

Are Korean Societies on the Road to a Supported Decision Making System Required by Article 12 UN CRPD?

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Introduction

- Traditional ways to care for adults with decision making disabilities
- Recent approach to adults with decision making disabilities in Korea
 - From family responsibility to state or social responsibility
- Reformation of adult guardianship system and its limitation from the perspective of Article 12 CRPD

Importance of the Right to Self-Determination

- Self-determination and Personhood
- But, the difficulties of family members and caregivers in coping with adults with decision making disabilities
- The meaning of “from family responsibility to social responsibility”?
- So far resulted in segregation and a substituted decision making system, which tend to listen to the voices of substituted decision makers rather than those of persons with decision making disabilities. It leads to their disappearance from the world. They remain objects, not subjects.

Table 1 Number of Persons with Impaired Decision-making Abilities

Number/ Type	Persons with Dementia (estimated)	Persons with Brain Injury	Persons with Developmental Disabilities	Persons with Mental Illness
Registered Number-2013	540,755	257,797	190,163	94,638
Registered Number-2017	770,000 (estimated in year 2018)	252,819	225,601	101,175

Table 2 Changes in Bed Numbers in Hospitals and Institutions for the Elderly and Persons with Disabilities

	2010	2011	2012	2013	2014	2015	2017
Persons with Disabilities Accommodated in Institutions	24,395	25,345	30,640	31,152	31,406	31,222	30,693
Persons with Mental Illness in Psychiatric Hospitals and Other Institutions	75,282	78,637	80,569	80,462	81,625	81,105	69,220 (year 2016)
Elderly in Nursing Homes	107,506	111,417	118,631	121,774	132,387	141,479	170,926
Elderly in Care Hospitals		134,930	159,506	189,446	215,841	237,669	259,021 (year 2016)

Table 3 Number of Applications for Adult Guardian Appointments under New Adult Guardianship System

Types of Guardianship	2013 (July-)	2014	2015	2016	2017	Total
Full Guardianship	727	1,967	3,013	3,716	4,571	13,994
Limited Guardianship	116	245	276	282	897	1,816
Specific Guardianship	50	355	181	158	464	1,208
Contractual Guardianship	7	8	8	17	26	66
Total	900	2,575	3,478	4,173	5,958	17,084

What is a supported decision making system required by Article 12 CRPD ?

- Various support schemes are operated in concert with each other: individual support schemes, universal support schemes and ancillary support schemes.
- **Universal support schemes** are universally designed supports to the exercise of legal capacity: Plain language and sign language, inclusive education of children with and without disabilities, where assistant teachers are provided for; positive behavior support education to school teachers, family members, and service providers to cope with challenging behavior of students and family members; deinstitutionalization etc.
- **Ancillary support schemes** are e.g. registry of power of attorney documents, office of the public guardian etc.

Table 4. Individual Support Schemes for Persons with Decision Making Disabilities

Degree of Difficulties in Communicating their intention and decisions	Cognitive Impairments. e.g. Dementia	Psychosocial Disabilities	Developmental Disabilities
Light and Medium	<ul style="list-style-type: none"> •support to make their own decisions and communicate them to others •Advanced Directives •Power of Attorney •assist future planning 	<ul style="list-style-type: none"> • Peer support • Advocate •Advanced Directives •Power of Attorney 	<ul style="list-style-type: none"> •support to make their own decisions and communicate them to others •assist future planning
Serious Stage	<ul style="list-style-type: none"> •Advanced Directives •Power of Attorney •Future Planning in action •Investigate the rights, will and preference by individual supporter, regardless of being appointed by persons with dementia themselves or by other responsible authority, who has the power and authority to represent 	<ul style="list-style-type: none"> • Peer support. Despite dangerous behaviours due to acute illness • Advocate •Advanced Directives •Power of Attorney 	<ul style="list-style-type: none"> •Positive Behaviour Support at the time of challenging behaviour • Investigate the rights, will and preference by individual supporter, regardless of being appointed by persons with dementia themselves or by other responsible authority, who has the power and authority to represent

