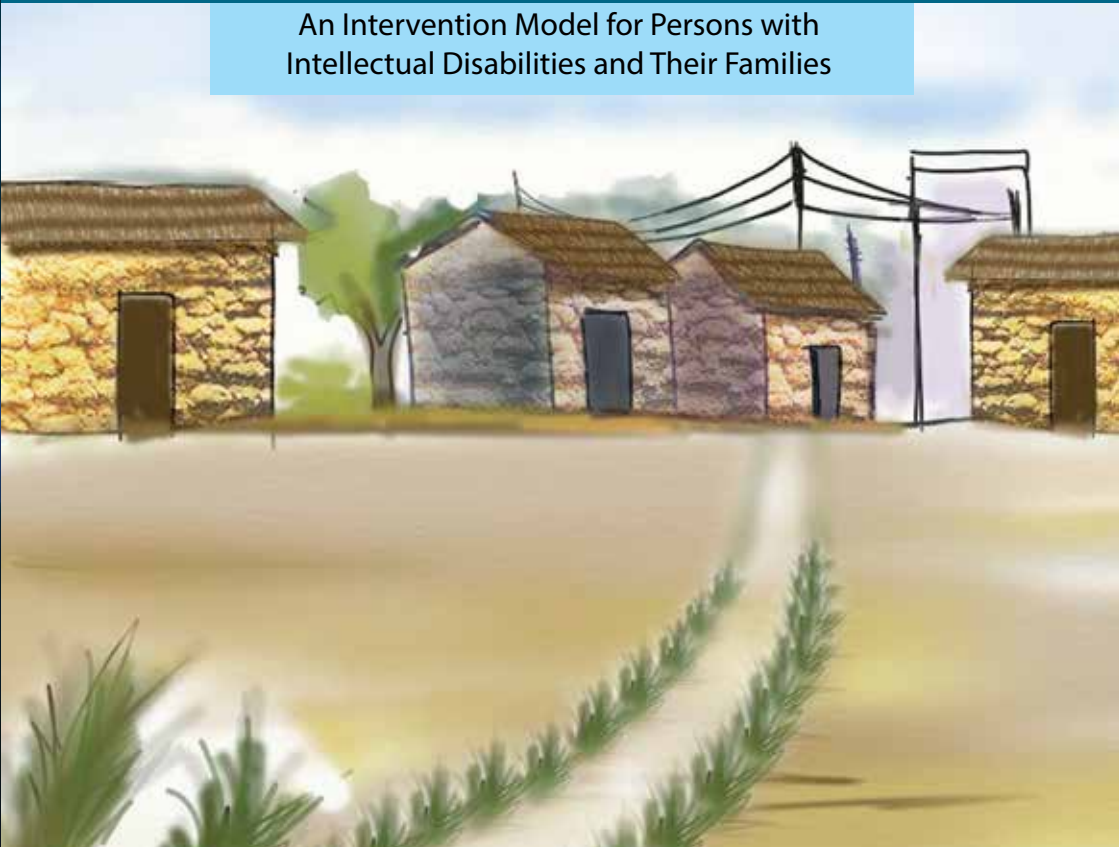




FINDING OUR WAY IN THE COMMUNITY

An Intervention Model for Persons with
Intellectual Disabilities and Their Families



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An Intervention Model for the Inclusion
of Persons with Intellectual Disabilities
and their Families



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FOREWORD

Persons with intellectual disabilities (PWIDs) are amongst the forgotten and voiceless people of our country. They are often faced with discrimination and denied their fundamental human rights. Parents and families of PWIDs are also stigmatised in the community in which they live in. It is sometimes difficult for them to access government services available in the communities for their children and this is usually due to the stigma and discrimination they suffer in their communities. This compels some of the parents or families to abandon their children and in other cases succumb to societal pressures and have the children exterminated.

Inclusion Ghana after several years of engagements with parents and families of PWIDs has realised the need for parents and families to play a central role in the survival, care and growth of their children with intellectual disabilities. This intervention model designed by Inclusion Ghana outlines the various models to use to facilitate the acceptance and inclusion of PWIDs by parents and relationship building among the family and the community. It also encourages the formation of Parent Self Help Groups for support and advocacy for PWIDs to access social services. It is a model that builds community acceptance, participation and access to government interventions/services, education and health.

The intervention model can be used by parents/caregivers of Persons with Intellectual Disabilities (PWIDs), Organisations of Persons with Disabilities (OPWDs), organisations working with or for PWIDs and social workers as the basis towards a systematic approach to understanding the context and challenges of persons with intellectual disability and their families and using inclusion as a key tool in advancing quality life for PWIDs.

Inclusion Ghana wishes to thank the people who contributed to the development of this model. We would like to thank our Parent Self Help Groups (PSHG) and our Member Organisations (MOs). We are also indebted to the Danish Disability Fund who gave us financial support for the development of this model. Many thanks to Landsforeningen LEV for the technical support. Finally, we would like to show special appreciation to the entire staff and board of Inclusion Ghana for the great support in the development of this intervention model.



Auberon Jeleel Odoom
National Co-ordinator

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1.0 About the Intervention Model

This is an intervention developed by Inclusion Ghana for parents/caregivers of Persons with Intellectual Disabilities (PWIDs) and also organizations working with or for PWIDs. It outlines the various models to use to facilitate the acceptance and inclusion of PWIDs by parents and relationship building among the family. It also encourages the formation of Parent Self Help Groups for support and advocacy for PWIDs to access social services, and lastly, it builds community acceptance, participation and access to government interventions/services.

