

SOCIALINIO DARBUOTOJO REPREZENTAVIMAS VALSTYBINĖJE PARAMOS SISTEMOJE: ŠEIMŲ, ESANČIŲ SU SUNKIOS NEGALYBĖS SITUACIJOJE, SUBJEKTYVI NUOMONĖ

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Straipsnyje analizuojama, kaip šeimos, auginančios vaikus, turinčias sunkią negalą, reprezentuoja socialinio darbuotojo valstybinėje paramos sistemoje. Ši sistema apibrėžiama kaip parama medicinos, socialiniame ir švietimo sektoriuose, kuriuos reglamentuoja Lietuvos Respublikos statymai. Socialinis darbas gali būti vadinamas nauju reiškiniu, palyginti trumpai gyvuojančiu praktikoje.

Šeimos, auginančios neįgalius vaikus, tyrimas svarbus tuo, kad nebuvo siekiama pateikti objektyvius rezultatus, nes šis tyrimas orientuojasi į šeimos subjektyvias nuomones atskleidimą. Nuomones apie valstybinę paramos sistemą tyrimas atskleidė, jog parama vertinama kaip nepakankama šeimoms susidurusi su sunkumais. Pozityviausia šeimos nuomonė buvo apie švietimo sektorių, mažiausiai pozityvi – apie medicinos. Palyginti su kitais sektoriais, pedagoginis sektorius buvo apibūdinamas kaip atviriausias bendradarbiavimui su šeimomis. Pagrindinės šeimos minimos problemos medicinos sektoriuje buvo šios: neigiamas požiūris „kitok“ vaikui, etiketizavimas ir nesidalijimas informacija su tėvais. Ypatingos reikšmės socialiniam darbuotojui sistemoje šeimos nesuteikė, tačiau jos kalbėjo apie egzistuojantį ilgalaikį paramos poreikį. Šeimos sivaizdavimu socialinis darbuotojas galėtų būti ilgalaikis palaikantis ryšius su šeima specialistas.

Esminiai žodžiai: socialinis darbas, paramos sistema, negalūs, šeima.

vadas

Atkūrus nepriklausomybę Lietuvoje 1990 metais, socialinio darbo ir negalūs s s vok aiškinimas gavo naują prasmę. Buinsko (2009) teigimu, šiuo periodu pokyčiai palietė visas kasdienio gyvenimo sritis. Keitėsi ne tik negalūs s diskursas, bet ir teisinė bazė – buvo priimti nauji statymai.

Vienas esminių statymų, kuris tapo postmiu požiūriu neįgaluosius visuomenėje kaitai, buvo *Ne galiu socialinės integracijos statymas*, sigaliojus nuo 2005 metų. Šio statymo priėmimas atvėrė naujas galimybes neįgaliems žmonėms. Lietuva, priimdama šiuos statymus, reglamentavo interpretatyvistinį negalūs s supratimą. Išplėstas negalūs s supratimas neapsiribojo vien biologiniais aspektais kaip anksčiau. Minutame statyme pristatomos naujos s vokos, nubrėžtos gairės veikiančios socialinės integracijos sistemai trijuose pagrindiniuose valstybiniuose sektoriuose: medicinos, socialiniame ir švietimo. Socialinės apsaugos ir darbo ministerijos¹ teigimu, šio statymo priėmimas reiškė teisinę negalūs j

integracijos modelio priartinimą prie Europos šalių konteksto². Gudžinskienės ir Jurgutienės (2010, p. 21) manymu, svarbiausia, jog šiame statyme naujai vertinama žmogaus negalūs ir jam atsiveriančios galimybės.

Socialinės apsaugos ir darbo ministerijos duomenimis, Lietuvoje vaikų, turinčių negalūs s, skaičius kasmet auga. Dėl šios priežasties yra realu kalbėti ir apie didį paramos poreikį. Guscia, Harries, Kirby, Nettelbeck ir Taplin (2006) tyrimas parodė, jog žmonės, turintiems kompleksinį sutrikimą, parama yra ypač svarbi. Kreiviniene (2007, 2011), Vaiėkauskaitė (2009) teigimu, paramos būtinybė išskyla, nes negalūs yra labiau pažeidžiami dėl visuomenės socialinio pokyčių. Šie autoriai (Kreiviniene, Vaiėkauskaitė, 2010) nuomone, tokios šeimos situacija yra sudėtinga, todėl parama turi būti orientuota į šeimos stabilizavimą ir harmonizavimą.

² statyme numatyta nuolatinti paramos galimybės. Taip pat teigiama, jog negalūs būtų suvokti iš gyvenimo perspektyvos, t. y. pastebinti ne tik gydymo galimybes, bet ir negalūs j gyvenimo kokybę.

¹ www.socmin.lt.

Šeimai negal s situacijoje tenka bendrauti su daugybe profesional , ta iau socialinis darbuotojas gal t b ti artimiausiu specialistu, teikian iu param visos sistemos lygiu (Kreivinien , 2011). Socialinio darbuotojo vaidmuo šeim , esan i negal s situacijoje, poži riu nepakankamai ištyrin tas d l paties reiškiniu naujumo. Daugumoje tyrim siekiama duomenis objektyvizuoti, tod l subjektyvi respondent patirtis ir išgyvenimai lieka neatskleisti. M. Foucault (cit. Cannella, 1999) teigimu, ilgus metus ne gal s žmon s nebuvo tyrin jami, nes j nuomon laikyta nesvarbia. Mokslini studij , tyrin jan i šeim , auginan i ne galius vaikus, ar žmoni , turin i negal , poži r valstybin paramos sistem , n ra daug (pvz., Ališauskien , 2007; Ališauskien , Ališauskas, Gerulaitis, Melien ir kt., 2008; Navaitis, 2007; Skeryt - Kazlauskien , Barkauskien , 2010). Menkai tyrin tas ir šeim negal s situacijoje poži ris socialin darbuotoj sistemoje (pvz., Butkevi en , Majerien , Harrison, 2006).