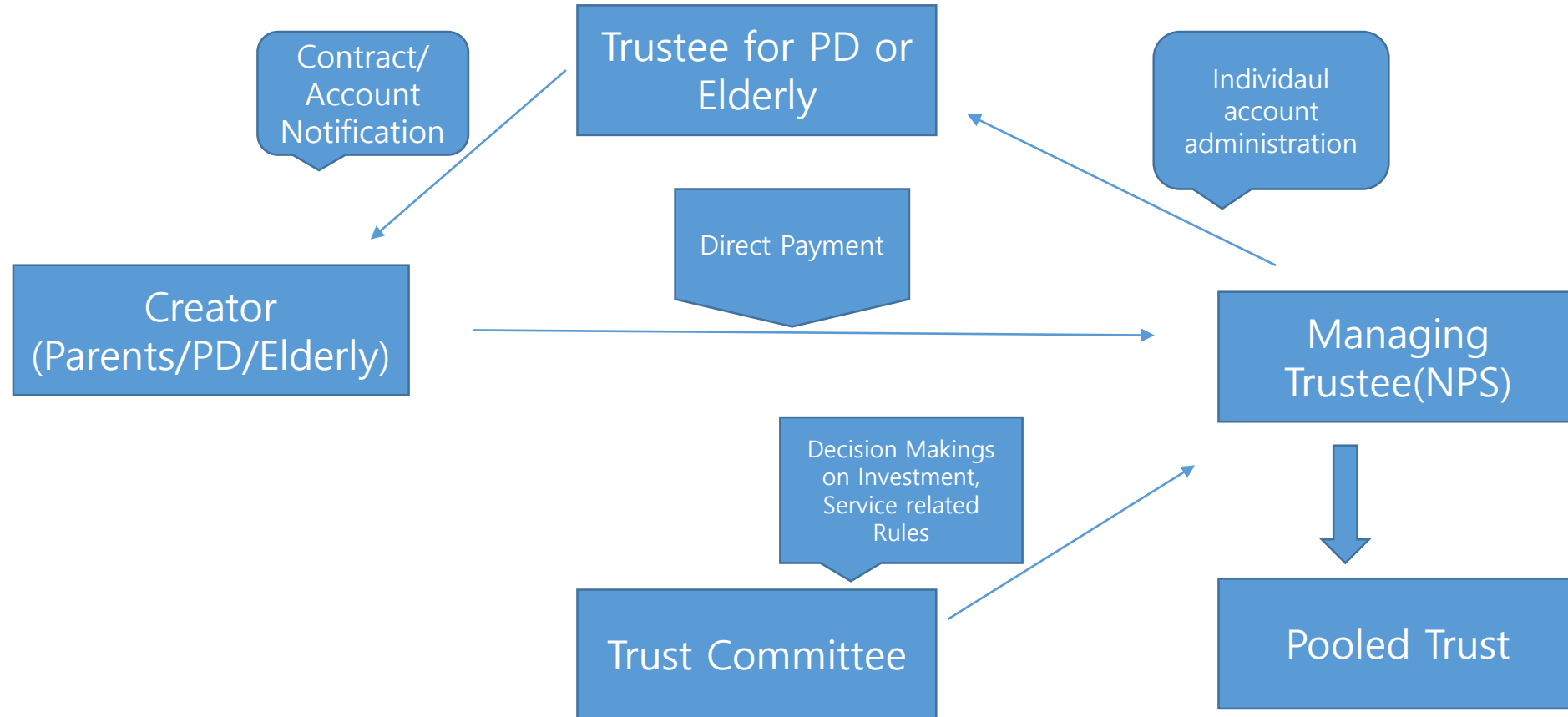
The Social Environment Where Supported Decision Making Systems Can Develop

- Be encouraged and learn to make their own decisions from early childhood
- Inclusive education of children with and without disabilities, by supportive personnel
- Continuous social education for respect to self-determination
- Education of positive behavior support activities to teachers, parents, and service providers

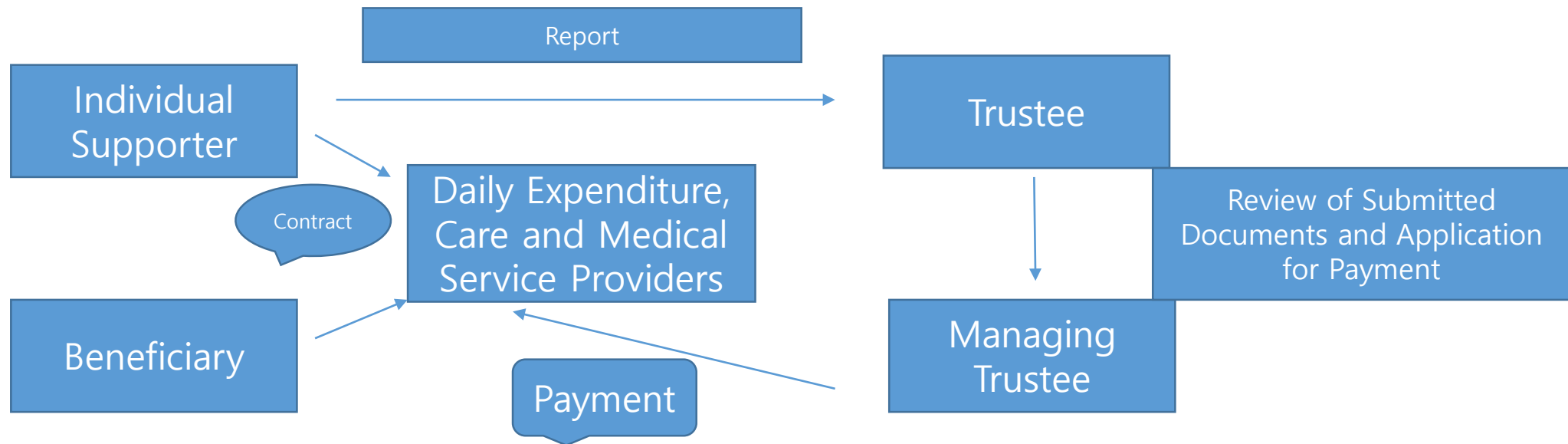
Civil Society Initiatives for a Supported Decision Making System in Korea