The intervention provides social workers with the basis for a systematic approach to understanding the context and behavioral patterns of intellectual disability, as the lens through which a child's disability is comprehended as a family and societal issue. It also gives a clear direction on how to include and ensure the participation of persons with intellectual disability and their families in a system that ensures community growth focusing on the PWIDs.

This intervention is designed to foster the quality of attachments and relationships within the family, the emotional well-being of individual family members, as well as the general development of the PWIDs.

2.0 Context

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18. Persons with intellectual disabilities have limitations in two or more of the below adaptive skills:

- Self-care and home living
- Social skills and functional academics
- Communication and self-direction
- Health and safety
- Leisure and work

Parents and family play a central role in the survival, care and growth of a child with intellectual disability. In Ghana, most parents especially mothers of children with intellectual disability become victims of discrimination and stigmatization. This situation usually compels them to either abandon the child or in other cases succumb to the societal pressures and sometimes have the child exterminated.

Through the parent self-help groups' support system, most of the children with Intellectual Disability (ID) are saved. Parents are supported through counselling and experience sharing sessions at group meetings. This empowers parents to overcome the discrimination and stigmatisation from the family and community at large.

Parents get to see their children's condition as a disability and thereby can relate to any other person with disability like the deaf, blind and persons with physical disability. As PWIDs are faced with communication and self-direction challenges, parents and caregivers are usually encouraged to represent them in the disability movement through the Parent Self-Help Groups (PSHG) as members of Inclusion Ghana.

3.0 Principles

For many people with disabilities such as PWIDs, assistance and support are prerequisites for their participating in the society. No one model of support services will work in all contexts and meet all needs. Persons with intellectual disability and their families, best know what mix of models/services and supports are likely to meet their needs. However, Inclusion Ghana after several years of engagements with parents and families have developed this intervention model considering the following:

- The best interests of the PWID and their parents are paramount.
- The services and supports that protect and promote the rights of PWIDs are key in ensuring their inclusion
- To create an enabling environment for their inclusion, the child- and family-centered approach (which promotes acceptance,

inclusion, participation, choice and opportunity) should be adopted

4.0 Building on good practices

We believe that there is a need to empower, motivate and support parents, through our member organisations. Parents of PWIDs are often confronted with stigmatization and discrimination because of their children's disability. By forming Parents Self- Help Groups (PSHG), parents will have a platform to meet people with the similar circumstances with whom they can engage and share their experiences and emotions. Together parents can support each other as they learn how to cope with the difficulties in caring for their children and gather tools and knowledge that can be helpful in their lives and those of their children. Member organisations are trained and guided to provide support for the parents through counseling and facilitating access to support services at the district and communities levels.

The PSHGs model goes a step further to empower parents to advocate for their inclusion and participation in the disability movement in Ghana at the local districts and communities. It create awareness about their child's condition as a disability as against the cultural and religious misconceptions of it either being spiritual attacks on the family, the parents (mother) being a witch or a curse on the family.

This intervention model is developed to address all the challenges PWIDs and their families might face in seeking for their inclusion in the family, community, disability movement and accessing government services. It has reviewed the above practices on success, challenges and prospects and has expanded on them.

5.0 Working with families

Relationships between Inclusion Ghana, its member organisations and the family are critical because the acceptance, care and growth of the child with ID starts with the family. Many families find it difficult to talk openly about their situation due to the stigma attached to intellectual disability in Ghana.

Inclusion Ghana hopes to create a platform where parents and family members of the child with ID will first and foremost accept the child as a human being and their own, before advocating for access to support services and government interventions.

To ensure acceptance, Inclusion Ghana will support the family by:

- Ensuring family members understand the issues of intellectual disability.
- Giving advice and suggestions on specialists who can help to support the family.
- Empowering parents' self-help groups in the community to support and share their experiences with the family.

Additionally, Inclusion Ghana through its member organisations will engage with the appropriate social workers to support the family through the acceptance stage.

6.0 Being part of 'the System'

Most families of persons with intellectual disabilities use many different services. Discussions held with parents have highlighted that many families experience difficulties with inadequate information on available services, communication gaps between themselves and helping professionals and confusion about their roles and responsibilities, and sometimes contradictory information or advice from professionals.

PWIDs will benefit from better communication between their families and professionals involved in providing services to them such as medical care, respite services, information and advice services and other allied health services.

Coordination and communication is likely to be more straightforward when the Family, Parents Self-Help Groups (PSHG) and the Community are involved. However, whenever possible PSHGs should endeavour to coordinate with other service providers involved with PWIDs

and their family. Strategies might include direct communication, information sharing, and invitations for service providers to attend PSHG meetings.

6.1 The Family Inclusion Model

The Family Inclusion model includes a set of values, skills, behaviours and knowledge that recognises that the family plays a pivotal role in the lives of PWIDs. It puts the strengths, needs and choices of the PWIDs and their families at the center of service planning, development, implementation and evaluation.

Studies show that the way support services are provided has an impact on families. The Family Inclusion Model is therefore informed by reports from the families of Persons with intellectual disability and some professionals. (see Figure 1).