Tyrimai, orientuoti socialini darbuotoj pagalbos šeimoms negal s situacijoje analiz , rodo, kad egzistuoja skirtingos nuomon s. Pavyzdžiui, Varažinskien s (2009, p. 129) teigimu, teisin baz , reglamentuojanti socialin darb sistemoje, dar formuojasi, o socialinio darbo gyvendinimas praktikoje yra trumpas istoriškai. Butkevi en s, Majerien s ir Harrison (2006) tyrimas parod , jog šeimos negal s situacijoje vis dar susiduria su daugybe problem paramos sistemoje. Makštutyt s ir Naujanien s (2008) tyrimas atskleid , kad socialiniams darbuotojams tenka vadovautis ir klinikiniu modeliu, o Ivanauskien s ir Varažinskien s (2007) tyrimas liudija, jog socialinio darbo profesijos supratimas pa ioje visuomen je dar nesusiformav s. Bitino, Guogio, Migun ir Važgyt s (2010) tyrimas atskleid , kad socialiniai darbuotojai susiduria su daugybe problem praktikoje. Tuo tarpu Prakapo (2007, p. 14) teigimu, situacija yra priešinga. Jo teisin s baz s analiz leidžia daryti prielaid , jog visi reikalingi statym tobulinimai jau atlikti bei s kmingai diegti socialinio darbo praktikoje.

Tobulinant pagalbos sistem šeimoms, auginan ioms ne galius vaikus, b tini ne tik objektyvizuoti tyrimai, ta iau b tina siklausyti ir subjektyvias šeim nuomones, t. y. tirti pa i šeim , kurios naudojami paslaugomis, subjektyvi nuomon apie valstybin paramos sistem bei socialinio darbo praktik sistemoje.

Tyrimo klausimai: *kokios yra šeim subjektyvios nuomon s apie param valstybinuose medicinos, švietimo ir socialiniame sektoriuose? Kaip šeimos supranta socialini darbuotoj param sistemoje?*

Tyrimo tikslas – išanalizuoti šeim , esan i sunkios negal s³ situacijoje, nuomon apie valstybin paramos sistem , pabr žiant socialin darb .

Reprezentacij konceptualizavimas

Reprezentacij (angl. *representation*) analiz tyrimo tikslui suteikia asmeniškumo. Tyrimo dalyje subjektyvios nuomon s apie valstybin param buvo analizuojamos kaip išgyventa socialin realyb , t. y. *šeimos jausmu* (cit. Gabb, 2009, p. 37).

Souza-Filho ir Beldarrain-Durendagui (2009, p. 772) teigimu, reprezentacijos yra analizuojamos, siekiant tam tikr tiksl , pavyzdžiui, siekiant atskleisti poky i poreik praktikoje. Nuomoni apie valstybin paramos sistem analiz yra tarsi *priemon ir rankis poky iams inicijuoti* (Moscovici, cit. Gillespie, 2008, p. 377).

E. Durkheimas buvo pirmasis, kuris pavartojo s vok *reprezentacijos* (cit. Gillespie, 2008, p. 375), ji v liau buvo išpl tota Moscovici (ten pat, p. 375) kaip *socialin s reprezentacijos* s voka. Prieš Moscovici kiti autoriai taip pat vartojo ši s vok : Lévy-Bruhl (1927) kalb jo apie „kolektyvin siel“, Vygotski (1962) raš apie kolektyvines reprezentacijas, o Piaget (1932) min jo s vok *socialin reprezentacija* (Orfali, 2002, p. 399).

Šiame straipsnyje reprezentacij suprati mas artimiausias Gillespie (2008) alternatyvi reprezentacij (angl. *alternative representations*) sampratai. Ši s vok jis išpl tojo pagal Moscovici socialini reprezentacij id j , priskirdamas subjektyvumo savybes. Tuo remiantis, nuomon s apie valstybin param yra analizuojamos kaip subjektyvios reprezentacijos, kurias pateikia šeimos, kalb damos apie specialistus bei valstybin paramos sistem .

Šeim subjektyvios nuomon s yra suprantamos kaip tam tikr nuomoni specialistams priskyrimas (skirstant kategorijas *jie visi, jie yra* ir pan.) ir vairi situacij valstybin je paramos sistemoje turinio atpasakojimas. Šeimoms kalbant apie specialist asmenines savybes, darbo model , poži r vaik bei kitus kokybinius aspektus ir yra išryškintas j subjektyvus paramos supratimas.

³ Pagal taikom LR sveikatos apsaugos ministro, LR socialin s apsaugos ir darbo ministro ir LR švietimo ir mokslo ministro 2005 m. kovo 23 d. sakym Nr. V-188/A1-84/ISAK-487, „D l ne galumo lygio nustatymo kriterij ir tvarkos aprašo“.

Sunki negal s supratimas

Tyrime, siekiant apibr žti *sunki negal*, buvo susidurta su etikos dilema. Kadangi buvo siekiama atskleisti nuomones šeim , kurioms teko naudotis medicinini mis, socialini mis ir švietimo paslaugomis, vienas iš respondent atrankos kriterij buvo paremtas vaiko medicinine diagnoze. Viluckien s (2008, p. 51) teigimu, negal s paradigm kaitos problema slypi biologini ir socialini aspekt supriešinime. Vis d lto formuojant negal s supratim per socialinius aspektus, ta iau nepamirštant ir biologini , galima atskleisti variapus šeimos situacij .

D l šios priežasties straipsnyje *sunki negal* yra suprantama kaip *sukonstruota prasm* (Bruner, cit. Swartz, 2009) konkre iai situacijai, t. y. šiam tyrimui.

S voka *negal (negalia)* yra panašiai apibr žiama daugelio šiuolaikini Lietuvos tyr j (Ruškus, 2001; Kreivinien ir Vai ekauskait , 2010; Ališauskas, Ališauskien , Gerulaitis, Melien , Miltenien ir kt., 2009; bei kt.) – orientuojantis ne tik medicininius faktorius, ta iau ži rint pla iau – kaip konstrukt , kylant iš asmens ir aplinkos s veikos. Viluckien (2010, p. 116) net si lo vartoti Bury *biografinio l žio* s vok , kai negal ženkliai lemia gyvenimo poky ius.