- Developmental Disability Trust as Future planning
- Registration of Advanced Directive Documents as Future Planning Tools
- Peer Support Work to Persons with Mental Illness
- Positive Behaviour Support to Adults with Severe Developmental Disabilities
- Public Guardianship Services

Picture 1. Structure of Special Needs Trust for Persons with Decision Making Disabilities



Picture 2. Special Needs Trust Service Delivery System



Flow chart above is described as typical one. In praxis, there can be many applications: individual supporters pay with a designated card and managing trustee pays with confirmation of the trustee; pre-fixed amount of cash is transferred to a designated bank account and individual supporters and beneficiaries pay with a designated card and report

Table 5. Current Situation of Trust Contracts made by the Korean Autism Association (May 2015 to May 2017)

Types of Creators	Assessments	Contract Process	Contracts Concluded	End
Parents	26	1	23	2
Persons with Developmental Disabilities Living in the Community	12	2	9	1
Persons with Developmental Disabilities Living in Institutions	7	1	4	2
Total	45	4	36	5

Registration of Advanced Directive Documents as Future Planning Tools

고령자를 위한 미래설계란?

당신의 편에서
당신을 위하여

보수없이 의료진, 요양시설, 복지센터,
가족으로부터도 독립하여
오로지 당신의 편에 서서 제공되는
고령자를 위한 권익옹호서비스입니다!

APPLICATION

어떻게
신청하나요?

- 고령자 당사자가 신청할 수 있습니다.
- 고령자 당사자의 가족, 친족, 기타 긴밀한 관계에 있는 사람이 신청할 수 있습니다.
- 고령자가 입원한 병원, 지방자치단체의장이 신청할 수 있습니다.

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당신을 위해 일하는
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한국후견협회
Korea Guardianship Association

Registration of Advanced Directive Documents as Future Planning Tools

고령자의 자기 옹호와 지원이란?



고령이 진행되면 누구든지 신체적, 정신적으로 쇠약해질 수밖에 없습니다.

그 시점에서도 당신의 존엄한 삶이 보장될 수 있도록 지원합니다.

치료, 요양, 약물복용, 임원 및 입소, 일상생활에 관한 당신의 희망이 의료진이나 서비스 제공자에게 충실히 전달될 수 있게 지원합니다.

자기 옹호와 지원은 왜 중요할까요?



고령자의 자기결정이 존중받아야 인간으로서의 존엄성이 보장될 수 있습니다.

이런 삶은 고령자 자신만이 아니라, 가족, 나아가 사회에도 큰 기여를 합니다.

가장 약한 상태에 있는 개인의 삶이 존중되는 문화를 만들기 때문입니다.

SERVICE

고령자 미래설계지원센터가 제공하는 서비스는 무엇인가요?



고령자 남사자 및 가족 면담을 통한 미래설계 상담



판단능력이 없어질 때에도 고령자가 희망하는 대로 임상생활, 치료, 요양 서비스가 제공될 수 있도록 보장하는 신탁계약의 체결 지원



의료 및 요양 서비스 제공에서 고령자의 희망과 선호도가 반영될 수 있도록 사전의료·요양 지시서의 작성 지원



고령자의 사전의료·요양 지시서의 등록 지원



고령자를 위한 의사결정지원자의 지원과 감독 업무

SITUATION

어떤 상황일 때 고령자 미래설계지원센터를 이용하는 것이 좋을까요?