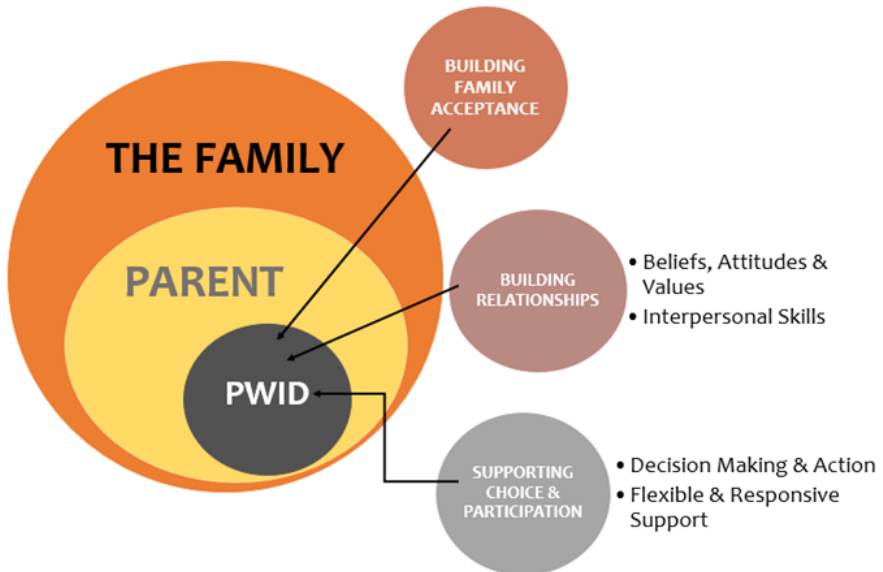


Figure 1: Elements of the Family Inclusion Model

6.1.1 Building Family Acceptance

Working in family-centered ways enables society to understand better what families want and need. There is indication that increased family involvement leads to improved communication, health and wellbeing for PWIDs. The impacts of successful family acceptance can include:

- Better learning and development outcomes in the early years.
- Improved confidence, social skills, emotional resilience, communication skills and general wellbeing.
- Increased opportunities to social support and services for the family.
- Increased parental self-efficacy.
- Improved PWID behaviour and wellbeing.

In disability services the central focus remains the PWIDs themselves. This is because supporting their potential, wellbeing, inclusion and participation is the ultimate goal. It is also because almost all PWIDs, as they mature, want a greater say in their day-to-day lives and futures. As they grow towards adulthood, all young PWIDs require support to develop the skills and confidence needed to make their own decisions or to contribute to decision making according to their capacity. With support from families and professionals, this process can start when PWIDs are quite young.

6.1.2 Building Relationships

Research demonstrates that open, trusting and collaborative relationships are very important to support PWIDs and their families to adapt to the changes and challenges that intellectual disability brings to their lives. In the family setting, positive relationships are critical to ensure that PWIDs and families achieve their desired goals. Relationships are shaped by the experiences, behaviours and values of PWIDs and their families as well as those of PSHGs and the Community. Families' prior knowledge and experience of intellectual disability and other services are critical to build trust, optimism and a sense of partnership.

6.1.2.1 Beliefs, Attitudes and Values

Each family member's deepest values and beliefs are shaped by a blend of ethnicity, history, socio-economic status, location, language, education, lifestyle, politics, family make-up, gender and spirituality. We rarely state them aloud, but they shape everything we do. These values influence how family members relate, interact and communicate with each other. However, it is important to consider these helpful tips when communicating and building a relationship with PWIDs within the family to allow the PWID appreciate the effort and follow suit to enable the relationship to be complete:

- Reflect on situations that make you uncomfortable (for example, not being able to understand a person's speech) and seek support such as mentoring from professionals.
- Appreciate and value the knowledge and experience of PWIDs, however way they are expressed.
- Try to engage with PWIDs on their own terms.
- Support the PWID to communicate and reciprocate.
- Reflect on any assumptions you might have about intellectual disability.
- Challenge the 'negative stories' about a child or family that can arise.

Irrespective of each family member's beliefs, values and attitudes, considering the above mentioned tips would aid in a better relationship with the PWID.

6.1.2.2 Family's Relationships with Religious Leaders, Medical Practitioners and Social Workers

A central concept in the Family Inclusion Model is that the dynamics between professionals and families are transformed from traditional relationships to relationships of collaboration and information sharing.

Relationships between medical practitioners, social workers, Religious Leaders, and families are also shaped by broader power structures and

family stressors. These include families' level of access to education, financial resources and support networks. Family members who have had limited education or poor school experiences themselves are also more likely to feel disempowered in their interactions with the medical practitioners, religious leaders and social workers.

In order to create a relationship of collaboration and information sharing:

1. Family members must be willing to share information and take the initiative of seeking professional support for PWIDs.
2. Empowered Member Organisations (MOs) of Inclusion Ghana (IG) must support in linking these professionals to the families.
3. IG and its MOs should extend its awareness and advocacy efforts to religious leaders at both the national and local level, to understand intellectual disability.

6.1.2.3 Support from Siblings in Building Relationships

Siblings are seen as the first point of call when it comes to peer support and play for PWIDs. They play a crucial role in engaging the PWID to understand the basics of:

1. Communication
2. Social Skills
3. Decision making and
4. Performing simple house chores, which promotes their participation

Siblings can achieve this by:

1. Creating an enabling environment where PWID will observe siblings' action or chores.
2. Engaging the PWID directly in the activity or chore.
3. Acting as the intermediary between the PWID and their playmates (cousins, colleagues, friends etc.)

