf
- provide financial support to train appropriate service providers to provide inclusive supports
- provide financial support for further education
- ensure that appropriate skills are being taught to those who will be providing supports
- ensure that information available at colleges & universities is accurate and up to date
- educate society on the nature of disability to dispel myths because it is mostly ignorance not unwillingness that create barriers
- provide incentives and support to community entities willing to integrate individuals with disabilities
- to review agencies resistant to changing trends denying individual true rights as citizens

- develop policies that are
 - clear, fair and equitable
 - reflective of the times
 - enabling individuals/families/support networks to have access to funding
 - person centered
 - person directed
 - person & family controlled
 - flexible
 - portable
 - consistently applied to avoid discrimination
 - inclusive of all disabled individuals

Service Providers

- school boards need to connect individuals/families/support networks with service agencies, support groups, employment opportunities
- focus funding on inclusive activities and partnerships to increase community awareness and participation
- listen to the individuals, their families/support circles and respond to their needs in a flexible and creative way
- develop service contracts that are truly individualized according to needs, it is not enough to just change a few things
- be accountable to individuals and government
- recognize that their services may one day no longer be necessary
- properly trained to provide services and care according to needs
- recognize that they are working with community not for bureaucracy
- develop knowledge of services and opportunities available
- ensure policies, rules & regulations are not contrary to citizenship rights of individuals to have true choice
- free up dollars from restrictive formal programs/services which deny true choice
- service providers must ‘unbundle’ existing dollars and new monies should not be used to promote old ways as these prevent true choice, individuality and opportunity to be true citizens
- remember that they are serving ‘people’ not ‘things’
- recognize that this is ‘our life’
- recognize individual / families/networks as true stakeholders/partners not prisoners in a system
- recognize that their services/supports are not the only options
- give up ‘control’ of individual

Other Members

- acceptance of the diversity of the entire population
- remove all barriers, attitudinal and physical
- seek knowledge and skills to interact with all members of society
- provide supports needed for full participation
- welcome all people
- encourage involvement & participation
- be open to change
- be accessible
- be supportive
- request assistance when needed from individuals/families/support networks as well as service providers and government

NOTE: being part of community from birth, individuals are accepted and viewed as valuable contributing members of society. If individuals/families/support networks, government and service providers all work together modeling citizenship, then community will follow.