Straipsnyje remiamasi Morrow, Quine ir Craig (2006, p. 529) išskiriamais biologiniais ypatumais, t. y., jog vaikai, turintys sunki negal , gali kent ti nuo biologini , fiziologini ir funkcionavimo sutrikim , toki kaip nekoordinuotas rijimas, gastroenteritas ir chroniškos plau i ligos, padidinan ios sergamumo bei mirtingumo rizikas. Taip pat tyrime negal ži r ta ir per interpretatyvistin prizm , kai negal s supratimas formuojamas per asmens ir aplinkos s veikos prizm (Ruškus, 2001). Reprerentacijos šiuo atveju atveria galimyb priart ti prie „tikrojo šeimos subjektyvumo“, t. y., kaip, b damos ypatingoje situacijoje, jos suvokia valstybin paramos sistem .

Respondent atranka

Tyrime dalyvavo dešimt šeim ⁴, auginan i vaikus, kuriems diagnozuotas cerebrinis paralyžius. Ne gali j socialin s integracijos statymas (2005) numato param per medicinos, socialin ir švietimo sektorius, tod l atrankos kriterijai buvo:

- Šeima, auginanti vaik , sergant cerebriniu paralyžiumi (atrinktos šeimos, kuri vaikai tur jo kompleksin negal).

- Vaiko amžius 4–15 met .
- Pilna šeima: mama, t tis ir bent du vaikai. Vienas iš vaik , sergantis cerebriniu paralyžiumi, antrasis ir kiti – neturintys negali . Tyrime buvo siekiama sudaryti kuo panašesni respondent grup , tod l b tent šiuo *pilnos šeimos* supratimu ir buvo remiamasi.
- Ne galus vaikas lanko ugdymo staig .

Tyrimo procesas ir duomen analiz

Tyrimo duomenys buvo surinkti pusiau strukt ruot gilumini interviu su šeimomis metu. Kiekvienas interviu truko nuo vienos iki trij valand , su keturiomis šeimomis buvo susitikta papildomiems tyrimo duomenims surinkti. Šeimos buvo užkoduotos, priskiriant skai i nuo 001 iki 010. Interviu su vis kita šeima buvo planuojamas kas dvi savaites. Interviu temos ap m visus sistemos sektorius: medicinos, socialin ir švietimo. Interviu metu šeimos buvo prašomos laisvai kalb ti apie visus paramos sistemos aspektus.

Kokybinio tyrimo duomenys buvo apdroti turinio (*content*) analiz s b du. Naudotas atviras kodavimas. Elo ir Kyngäs (2008, p. 109) atvir kodavim apib dina kaip teksto skaitym , pasižymint antraštes. V liau antrašt s buvo susistemintos kategorijas. Tyr jas po kiekvieno interviu susirašydavo šeim temas, mintis, id jas, kurios iš naujo buvo aptarin jamos su šeima kitomis dienomis ir tokiu b du kartu buvo kuriamos kategorijos.

Tradicin turinio analiz yra atliekama skai iuojant žodžius, tod l iškyla rizika, jog respondento išgyvenimai bus analizuojami atsietai nuo bendro konteksto, apie kur buvo kalb ta (Angelique ir Culley; Brabant ir Mooney; Krippendorff; Milburn, Carney ir Martinez, cit. Baker ir Stahl, 2004). D l šios priežasties tyrime buvo analizuojamos šeim fraz s kaip kokybin s prasm s. Tokia *frazi analiz* leido susidaryti visumin vaizd apie šeim matom paramos sistem Lietuvoje. Fraz s buvo skai iuojamos, skliaustuose pateikiant j skai i , pvz., (5). Skai ius rodo, kiek šeim pasakojo apie panašius išgyvenimus ar net vartojo tuos pa ius žodžius.

Tyrimo dalyviai buvo traukti kategorij , subkategorij ir pirmo lygmens subkategorij konstravimo proces . Pirmo lygmens sukategorijos buvo išskirtos tokias subkategorijas: specialist apib dinim , poži r vaik , darbo modelio apib dinim ir intervencijos rezultat apibr žim . Šeimos šias subkategorijas priskyr medicinos, švietimo ir socialinio sektori kategorijoms (žr. lentel).

⁴ Atrinkti respondantai buvo iš Birž , Elektr n , Klaip dos, Palangos, Kauno, Mažeiki , Vilkaviškio, Plung s, Kupiškio ir Telši miest .

Tyrimo duomen analiz s sritys medicinos, švietimo ir socialinio sektoriaus kategorijose

| Subkategorijos | Medicinos sektoriaus pirmo lygmens subkategorijos | Švietimo sektoriaus pirmo lygmens subkategorijos | Socialinio sektoriaus pirmo lygmens subkategorijos |
|--|---|--|--|
| Paramos teik jai: specialistai | abejingi | palaikantys | neteisingai juos suprantant |
| | nesir pinantys | | |
| | pripaž stantys tik cheminius preparatus | netenkinantys | kaip egzistuojantis pavadinimas |
| | perkeliantys atsakomyb | metodologai | profesionalai |
| Paramos teikimas: poži ris vaik | etiketizuojantis | išryškinantis vaiko stipri sias puses | empatiškas |
| | eksperimentinis | | |
| | nelygios lygyb s | išryškinantis vaiko silpn sias puses | kaip našt |
| | prisitaikantis | kaip našt | pasigail tinas |
| Paramos teikimas: taikomas darbo modelis | palaikantis | individualus | užrašin jimo |
| | išbarstytas | | |
| | apribojantis | | informacinis |
| | aiškus medicininis | | joks |
| | kitas | | „tau reikia“ |
| Paramos teikimas: intervencijos rezultatas | teigiamas | suvokiamas kaip vaiko | dalijimasis informacija |
| | neigiamas | vystymasis | netenkinantis |
| | neutralus | ribotas sivaizdavimas | ret susitikim |