6.1.2.4 Interpersonal skills

Interpersonal traits like empathy and warmth can help build positive relationships within the family. These traits help family members to really understand the conditions of PWIDs and to adjust accordingly. Additionally, these traits can also help in the following ways:

- Active listening builds trust and helps family members gather the information needed to deliver effective support for PWIDs.
- Making space for the whole ‘story’ enables PWIDs to feel heard and builds a picture of their needs. Although family members get tired of repeating basic information and routine action, it is imperative to still have space for the whole ‘story’ in order to build on the confidence and the relationship that exists between PWIDs and family members.
- Communicating directly with the PWIDs demonstrates respect for their dignity and right to participate, and helps build the relationship with them and their family. A PWID does not need to be verbal to communicate; it is first about getting to know them, and how they express their needs and preferences. Resources are available to aid effective communication with PWIDs.
- Tuning in to non-verbal signals can enhance communication. Remember, however, that body language is not universal, but rather has its own cultural meanings. Family members can reflect on non-verbal cues they might need to be sensitive to, when interacting with PWIDs.

Above all, PWIDs appreciate genuine warmth and concern and family members must not take this for granted.

6.1.2.5 Keep people in the loop

An important issue to discuss among family members are observations regarding the PWIDs’ developing abilities, skills and knowledge, and the family’s growing capacity to meet the needs of the PWID.

Other issues that can be discussed include:

- How changes such as the PWID's development or care needs or the family's circumstances affects the overall wellbeing of the PWID.
- The family's plan to take the PWID's needs into account in all events.

6.1.3 Supporting Choice and Participation

In supporting choice and participation, family-centered practice requires that family members recognise and address the factors that affect PWID's power to make choices in their lives. To achieve this, the family members must consider the role they play in decision making, as well as their flexibility and responsiveness in providing support.

6.1.3.1 *Decision making and action*

Many choices are made during a family's engagement with the community. For example,

- Is this the right school for their children with ID?
- Might the PWID's needs be better met by changing to either a special or mainstream setting?
- How and where will recommended therapeutic activities take place?
- How will the family be kept informed and involved?

The Family Inclusion Model asks that, as much as possible, these decisions be made by families most affected.

6.1.3.1.1 Take a proactive approach to disagreements

The possibility that others might disagree with a family's choices is high, especially if they seem likely to affect the PWID negatively. In this context, it might be helpful to consider (in the context of your role and responsibility in relation to the PWID and family) whether:

- Other family members have gathered enough information to have a sufficiently informed opinion.

- Other family members are simply feeling challenged by values different from their own.
- The suggested course of action is informed by family-directed outcomes and response to the family with the PWIDs' needs.
- Adequate, appropriate, and accessible information has been provided for the family to make informed decision.
- The family's way of thinking might change with additional support, such as a second opinion or counselling.

It is appropriate to respectfully discuss any strong concerns you have with family members. Ultimately, unless there are protective concerns, families make choices on their own discretion.

6.1.3.1.2 Support informed decision making

In general, most people have a prejudice that PWIDs cannot make informed decisions on their own and for this reason, a lot of parents and other family members continue to make substituted decisions on their behalf.

However, this is wrong. Just like everyone else, PWIDs must be allowed and supported to make independent decisions because it is their right.

PWIDs at some point in time will have to make decisions about these and more.

1. Basic needs. Example: what to eat, what to wear, etc
2. Who to associate with
3. Which school to attend
4. Where to fellowship

In making these decisions, family members are required to support PWIDs to consider their needs and the relevant options available. For PWIDs to make independent and informed decisions, family members must:

1. Explain to the PWID why he/she must make a decision.
2. Ensure that the PWID understands that he/she is exclusively responsible for the decision about to be taken.
3. Provide options for the PWID.
4. Explain the options to the understanding of the PWID.
5. Allow time for PWID to process the information and make a decision.
6. Provide further support to PWID to implement the decision that has been taken.

Although cultural values might influence how and why family members would support PWIDs in decision making, it is important to note that when PWIDs are supported and empowered to make independent decisions, it increases their confidence and encourages their participation in the family life cycle and even beyond.

In the end, the family becomes more united and happier because everybody is brought along in the family growth.

6.1.3.2 Flexible and Responsive Support

Flexibility means being willing and able to tailor experiences and supports to PWIDs' needs and wishes. Responsiveness on the other hand means being on the alert to adjust to the changes.

Both flexibility and responsiveness will depend on the family member's role and capacity to support the PWID. Family members must support PWID to make informed and independent decisions by considering the following:

- Acknowledging the challenges associated with his/her disability.
- Acknowledging the mood and desire of the PWID at the time.

- Determining the relevance of the decision to be made.

6.2 The Parent Self-Help Group (PSHG) Model

Parents are the focus of Parent Self-Help Groups (PSHGs), not their children. This is because most persons with intellectual disabilities (PWIDs) are unable to speak for themselves and have difficulty coordinating their communication. As such, their parents speak on their behalf to give them a voice. Most parents know better their children’s needs and interest and so help them to convey their message. Parents need to be strong to be able to take care of their children. When parents are empowered, it is then that their children have possibilities. A parent can only help a child when they themselves are strong.

The PSHG is about parents of children with intellectual disabilities coming together to share experiences, difficulties and successes. These parents should be drawn together by a common background, exclusion and isolation from their families and society as a result of their intellectually disabled children.