동행 가족들이 먼 타지나 해외에 있어서 고령자를 돌보기 어려울 때



자녀나 배우자가 고령자를 돌볼 역량이 되지 않을 때



자녀나 동행 가족이 없을 때



신뢰할만한 금융기관, 유능한 변호사 등 전문가를 활용할 만큼 재력이 없는 경우

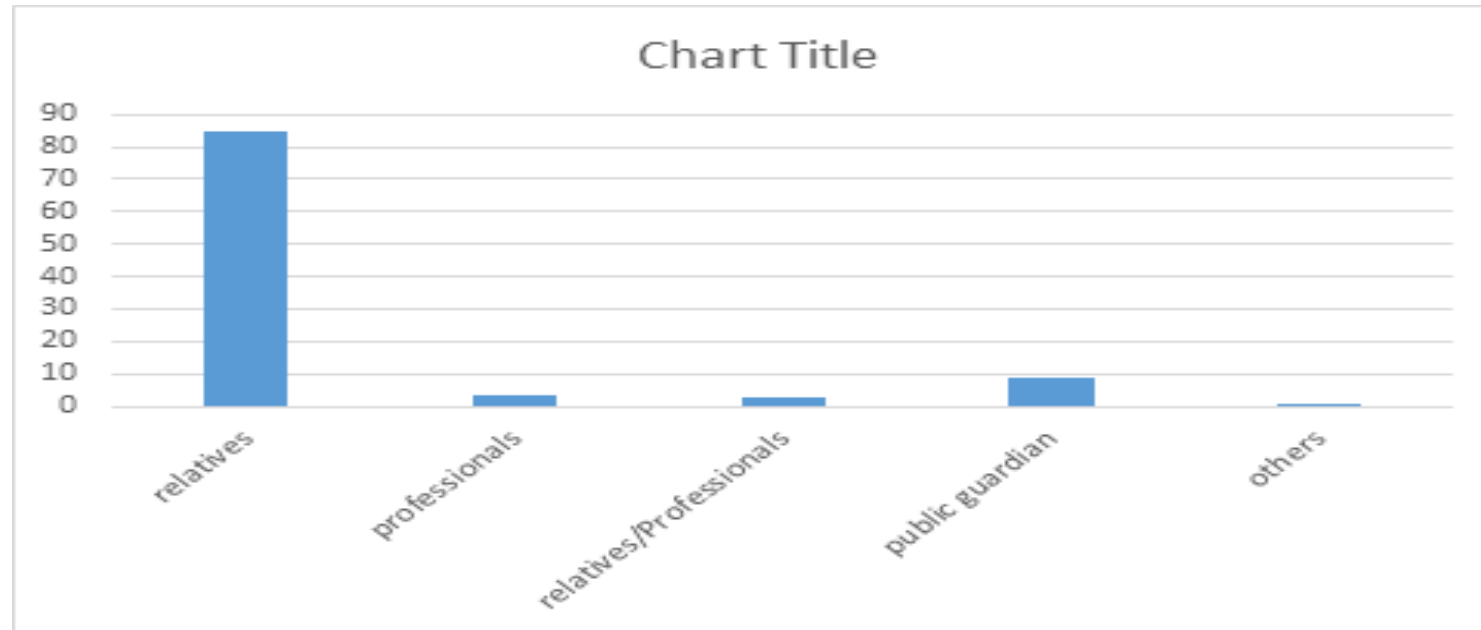
Peer Support Work to Persons with Mental Illness

- Pilot Project of the Ministry of Health and Welfare
- 3 agencies: Service Users Organization(Padoson), Rehabilitation Center, and Regional Mental Health Center
- Services: Advocacy to persons with Mental illness, who are involuntarily admitted to psychiatric hospitals to support them to make their own decisions with mental health services

Positive Behaviour Support to Adults with Severe Developmental Disabilities

- positive behaviour support services began to be provided to small group of those persons with severest developmental disabilities as a pilot project by Seoul municipal government.
- After one year experimental period, communication skills by care givers and persons with developmental disabilities have significantly improved that challenging behaviours in turn are reported to begin to decrease. In this pilot project, 10 day-care centers located in Seoul have participated to serve 42 persons with developmental disabilities.
- Inspired by such results, Korean Ministry of Health and Welfare announced recently The Ministry of Health and Welfare announced that day care services would be provided for to 2,500 adults with developmental disabilities, who have so far been forced to stay at home, due to their challenging behavior, and that government would increase the services to benefit 17,000 adults with developmental disabilities by 2022: among them, 20% of service users should be persons with severe developmental disabilities.

Public Guardianship Services, funded by Government, to Persons with Decision Making Disabilities



Conclusion

- Korean societies have so far been far away from the road to a supported decision making system, even though there have been lots of endeavors in favor of a supported decision making system. The weakness of civil societies' initiatives in Korea may be the lack of consumer or user initiatives
- A supported decision making system in Korea is hardly introduced and developed without service users' independent organizations seeking such goals.

Thank you for attention!