Tyrimo patikimumas

Kimberlin ir Winterstein (2008) teigimu, tyr jas gali sukurti tyrimo patikimum ir j pagr sti aprašydamas. Tyrimo patikimumas buvo sukurtas apsisprendžiant d l:

- **Respondent atrankos.** Tyrime dalyvavusios šeimos buvo kruopš iai atrinktos pagal jau min tus kriterijus: socialin s situacijos panašum , vaiko diagnoz ir jo socialin dalyvavim .
- **Šeim traukimo.** Habermas (cit. Moilanen, 2000, p. 384) rašo, kad, kuriant atgalin ryš su respondentais, turi vykti nat ralus dialogas, kurio metu jie vertina ir pagrindžia savo teiginius. D l šios priežasties po kiekvieno interviu su šeimomis buvo susitinkama papildomai, siekiant suprasti j pasisakym „tikr j reikšm “. Taip pat šeimos dalyvavo kuriant kategorijas.

Tyrimo rezultatai

Tyrimo rezultatai pateikiami atskirai, pristatant šeim subjektyvi nuomon apie kiekvien sistemos sektori : medicinos, švietimo ir socialin . Šios kategorijos analizuojamos per keturias subkategorijas: specialist reprezentavim , specialisto poži r vaik , taikom darbo model ir intervencijos rezultatai .

Valstybin paramos sistema medicinos sektoriuje Medikai

Analizuojant *nuomones apie specialistus*, buvo išskirtos juos apib dinan ios pirmo lygmens subkategorijos: *abejingi, nesir pinantys, pripaž stantys tik cheminius preparatus, perkeliantys atsakomyb* .

Visos šeimos, dalyvavusios tyrime, kalb jo apie konkre ias *asmenybes*, sutiktas tam tikrose institucijose. Bent kart neigiamai vertinusios susitikim su mediku, šeimos pasakojo apie suformuot neigiam nuomon viso medicinos sektoriaus atžvilgiu. Pus šeim (5) min jo, jog jiems teko sutikti *abejingus* medikus.

Labai panaši pirmo lygmens subkategorija buvo išskirta apib dinant medikus kaip *nesir pinan ius* (3). Šeimos pasakojo apie empatiškumo stok ypatingiesiems poreikiams. Taip pat jos min jo apie patirt segregacij lankantis lignonin je su *kitokiu* vaiku. Šeimos 007 atvejis: *Medikai, matydami vaiko negal , specialiai nesir pinā*⁵.

Beveik visos šeimos (8) apib dino medikus, *pripaž stan ius tik cheminius preparatus*. Ši pirmo lygmens subkategorija apib dina gydytojus, kurie, siekdami pagerinti situacij , pasi l tik medikamentin pagalb . Šeim teigimu, vaiko negal yra neišgydoma, tod l vaikas turi b ti priimamas kaip asmenyb , turinti

⁵ Respondent kalba netaisyta. – Red. pastaba.

negal . Šeimos 004 atvejis: *Kiek sutikome gydytoj , visi jie si l tik chemines intervencijas.* Šeimos 010 atvejis: *Mes nepripaž stame cheminio gydymo.* Visi t vai min jo bijantys *chemin s intervencijos d l turimos ankstesn s nes kmingos patirties.*

Šeimos, kalb damos apie pirmo lygmens subkategorij *perkeliantys atsakomyb* (9), min jo, kad susitikim metu gydytojas atrodo siekiantis perkelti kam nors atsakomyb , pavyzdžiui, link s pabr žti t v atsakomyb už vaiko gydym . Šeimos 007 atvejis: *Gydytojas man pasak : „Aš GALIU išrašyti, jei J S to norite“ <...>. Tokie pasakymai man suk l siaub <...> Jei AŠ NORIU – aš juk ne medik <...>.*

Poži ris vaik

Poži ris vaik buvo išskirtas pirmo lygmens subkategorijas: *etiketizuojantis, eksperimentinis, nelygios lygyb s ir prisitaikantis.*

Etiketizuojant (10) poži r iliustravo šeimos 010 atvejis: *Mes pasijutome ten visiškai <...> nužeminti.* Etiket buvo priskiriama ne tik vaikui. Šeimos pasakojo apie tai, jog toks poži ris buvo naudojamas platesniame kontekste, t. y. parodant, kad *negal turi visa šeima.* D l šios priežasties t vai, pasakojantys apie tai, kaip gydytojas apži r jo vaik , kalb jo vardžiais *mes* vietoje *jis (ji).* Šeimos gydytojo abejingum suprato kaip etiketizavim .

Šeimos buvo labai nusivylusios sutiktu medicinos personalo *eksperimentiniu* (5) poži - riu. Užuo t sulaukusios patarimo, jos pasijuto tarsi dalyvaut eksperimente. Šeimos 010 atvejis: *Vaikas buvo kaip eksperimentinis triušiuukas <...> jam suparalyžiavo kojytes d l t medicinini bandym <...> ir ištirpo dantukai.*

Nelygios lygyb s poži ris buvo išskirtas pagal šeim pasakojimus apie susitikimus su abejingais medikais. Šeim teigimu, ne galumo ir darbingumo nustatymo komisijos gydytojai nevengia išreikšti galios santyki . Šeimos 003 atvejis: *Kai ateiname d l ne galumo <...> mes turime b ti pasiruoš susidurti su nesiskaitymu, laukimu ir s d jimu <...>.*

Paskutiniai pirmo lygmens subkategorija buvo vardyta kaip *prisitaikanti* (6). Šeimos 007 atvejis apie gydytojo žodžius: *„Mama, J s nesureikšminkite vaiko diagnoz s, dabar jau nieko nebepakeisite, jis laimingas, kad gim tokioje šeimoje“ <...> Manau, gydytojas tur jo omeny ne asocialioje šeimoje <...> ir d l to aš turiu s d ti ir steb ti vaiko merd jim ?* Šeimos nuomone, gydytojas apie mirštant vaik kalb jo kaip apie tam tikr *daikt* , kur galima pakeisti.