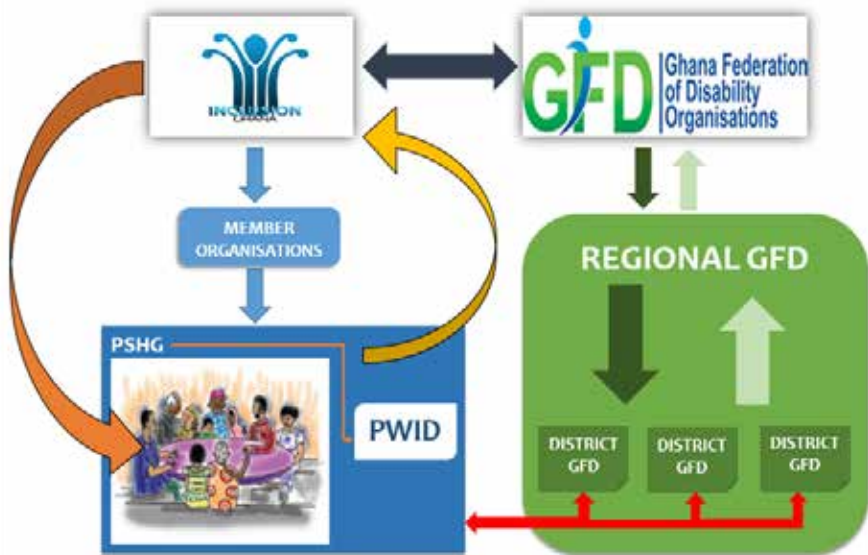


Figure 2: The Parent Self-Help Group Model

6.2.1 Characteristics of a well-functioning PSHG

- 1. Common Background** -Parents in the group have similar problems. These problems include: the difficulties they face managing their children’s disability, and the stigmatisation and exclusion not only of the parents themselves, but that of their children with intellectual disability and their families, as well as friends and workers of institutions that provides any kind of support to their children.
- 2. A Need for Inclusion** - While parents may join initially out of a strong need for support and understanding, over time, they will form real bonds of friendship and partnership as they face their problems of exclusion and stigmatization together.
- 3. Independence** - Member organizations of Inclusion Ghana can facilitate and support the start-up of the PSHGs, however the end goal is for the independent functioning of these groups.
- 4. Co-operation and Mutual Support** - PSHGs are grounded on the principles of sharing and working co-operatively, as well as the mutual support cultivated between parents of children with intellectual disabilities. Ultimately, the benefits to the groups working together outweighs the costs.
- 5. Governance** - The group owns and enforces its rules and regulations. Having a by-law is useful as it provides for the structure of the group, and overall guidance for the group’s activities. Key issues such as the tenure of office for the leadership; sanctionable conducts; procedures on democratically electing and dismissing leaders; roles of the executives; purpose and activities of the group as well as quorum for meetings are embedded in the bye-laws of the group. At all times, equal opportunity is given to members of the group when taking up leadership positions, with some gender considerations.
- 6. Relationship** - There is mutual respect and understanding amongst members of the group, including leaders. Discussions held within the group are kept confidential at all times. Disputes are settled amicably within the groups, and if necessary, the bye-

laws provides further guidance and procedures for addressing the particular issue.

7. **Management** - The group has the capacity, leadership, knowledge and skills to manage the tasks. For situations where a group whose members are not literate, does not have the full capacity to manage some of the tasks (e.g. taking minutes at meetings), provisions are made in the bye-laws to permit literate non-members who would like to volunteer to support the group with such tasks. Also, should this volunteer express interest in becoming a member, he/she is permitted.
8. **Structure**-There is a clear understanding that members of the group report to the group's leadership who then convey the message to the Member Organisation, Inclusion Ghana and the Ghana Federation of Disability Organisations (GFD) at the district and regional levels. Communication during meeting is not one-sided as members are able to freely express themselves. Meeting times and venues have also been clearly outlined.

6.2.2 Understanding existing groups

To have a Parent Self-Help Group model that actually works, one must consider and try to understand how similar groups that are already in existence operate. To achieve this, the following specific questions must be asked;

- What kind of support group structure(s) exist?
- What are the criteria for membership?
- What are the functions, responsibilities, and rights of these groups?
- What (if any) are they prohibited from doing? and
- What is the nature and content of the bye-laws that govern these groups?

Furthermore, the following questions are useful in understanding the actual nature and performance of the groups in the community, beyond the mandated functions.

- How do existing support groups participate in disability affairs within the community?
- What level of participation is actually achieved by such groups?
- Does level of participation differ widely by region (rural/urban) or by the social and economic class of members of the groups?
- Do relevant organisations (Ministry of Gender, Children and Social Protection, GFD and Organisations of Persons with Disabilities (OPWDs)) simply assume these groups exist, or do they actively seek to learn if they exist and know about what they do?
- Is there any attempt made in relevant organisations (Ministry of Gender, Children and Social Protection, GFD and OPWDs) i.e. data gathering to learn about the existence and activities of such groups?

6.2.3 Engagement in the disability movement

The Parent Self-Help Group model, being one of the three pillars that supports Inclusion Ghana's Intervention Model, provides a district level community awareness and organizational development programme working for the inclusion of PWIDs in the disability fraternity and in the society at large. This is done through establishing and empowering Parent Self-Help Groups.

