

Development of Parents of Children with Disabilities: Identity, Supports, and Community

Aiko Abe

Nihon University, Japan

Goals

Many studies on the psychology of parents of children with disabilities have been reported. Solnit and Stark (1961) and Olshansky (1962) studied the psychological state of parents who were pessimistic about their children's disabilities. Droter (1975) and Perskey (1987) studied how parents accept the disabilities of their children. They reported that acceptance of disabilities is reached by parents stepping back and forth under the provision of adequate supports.

The theme of literature Nobel laureate Kenzaburo Oe's novel *A Personal Matter* (1964) dealt with his disabled son and the author's predicament on accepting him by presenting the situation as the problem confronting families and human beings in general. Studies suggest that the parents of children with disabilities often develop through caring for their disabled children.

In studying the development of parents who are anxious about how their progeny will cope after they die, Abe (2003) focused on three aspects: psychology, supports, and identity. She presented an integrated vision where parents, children with disabilities, and community develop through interaction between them. Based on this study, the author in the present paper examines sixteen cases of parents of children with disabilities.

Method

The author conducted semi-structured face-to-face interviews with parents of children with disabilities. Parents who had children aged eighteen or over were selected for studying the long-term process of parents' development while their children were growing up. The interviews lasted about ninety minutes on average. The interviewees consisted of four fathers aged fifty-one to seventy-five and twelve mothers aged forty-four to seventy-seven, who live in various districts of Japan. In sampling the interviewees, the disabilities of the children were not specified. The interviews were comprised of twelve open-ended questions focused on psychology, supports, and identity, e.g., "How did you feel when your child was found to have a disability?" "Have you asked for psychological supports for coping with your feelings?" "Have you changed as your child has grown?"

Results

The interviews were tape recorded and transcribed for analysis. The transcriptions were coded according to the integrated vision. The ages, disabilities, residential states, activities of the parents are shown in Table 1. The results are summarized as follows. (1) Many parents who had felt "really anxious" or "lonely and sad" when their children were infants talked positively about their transformation as their children grew up: e.g., "The experience was never negative for me." "The range of my relations has been enlarged because of my son." (2) To the question concerning psychological or living supports, many parents answered that they received supports from their families, parents of children with the same disabilities, school teachers, and medical doctors in the community: e.g., "I was very much relieved by help from parents in the same situation." More than 80% answered that at present (or in the future they would) contribute to counseling or clinical activities in the community. (3) Many parents actively do or plan to do activities related to their children (eight are actually doing and five are planning): e.g., "We have established a non-profit organization (NPO) through which I want to play a valuable role in my community. I trust in our possibility" (4) In eleven cases, the parents and children with disabilities lived together. In the sixteen cases they all hoped that their children would live or continue to live in a group home or live according to their own choices. None hoped their children to live in congregate

residential institutions in the future.

Discussion

Many parents have established their identities, created relating activities, and structured their relations with the community and people, through struggling with their disabled children. While doing so, they repeatedly asked themselves questions such as “What is the meaning of the disability?”, “Who am I?”, and “What is the support we need?”

There were processes where the parents recognized and accepted the disability of their children at an early stage, and then generated mental energy by reassessing their values, changed their will, and created new selves.

The psychological prospects of the parents have thus extended along with the time axis. Parents have developed through the meaningful experience of growing with their children for many years. Community and supports have had strong effects on the parents, who in turn have affected the community. The author concludes that the results obtained in this case study verify the validity of the integrated vision where parents, children with disabilities, and community develop through interacting with one another. The author plans to investigate the importance of the respective developments and their relatedness based on identity, supports, and the community.

Table 1. Individual Data

Cases	Parent's age and sexuality	Child's age and sexuality	Child's disability	Present residence	Future residence	Parent's identity and social activities
CASE1	77 F	50 M	MR	LWP	GH	Teacher of special education / Opened a GH
CASE2	75 M	35 M	MR	GH	GH	Opened a GH
CASE3	60 F	30 F	MR	CRI	GH	Established a parental association / Opened a picture class / Opening a GH
CASE4	55 F	25 F	MR	LWP	GH	Clinical psychologist / Researcher in psychology / Opening a GH
CASE5	55 F	31 M	MR	CRI	GH	Voluntary worker for welfare
CASE6	54 F	29 F	MR	GH	IC	Opened a bakery
CASE7	53 F	26 M	MR	LWP	GH	Teacher / Opened a bakery
CASE8	52 F	30 F	MR	GH	IC	Opened a GH / Established an NPO / Researcher
CASE9	52 M	29 F 24 F	CP CP	GH LWP	IC IC	Established an NPO
CASE10	52 M	20 M	CP	LWP	GH	Opened a horse riding club for the disabled / Voluntary financial planner / Opening a GH
CASE11	51 F	18 F	MR	LWP	IC	
CASE12	51 M	18 M	CP	LWP	GH	Established a parental association
CASE13	48 F	21 F	RS	LWP	IC	Established an NPO
CASE14	48 F	20 M	SB	LWP	IC	Established a parental association
CASE15	45 F	18 M	DS	LWP	GH	Established a parental association / Committee member of local government / Opening a GH
CASE16	44 F	18 M	MR	LWP	GH	Opening a GH

MR: Mental retardation; CP: Cerebral palsy; RS: Rett syndrome; DS: Down syndrome; SB: Spina bifida

GH: Group home; LWP: Living with parents; CRI: Congregate residential institution; IC: Individual choice