Taikomas darbo modelis

Taikomo darbo modelio subkategorijoje išskirtos šios pirmo lygmens subkategorijos: *palaikantis, išbarstytas, apribojantis, aiškus medicininis ir kitas.*

Šeimos (3) *palaikant* model apib dino kalb damos apie konkret gydytoj , kuris buvo patyr s specialistas ir išreišk nor bendradarbiauti su t vais. Pozityviausiai jos apib dino medikus, kurie suteik šeimai erdv s, ta iau kritin je situacijoje buvo šalia kaip ekspertai, pasireng suteikti pagalb . domu tai, kad šeimos, kalb damos apie gydytoj palaikym , kur kas labiau vertino profesional ind l gydymo procese nei galutin gydymo rezultat . Šeimos 010 atvejis: *Aš kalbuosi ir konsultuojuosi su savo neurologe. Jai priimtina tai, kad aš skaitau ir domiuosi vaistais. Ji, be joki abejoni , manimi pasitiki ir žino, kad aš savo vaik stebiu.*

Model kaip *išbarstyt* (9) min jo šeimos, kalb damos apie gydym : kurio t vai nesuprato, kuris buvo neefektyvus arba kurio nesuprato patys medikai. Šeim nuomone, sunkiai sergantis vaikas yra pats didžiausias širdies skausmas. *Mamos* pasakojo skirtingas situacijas, kurias lyd jo panašus beviltiškumo jausmas matant, jog gydytojas blaškosi, nežinodamas, kok gydym taikyti.

Kita pirmo lygmens subkategorija buvo pavadinta *apribojan iu* modeliu (10). Šis modelis glaudžiai siejosi su gydytojo poži riu vaik . Visos šeimos teig susid rusios su tokiu modeliu. Šeimos 008 atvejis: *Jei gydytojas neturi erdv s suvokimo, kad vaikas yra ilgas, o lova pernelyg maža <...> mes abu su vaiku dvi naktis miegojome toje mažoje lovoje.* *Mamos* pasakojimu, ji pajuto pa ios ir vaiko vertinim kaip *ribot žmoni vien d l sunkios negal s.*

Kita pirmo lygmens subkategorija buvo reprezentuojama kaip *aiškus medicininis* (9) modelis. Šis modelis netur t b ti painiojamas su klinikiu-korekciniu modeliu, turin iu neigiam atspalv . Priešingai, dauguma šeim š aišk medicinin model vertino labai teigiamai.

Šeimos buvo labai patenkintos sutiktais gydytojais ekspertais, kurie mielai dalijosi informacija su šeimos nariais. Šeimos labai teigiamai *vertino* gydytoj parodyt supratingum bei pagalb : *sutvark visus reikalingus popierius.*

Medicininis modelis kaip *kitas* (10) buvo reprezentuojamas priskiriant šiuos apib dinimus: *nejautrus, reikalaujantis pinig ir inicijuojamas t v .* Šeimos 008 atvejis: *Gydymas buvo organizuojamas iš lub <...> kadangi negalia jau vis tiek buvo diagnozuota.* Šeimos pasakojo, jog *sunkios negal s* diagnoz tarsi paslepia kitas sveikatos problemas. Tok model taikantys medikai buvo apib dinami kaip *nejautr s,* nes jie

ne siklaus t v žodžius. T v nuomone, jie yra esminis žini apie vaik šaltinis.

Intervencijos rezultatas

Intervencijos rezultatai buvo išskirti pirmo lygmens subkategorijas: *teigiamas*, *neigiamas* ir *neutralus*.

Šeimos, *teigiamai* (8) vertinan ios intervencijos rezultatus, kur kas dažniau vartojo frazes *m s gydytojas* kalb dami apie konkre i klinik ar sanatorij , kurioje buvo suteikta pagalba.

Intervencijos rezultat kaip *neigiam* (7) pamin jo dauguma tyrime dalyvavusi šeim . Jos neigiamai vertino gydym , jei teko susidurti su nedraugiška medicinos staig aplinka, pavyzdžiui, nebendravimu, nepagarba ir neprieži ra.

Neutralus rezultatas (4) buvo minimas beveik pus s šeim . Intervencijos rezultat šeimos vertino neutraliai, jei negal jo nieko konkre iai papasakoti, kaip pakito vaiko b kl apsilankius staigoje. Šeimos 002 atvejis: *Labai sunku pasakyti <...> jis truput kitoks, gal stipresnis, laiko pats galvyt <...> supranta <...> mes manome, kad jis supranta.*

Valstybin paramos sistema švietimo sektoriuje Pedagogai

Analizuojant šeim subjektyvias nuomones apie švietimo sektoriaus pagalb , *pedagogai* buvo išskirti šias pirmo lygmens apib dinan ias subkategorijas: *palaikantys pedagogai*, *netenkinantys pedagogai* ir *pedagogai* kaip *metodologai*.

Šeimos apib dino *palaikan ius pedagogus* (8) kaip profesionalus, kurie gali sukurti *saugi aplink* vaikams. Šeimos pasakojo, jog supranta, kad j vaikus ugdyti sud tinga, tod l labai teigiamai vertino pedagog ind l, kad vaikas jaust si laimingas mokyklos aplinkoje. Šeim nuomone, bendraujant su pedagogais labai svarbu sukurti tarpusavio pasitik jim .