The model rests on the logic that empowering parents of PWIDs through PSHGs and inclusion of PWIDs and their parents in the disability movement can ensure that rights of PWIDs are promoted and protected.

Some of the support PSHGs provide members with include, the opportunity to break away from the isolation they experience in their communities, get access to information and support for existing services (District Assembly Common Fund, National Health Insurance

Scheme, Local Development Fund & LEAP Cash Transfer, etc.), and finally gain membership to the national organisation, Inclusion Ghana, which is the umbrella voice for all working for the rights of PWIDs. At the district level, becoming members of IG will enable PSHGs to identify themselves with Ghana Federation of Disability Organisations (GFD), the non-governmental organisation which brings together the key organisations of persons with disabilities in Ghana. What this means is that PSHGs, together with PWIDs will now have access to opportunities that exist for persons with disabilities.

In view of this, GFD and its member OPWDs also have a critical role to play in creating the enabling environment and conditions for parents of children with intellectual disabilities and PWIDs themselves to be fully included in all aspects of the Community, Economic and Social life.

6.2.4 Participation

6.2.4.1 *What is participation?*

Parents who share similar situations come together in order to ensure that their children with intellectual disabilities are not left out. The need to ensure this is achieved requires effective participation in the Parent Self-Help Groups formed in the districts. Parents are the best to communicate the needs of PWIDs but they can achieve it through active participation in group meetings.

6.2.4.2 *Key factors for effective participation*

Participation in the PSHGs can include but not limited to the following:

- Sharing experiences more frequently to empower each other.
- Contributing money, materials, and labour to empower the group.
- Active in deliberations leading to decisions making.
- Being part of the actual implementation of decisions made.
- Consultation on particular issues relating to their children with ID.

Effective participation in the PSHGs will provide members with:

- Emotional support for one another.
- The opportunity to learn new ways to cope.
- The chance to discover strategies for improving the health of PWIDs and related issues.

6.2.5 Sustaining the groups

Sustainability is an important issue to address when forming a group like the Parent Self-Help Groups. Leaders of the groups as well as stakeholders must ensure that the groups exist perpetually in order to continue with the services it provides for persons with ID within the community. The groups would impact the lives of PWIDs over a long period if parents would change their perception by assuming full ownership and management of the groups formed in the districts. This would then bring on board ideas based on interest and attachment to the group. These factors would aid in the sustainability of the Parent Self Help Group:

6.2.5.1 Ownership

The group's purpose must be clearly stated and understood by all to shape the focus of group members. When parents clearly understand the purpose for which the groups are formed, and are aware that their participation would empower them to promote the rights of their children with ID towards acceptance and social inclusion, they will assume ownership and ensure continuity, especially since it is to their benefit.

6.2.5.2 Mutual Support

The essence of the Parent Self-Help Group is to ensure that parents benefit mutually as members of the group. The use of resource materials such as the IG Self-Help Group Guidelines and the Self-Help Kits would aid parents to address behaviours exhibited by their children with ID, which they may find difficult to manage. The sharing of ideas and experiences with other members of the group will aid the parents to find solutions to difficulties encountered in their

homes. The existence of solutions to these difficulties will aid in the sustainability of the group. Parents will now value Self-Help Group meetings and be present for their meetings. This will promote the groups' growth and development and better management of their children within the community.

6.2.5.3 Income Generating Ventures

The needs of parents within the groups are enormous and meeting them will require that steps are taken to make members financially stable. In order to ensure that parents within the group are financially sound, groups must engage in income generating activities that will yield returns. The involvement of the group in income generating activities would help in addressing the financial needs of members. Parents can engage in cooperative unions to support group members with soft loans which will help raise the standard of living of their members. Other forms of income generating activities may include:

- Animal production (For e.g. rabbit, goat & sheep rearing)
- Crop production (For e.g. pepper, ginger & maize farming, production of palm kernel oil, nursing cocoa seedlings)
- Corn milling
- Microfinance

These will provide group members with enough income to support their children with ID financially, help with advocacy activities within the community, support fellow group members, and offer parents the opportunity to work.

6.2.5.4 Awareness of Government Support

There is a myriad of opportunities available to persons with intellectual disability within the community. Parents may however not be aware of this fact. Parents are legal members of the disability fraternity and this knowledge has not been perpetuated. The group's attempt to ensure inclusion requires that they are first of all made aware of social services, including free National Health Insurance registration, Leap

cash transfer and the DACF available to PWIDs in the community. This will aid parents in taking measures to access these services. When this has been achieved, these services will now be accessible to all members of the groups without any form of discrimination. This will help sustain the groups, as parents now have tangible gains being members of the groups.

6.2.5.5 Capacity building workshops for leaders of groups

Leadership is a crucial role in group management and this requires that leaders are trained in order to manage the group effectively and efficiently. Leaders of the groups will require capacity building in leadership skills that will enable them better manage their groups and to advocate for the rights of their children with ID. The training will also prepare them for leadership positions within the disability fraternity and hence facilitate the projection of views of persons with ID within the community.

6.3 The Community Inclusion Model

Community inclusion model is a model that explains the opportunity to live in the community and be valued for one's uniqueness and abilities. It demands that Persons with disabilities are treated the same way as their counterparts without disabilities.

Often times, individuals with intellectual disabilities and their families experience barriers to participating in and enjoying the world around them. This model helps them to overcome limitations and the barriers through activities such as community based employment, education, social activities and assistance in finding community based health care.

