
UN Convention on the Rights of Persons with Disabilities
Article 19b

*”persons with disabilities should be ensured to have access to a range of in-home, residential and other community support services, including **personal assistance** necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community”*

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CHILD

The role of the external personal assistants for children with profound intellectual and multiple disabilities (PIMD) working in the children's home

Nka, Gothenburg, September 4th,

A part of the research project

**Children with profound intellectual and multiple disabilities
(PIMD) and their participation in family activities**

Children with PIMD

- Are heavily dependent on others (Nakken & Vlaskamp, 2002, 2007)

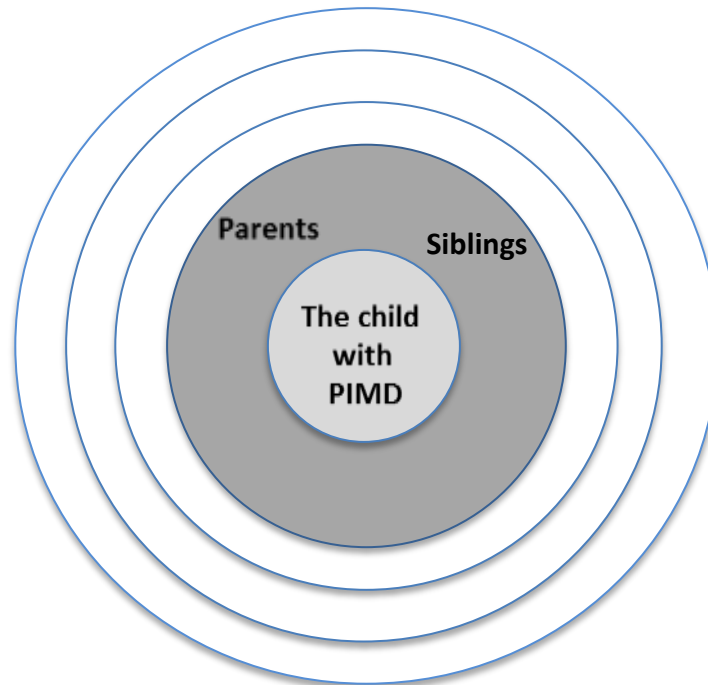
In Sweden, children with PIMD:

- Grow up at home together with their biological family
- Attend preschool and school (special classes)

A child's family is the most important part of the child's ecology

(Bronfenbrenner, 1986; Dunst et al., 2001)

The child and the family



The social security system in Sweden gives possibilities for personal assistance for these children.



The overall purpose of personal assistance is to promote equality of living conditions and full participation in the society (the family included)

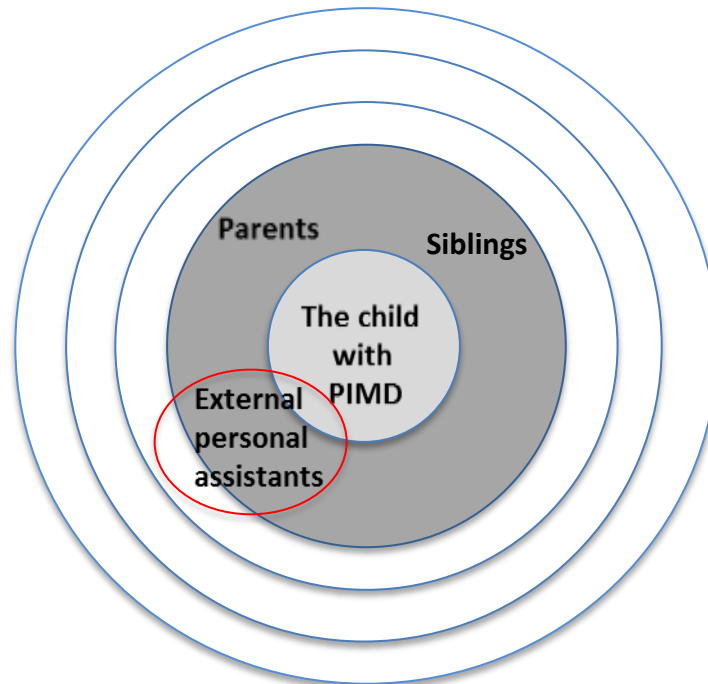
Parents as personal assistants

**Parents as personal
assistants**

**Hired external
personal assistants**

According to the child, the external personal assistant is also a part of his/her family (Wilder, 2008)

The child and the family



To find out about the role of the external personal assistant

Mixed method study including

- 60 questionnaires answered by parents of a child with PIMD
- 11 interviews with parents of a child with PIMD and 9 interviews with external personal assistants

Results

Reinforcing role in
relation to the child

A balancing role in
relation to the family

= DUAL ROLES

Results

Reinforcing role in relation to the child

- To substitute basic functions

- To support everyday life

- Relationship support

- To support maturation

"It is so wonderful, for the little girl, the two year old one, often asks about help: 'please help me to tie my shoes' and then he [the older brother with PIMD] becomes very happy and helps his little sister with help of his assistant"...(parent)



Results

Reinforcing role in
relation to the child

- A high level of assistance needs
to be given in the activities

Results

“Yes, it really is a unique situation. It is. You know that if the parents or those people in that home had been able to choose, then I wouldn’t be there. That’s the way it is, or, yes, since the situation is the way it is, then it’s a good thing that I’m there, but it’s not something that anyone would have chosen” (assistant 6)

A balancing role in relation to the family

- A shared understanding

- Exhibit relational skills

- Fulfill the function

Results

A balancing role in
relation to the family

- E.g. do activities with the child
outside the home

Reinforcing role in
relation to the child

A balancing role in
relation to the family

Conclusion

In planning and implementation of external assistance, the child's needs as well as considerations of the whole family should be regarded

Implications?

Implications

Discussions are needed about the personal assistant's role - in relation to the child as well as to the family

This in turn can help to achieve "stability" and sustainability desired in every family system



Jag är med! Om personlig assistans och delaktighet i familjeaktiviteter



Thank you!