Priešingai vertinama situacija, kai t vai pedagogus apib dino kaip *netenkinan ius* (4). Šeimos 002 atvejis: *Aš nesu patenkinta auklyte <...> ji nuolat skundžiasi, jog vaikui reikia keisti sauskelnes, o ji neturi tam laiko.*

Beveik pus tyrime dalyvavusi šeim apib dino *pedagogus* kaip *metodologus* (4). domu tai, jog medicinos sektoriuje šeimos labiausiai vertino informavim , o švietimo sektoriuje informacijos suteikimas buvo mažiausiai svarbus. Šeimos 003 atvejis: *Aš einu ten, pabendrauju, pab nu <...> parodau pedagogams, kaip j nuraminti, sužadinti aktyvum ir parodau, k galima su ja veikti.*

Šeimos švietimo sektori apib dino kaip *saug* , nes pedagogai r pinasi vaiko vystymusi, kuris vyksta vis gyvenim . Pozityviausiai šeimos

vertino pedagogus, kurie maloniai bendrauja, suteikia informacijos, siekia bendradarbiauti ir nebijo paklausti t v nuomon s.

Poži ris vaik

Poži ris vaik buvo išskirtas *išryškinant vaiko stipri sias puses, išryškinant vaiko silpn sias puses* ir poži r vaik kaip *našt* .

Jei pedagogai, nepaisydami vaiko negal s, *išryškina vaiko stipri sias puses* (5), šeimos pasakojo *pamirštan ios* diagnoz , apribojimus ir patys ima žvelgti vaiko galimybes. Šeimos 007 atvejis: *Jie pasakoja, kad mano vaikas bendraujantis <...> Kitiems vaikams jis labai patinka <...>. Joki problem , joki ašar .*

Šeimos perfrazavo tok pedagog pasakym : *Matote, koks J s vaikas socialus, visiems jis patinka.* Labiausiai t vai bijojo matyti savo vaik vieniš ir apleist . T vai, gaudami informacij iš pedagog apie vaiko b kl , kuri yra ar iau *normalumo* nei *negal s*, jaut palengv jim . Inkluzin ugdym t vai siejo su vaiko tobul jimu.

Carpenter (2005, p. 180) teigimu, panašios inkluzin s strategijos traukia šeimas ir jos pasijunta vertinamos.

Šeimos pateik ir kitok poži r , kai pedagogai buvo link *išryškinti vaiko silpn sias puses* (4). Šeimos pasakojo istorijas, kai vietoj palaikymo ar individualios programos suk rimo vaikui jos sulauk pedagog *nuomon s*, kas b t geriausia šeimai j sud tingoje situacijoje. Šeimos 003 atvejis: *Darželio direktor man pasi l tiesiog atsisakyti šio vaiko.*

Poži r , kai vaikas pedagog suvokiamas kaip *našta* (3), pateik tre dalis šeim . Šeimos 003 atvejis: *Jie dreb jo iš siaubo nuo mano dukters, nes ji tokia sunki <...> McLaughlin ir kt. (2006) teigia, jog toks etiketizavimas pedagogikos sektoriuje egzistuoja daugelyje pasaulio šali . Blogiausia, kad etiketizavimas susij s su neigiam stereotip , ekspektacij susiformavimu ir segregacija.*

Taikomas darbo modelis

Šeim nuomoni analiz išryškino vienintel vis min t *darbo su vaiku model* švietimo sistemoje – *individual* (9). Kluth, Biklen, English-Sand ir Smukler (2007) rašo, jog net ir inkluzinis ugdymas susiduria su kli timis: segregacija, mokymosi turinio nepritaikymu individualiems poreikiams, paramos tr kumu, paslaug kokybe ir nepripažinimu visuomen je.

Beveik visos šeimos pabr ž , kad individualus darbo su vaiku modelis reikalingas d l jo ypating j poreiki (9). Ta iau ne visais atvejais šis modelis yra matomas teigiamai, kartais jis gali

reikšti segregacijos principą gyvendinim . Šeimos 006 atvejis: *Po mano rašt valstyb leido jai mokytis gest kalbos <...> ta iau, galima sakyti, kad mes prad jome su vaiku bendrauti tik tada, kai ji prad jo lankyti mokykl .*

Šeima pasakojo apie savo situacij , kai jie vieninteliai mažame miestelyje augino dukr , turin i klausos sutrikim , kuriai buvo reikalinga individuali mokymosi programa. Problema iškilo tuomet, kai neatsirado n vieno specialisto, galin io vaik ir šeimos narius išmokyti gest kalbos: iki septyneri aštuoneri met šeima buvo priversta tarpusavyje *bendrauti* savo išgalvota ženkl kalba.

Intervencijos rezultatas

Intervencijos rezultatas buvo išskirtas pirmo lygmens subkategorijas: suvokiamas kaip vaiko *vystymasis* ir *ribotas sivaizdavimas*. Šeimos išreišk pasitenkinim pedagog darbu ir institucija, jei rezultatas buvo matomas kaip vaiko vystymasis, tobul jimas. Jei pedagogai mat vaiko tobul jimo galimybes ribotai, t vai pasakojo apie kilus stres ir nepasitenkinim .

T vams labai svarbu jausti ilgalaik palaikym pedagogikos sektoriuje. Pasakodamos apie rezultat kaip vaiko *vystym si* (4), šeimos pamin jo kelis svarbiausius aspektus: inkliuzin ugdym , vaiko geb jim ir savarankiškumo vystym si. Šeimos 004 atvejis: *Pra jusius metus jis mok si su sveikais vaikais mokykloje, jis buvo vienintelis su negalia, tod l akivaizdžiai matomas ne tik tinas šuolis priek .*

Jei pedagogai dirbo tur dami *ribot si-vaizdavim* (3) apie ne galaus asmens galimybes, tai, šeim teigimu, tik tis vaiko lav jimo yra beprasmiška. Šeimos pasakojo, jog, pasteb jusios tok pedagog poži r , steng si vaiko ugdymo staig nebevesti. Šeimos 003 atvejis: *Septyneri ji turi prad ti lankyti mokykl . Situacija yra tragiška ir sud tinga*. Šeima pasakojo apie tai, kad netur jo galimyb s vežioti vaik mokykl , esan i už 200 kilometr nuo nam , o ar iau nebuvo tinkamos staigos. Naujos ugdymo institucijos paieškas t vai suvokia kaip *sud ting* ir *tragišk* situacij .