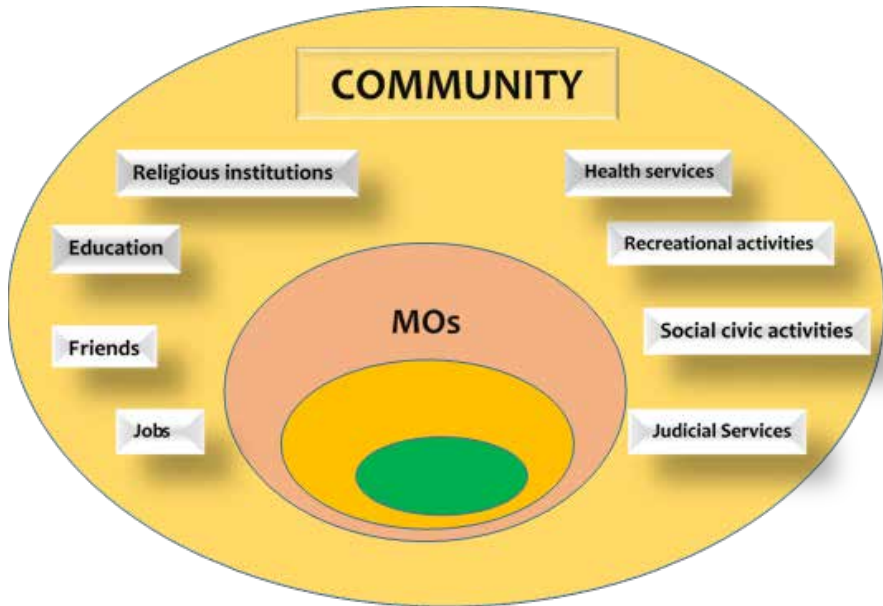


Fig. 3: The Community Inclusion Model

6.3.1 Building Community Acceptance

In the disability circles, community acceptance means opportunities for participation in schools, careers, homes, health institutions, justice system like every other person within the society.

PWIDs often experience discrimination and stigmatization from the community as a result of their disability. Parents can support their children with ID for social inclusion by creating awareness among community members to understand ID and how to relate with PWIDs within the community. This will begin the acceptance process. The community members will have to dismiss any prejudices they have previously had concerning PWIDs enabling them to become more accepting and appreciative of PWIDs and their parents.

Parent's effort at ensuring social inclusion would create a better relationship between community members and themselves as well as PWIDs. This will also facilitate their acceptance within the various institutions in the community. Just as every individual has a right to

access health, education and judicial services, PWIDs also deserve the same opportunities. However, PWIDs can access these facilities with support from community change agents, parents and other family members.

This would result in a good reception towards PWIDs from health, education, judicial and other professionals, as they access the health facilities, educational institutions, judicial services and other relevant bodies in the community. The continuity of this relationship would perpetuate community acceptance for PWIDs.

6.3.2 The role of the community

Being a part of a community and feeling included is extremely important in every individual's life but persons with ID are mostly discriminated against in the various communities. Being part of any community does not mean that the individual is present. Rather, it means the individual needs to participate in any activity in the community and is also accepted by other individuals in that community. Persons with ID and their families are in various communities but do not get involved in these community activities because of the stigmatization and discrimination against them.

Ways to improve lives of PWIDs in the community

One important role the community needs to play is the participation of persons with ID and their parents or other family members in activities and processes in the community. In meetings or in environments where decisions are being made by committees, it is often difficult for PWIDs to understand the information and decisions being discussed either because of the language being used or because of the speed of the discussion.

With support from parents and other family members and with adaptations to the way in which meetings and discussions are organized, PWIDs will be able to participate and contribute at par with others.

PWIDs have a right to participate in community groups, political activities, conferences, religious institutions and cultural events. To do so, meetings and participants in meetings need to adapt to the way in which PWIDs communicate. It is helpful to establish rules for meetings that can be adopted by various groups. Basic infrastructures in the community should be made easily accessible to PWIDs. By-laws should also be made in communities to discipline people who discriminate against persons with ID.

6.3.3 Access to Government interventions/services

There are social protection programmes implemented by the government in some districts and communities throughout the country. These programmes/interventions provide services/assistance to the poor and vulnerable societies. Persons with disabilities are recognized as one of the target groups for these interventions. These services are required by law, and for PWIDs to fully participate, the community must ensure that they get what is due them.

Some of these services for PWIDs include support in employment, education, public transportation and health care among others. These services can help PWIDs and their families have a meaningful life in the community which will lead to less discrimination and stigmatization. In order to get access to these government interventions, the parents must:

- Empower leaders of the PSHGs to engage the Department of Social Development.
- Register with the Department of Social Development.
- Further engage the Department of Social Development on updates on social protection models.

6.3.4 Access to Education, Health and Justice

6.3.4.1 EDUCATION

All children have equal rights and opportunities to be educated from pre-school to any level and a child with special needs has the same

right. PWIDs have the right to develop and acquire general and professional education corresponding to their mental abilities and desires and the right to take part in social life, as any other child. The unfortunate situation is that children with intellectual disabilities are found mostly at home with their parents. Few children with ID are found attending special schools and even fewer in the mainstream schools. This is because they are regarded as being incapable of coping with the regular education setting which focuses heavily on learning methods that are difficult for them to understand. Teachers are rarely educated to differentiate instruction and recognize the needs of a student with an intellectual disability.

Moreover, schools in the various communities are not equipped with adequate knowledge that will provide the preferred environment needed for the learner with intellectual disability to become successful. This is because these individuals learn at different rates, and with different degrees of success depending on their personal strengths and weaknesses.

Ways to improve the access to education for PWID

- Community sensitization and implementation of the inclusive education policy to ensure that children with intellectual disabilities of school going age can be enrolled in mainstream schools.
- Availability of Information, Education and Communication (IEC) materials in the mainstream schools to ensure that the needs of the child with ID are met.
- Training of teachers and caregivers on the handling of a child with ID to ensure the needs of the child at any particular time.

6.3.4.2 HEALTH

Persons with intellectual disabilities often have difficulties to access health care in the community because medical systems are complicated and professionals are poorly prepared to communicate with them. Health professionals will speak to the PWID's support person and ignore the individual's expressions and communications.

Health professionals often assume PWIDs cannot make decisions or understand and therefore do not attempt to provide information and support.

While it is clear that persons with ID can be healthy, it is understood that persons with ID are more susceptible to health issues than their non-disabled peers. They have very high rates of health problems that are often not diagnosed or appropriately treated. Studies have indicated that the most common causes of mortality for persons with an ID are respiratory, cardiovascular and gastrointestinal diseases, neoplasms and external causes such as accidents and poisoning.

The right to health is a universal human right. In broader terms, this right encompasses a right to health care and a right to healthy social and environmental conditions such as adequate sanitation, nutrition and safe drinking water in the community. It is important to note that the right to health is not limited to only medical treatment and social care, neither should it be understood as the right to be healthy. Instead, it should be understood as the right to enjoy a variety of facilities and conditions for which the community has a role to play, and which are necessary for the attainment and maintenance of good health.

How these problems can be solved in the community

- PWIDs should be provided with the same range, quality and standard of free or affordable health care and programmes as provided to other persons in the community, especially in the area of sexual and reproductive health and population-based public health programmes (e.g. immunizations).
- Community health services should provide the needed health services to PWIDs specifically because of their disabilities. This includes early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities among these children and older persons with ID.
- Required health professionals in the community should be trained to provide care of the same quality to PWIDs as to others. This should be done on the basis of free and informed

consent by raising awareness of the human rights, dignity, autonomy and needs of PWIDs through training and the promulgation of ethical standards for public and private health care.

- Discrimination against PWIDs in the provision of health insurance where such insurance is permitted by national law, should be prohibited.
- Discriminatory denial of health care or health services or food and fluids on the basis of intellectual disability should be prevented in the community.

The form of services provided by Health centers must be premised on Accessibility, Acceptability, Availability and Quality (AAAQ).

6.3.4.3 JUSTICE

While PWIDs are more likely to fall victim to violence and abuse in various communities, many of these abuses go unreported or never go to trial because their voices go unheard. Police and community workers are inadequately trained and many judicial systems do not provide support for PWIDs to testify or provide evidence because of their perceived incompetence.

How this problem can be solved in the community

- Law enforcement agencies should be given adequate training on issues about PWIDs and how they can be supported.
- Laws protecting PWIDs should be enforced so that abusers of such persons can be arrested and dealt with accordingly.
- PWIDs who witness crimes can provide testimonies through several ways without having to go to the court room which makes them uncomfortable. An example is the use of video recordings of sworn testimonies from PWIDs.

7.0 Making it all work together: The ‘Systems Inclusion’ Model

All the models that have been mentioned; thus the Family Inclusion Model, the Parent Self-Help Group Model and the Community Inclusion Model work together and co-depend on each other to ensure the inclusion of PWIDs in mainstream society. This co-dependence of the various models results in the ‘Systems Inclusion’ Model.

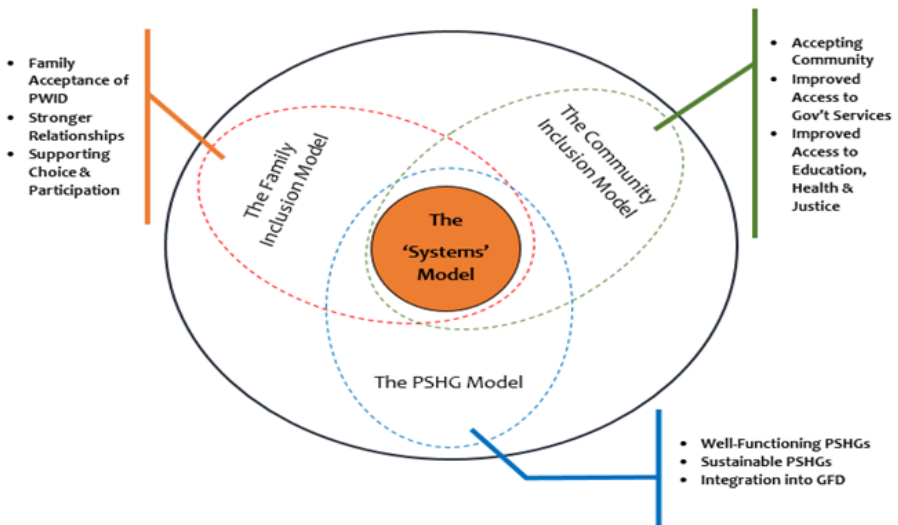


Fig. 4 The ‘Systems’ Inclusion Model

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