Valstybin paramos sistema socialiniame sektoriuje

Socialiniai darbuotojai

Šios tyrimo dalies rezultatai buvo labai netik ti. Buvo manoma, jog šeimos, auginan ios vaikus, turin ius sunki negal , per 4–15 met sutiko socialinio darbo specialist . Ta iau tyrimo metu paaišk jo, kad beveik visos šeimos teig niekada nesutikusios socialinio darbuotojo. Kai kurios iš šeim net negal jo sivaizduoti, kokiai sferai šis specialistas gal t priklausyti (3), kita

pateikta t v nuomon buvo ta, jog socialinis darbuotojas yra *specialistas*, kuris užima (3) t vus linksma veikla, kai *n ra k veikti*.

Socialinis darbuotojas buvo apib dintas: *neteisingai j suprantant* (bet vardijant kaip padedant), kaip egzistuojantis *pavadinimas* ir kaip *profesionalas*.

Šeimos pasakojo apie sutiktus kitus specialistus, kuriuos man esant socialiniais darbuotojais. Ta iau šiuos *neteisingai suprustus* (3) specialistus vertino teigiamai. Apib dindamos socialin darbuotoj , šeimos negal jo pateikti informacijos, kas yra socialinis darbuotojas, tod l, kalbant apie j pagalb , šeimos *socialinius darbuotojus* painiojo su kitais specialistais. Šeimos 002 atvejis: *Geri darbuotojai. Ateina vaikui atlikti masažo iš tre io aukšto pirm <...> atsidav darbui*.

Kai šeimos nežinojo, kaip apib dinti socialin darbuotoj , jos sivaizdavo, jog socialinis darbuotojas tikrai *kažk daro*, ta iau k konkre iai, negal jo pasakyti.

Šeimos išreišk nuomon apie socialin darbuotoj kaip egzistuojant *pavadinim* (8), nes šio specialisto niekada nesutiko arba sutiko, ta iau vis tiek nieko apie j negal jo pasakyti.

Kitas domus tyrimo rezultatas buvo šeim teiginiai, kad jie niekada nesutiko socialinio darbuotojo, o v liau, kalb damos apie lankym si sanatorijoje, kai kurios iš šeim jau pamin jo socialin darbuotoj . Tokie teiginiai atskleidžia, jog socialinis darbuotojas ne sivaizduojamas kaip socialin s paramos teik jas. Dvi šeimos pasakojo apie neprofesionali socialinio darbuotojo pozicij . Šeimos 006 atvejis: *Kai n ra k veikti, mes einame pas socialin darbuotoj ir geriamė kav .*

Šeimos suprato supaprastint socialinio darbuotojo vaidmen – kavos g rim kartu ir *plep jim* . Šeimos apib dino socialin darbuotoj kaip tam tikr bendr j specialist , asmen , su kuriuo galima praleisti laisvalaik sanatorijoje ir nieko daugiau. Šeimos net nesitik jo teisin s konsultacijos. Tokia id ja šeimoms atrod ne tik tina. Socialinis darbuotojas buvo matomas labai paprastai – draugyst s santyki kontekste. D l šios priežasties socialinis darbuotojas buvo suvokiamas kaip silpnas specialistas.

Profesionalais (10) buvo vardyti socialinio sektoriaus darbuotojai – socialiniai darbuotojai ir specialistai, kurie r pinasi ne gali j klausimais valstybin se ir nevyriausybin se organizacijose. Profesionalai, sutinkami nevyriausybin se organizacijose, buvo vertinti pozityviai, valstybin se – priešingai. Kalb damos apie valstybin sektori , šeimos vienareikšmiškai sak , kad *tokios* šeimos *jiems* ner pi.

Poži ris vaik

Pagal šeim pasisakymus *poži ris vaik* buvo išskirtas pirmo lygmens subkategorijas: *empatiškas, našta, pasigail tinas*. Kalb damos apie visus analizuojamos valstybin s pagalbos sektorius, šeimos kartojo, jog vaikas priimamas kaip našta.

Dvi šeimos apib dino poži r vaik kaip *empatišk* (2). Viena šeima pamin jo, kad toks empatiškas poži ris buvo parodytas ne tik vaikui, bet ir visai šeimai. Šeimos 007 atvejis: *Socialinis darbuotojas mane išmok myl ti širdimi, tur ti nor , suvokti save ir nepalikti (vaiko). Tik kovoti, kovoti ir viskas bus gerai.*

Šeimos empatiški socialini darbuotoj poži r aiškino kaip j sud tingos situacijos *supratim* ir profesionalias konsultacijas, taip pat ir poži r , jog vaiko *negalima palikti*.

Beveik visos šeimos pasakojo, kad joms teko susidurti su poži riu vaik , jog jis yra *našta* (9). Šis poži ris turi s saj ir su kita nuomone, kai ne tik vaikas, bet ir visa šeima buvo vertinami kaip *pasigail tini* (7).

Šeimos teig su tokiu poži riu susid rusios valstybin se institucijose. Vaikas buvo suprantamas kaip našta, d l kurios visa šeima tampa pasigail tina. Šeimos pasakojo, jog vežim liai n ra pakankamai pritaikyti specialiesiems poreikiams, tod l jie tarsi ver iami laukti labdaros iš užsienio ar priversti susikonstruoti patys.

Šeim teigimu, poži ris šeim kaip *pasigail tin* (7) buvo sutiktas tik valstybin se institucijose. Šeimos 001 atvejis: *Mes gavome dvigubai daugiau pinig li , kai ji buvo namuose. Dabar gauname perpus mažiau, nes ji prad jo lankyti mokykl . Šis pavyzdys iliustruoja, jog mamos tarsi neturi kito pasirinkimo, kaip tik kuo ilgiau namuose priži r ti vaik .*

Šeim nuomone, poži ris vaik socialiniame sektoriuje yra dažniau nepalaikantis nei padedantis. Dauguma šeim pasakojo apie sunkias gyvenimo situacijas, kada pagalba buvo gyvybiškai svarbi, ta iau vien užklausimai d l pašalp jiems pasirod keliantys papildom problem specialistams.

Taikomas darbo modelis

Taikomo darbo modelio subkategorijoje išskirtos keturios pirmo lygmens subkategorijos: *užrašin jimo, informacin , jokia* ir *tau reikia*.

Užrašin jimo modelis (2) išskirtas pagal t v pasakojimus, jog socialinis darbuotojas nuolat pild pa ius vairesius dokumentus. Šeim nuomone, šis nuolatinis užrašin jimas atitolino b tin pagalb , nes socialiniam darbuotojui reik jo surinkti kuo daugiau informacijos apie vaik . Ta iau v liau šeimos pasakojo, kad

socialinis darbuotojas pild šiuos dokumentus apklausai ar pan., ta iau ne tam, kad panaudot duomenis pagalbai kurti.

Informacinis modelis (5) buvo minimas t šeim , kurios teig , jog sutiko socialin darbuotoj arba gal jo j apib dinti. Šeimos reprezentavo š model tiek teigiamai, tiek ir neigiamai. Tam tikrais atvejais šeimos pasakojo, kad socialinis darbuotojas tik atsakin jo klausimus, be jokios asmenin s iniciatyvos.

Gana dažna šeim min ta praktika – pa ioms šeimoms gyvendinti *informacin* model savipagalbos grup se. Mitchell ir Sloper (2002, p. 74) teigimu, pastar j met tyrimai rodo, kad valstybin se staigose informacija n ra sklandžiai teikiama, dažniau nutylima nei ja pasidalijama.

Itin dom s tyrimo rezultatai, jog šeimos siek gauti informacijos iš kit t v vietoj kreipimosi socialin darbuotoj .

Šeimos ši informacin socialini darbuotoj funkcij gyvendino pa ios (4). Šeim teigimu, socialinio darbuotojo pagrindin veikla tur t vykti su tais žmon mis, kuriems reikia pagalbos. Viena šeima (001) pamin jo, kad *jei socialinis sektorius b t stiprus, turb t t vai taip dažnai nebendraut* . Šeimos man , jog nevyriausybin s organizacijos buvo kurtos bendriems klausimams spr sti kaip atsvara silpnai valstybinei paramos sistemai.

Kita pirmo lygmens subkategorija, kai taikomas darbo modelis, apib dinamas kaip *joks* (8). Šeimos 001 atvejis: *Visos tos socialin s pašalpos buvo suorganizuotos m s neurolog s <...>*. Šis darbo modelis pamin tas šeim , kurios teig , jog niekada nesutiko socialinio darbuotojo arba beveik nieko apie š specialist negal jo pasakyti.

Modelis *tau reikia* (9) buvo reprezentuojamas beveik vis tyrime dalyvavusi šeim , net jei socialinis darbuotojas ir nebuvo sutiktas. Šeimos pasakojo, jog taikomas modelis *tau reikia* ver ia šeim as jaustis esant nuolatinio maldavimo ar skolos situacijoje (3). Šeimos 001 atvejis: *Tikrai b t puiku tur ti kažkok žmog , kuris pasakyt , jog mes turime teis tai ir tai <...>, priešingu atveju tu nežinai.*

Tyrimo rezultatai parod , jog *tau reikia* modelis pareigoja šeim as nuolat ieškoti informacijos iš vis manom šaltini . Šeimos pasijuto izoliuotos, nes vis laisv laik turi skirti naujai priimt statym paieškai ir analizei.

Šeim subjektyvios nuomon s apie socialinius darbuotojus atskleid , kad jie nevertinami, kaip turintys *ekspertiz s geb jim* . Taip pat, jog jie n ra stipr s profesionalai, galintys tiek pat pad ti, kiek kit sektori profesionalai. Nuomoni analiz parod , kad socialinio sektoriaus darbo

modelis remiasi pa i šeim iniciatyva. Šeimos pateik situacij , kuriose jos tur jo atlikti tarpininko vaidmen tarp vaiko ir specialist .

Intervencijos rezultatas

Intervencijos rezultatas buvo išskirtas tokias pirmo lygmens subkategorijas: **dalijimasis informacija, netenkinantis ir ret susitikim** .

Rezultatas kaip **dalijimasis informacija** (9) buvo reprezentuojamas beveik vis šeim . Tai reišk , jog, nepaisant šeim poži rio socialin darbuotoj kaip svarbiausi specialist – informacijos teik j , šeimos dažniausiai pasakojo, kad informacija jas pasiekia iš kit t v . V liau ši informacij šeimos tikrina socialin s paramos skyriuose.

Šeim teigimu, kitos šeimos, auginan ios vyresnius vaikus, yra labai svarbus paramos ir informavimo šaltinis, nes joms teko susidurti su panašiais sunkumais (3).

Kita pirmo lygmens subkategorija buvo vardyta kaip **nepatenkinamas** (10) rezultatas. Šeimos 004 atvejis: *Visos priemon s tokiems vaikams yra labai brangios. Mes negalime j sigyti. Kai kurias iš priemoni galima naudoti tik vaik darželyje.*

Šeim supratimu, socialini lengvat schema, vienodai taikoma visoms šeimoms, yra netinkama, nes jos sukuria nelygyb tarp vaik . J teigimu, vaikai yra itin skirtingi, tod l *bendra formul* negali b ti taikoma.

Šis tyrimas atskleid , jog t vai suvokia socialines paslaugas kaip pernelyg nespecializuotas, tod l neatliepian ias individuali vaik poreiki . Kai kurios šeimos pasakojo, kad j vaikai negal jo nei pasinaudoti statym numatytais resursais, nei gauti individualias paslaugas.

Dauguma šeim min jo, jog dažniausias valstybin s paramos rezultatas yra šeimos palikimas b doje. Šeimos 009 atvejis: *Aš nor iau pasakyti, kad socialin s paramos skyrius gal t atsi sti broši r , juk jie mus paž sta <...> jei kei iasi statymas.*

Pirmo lygmens subkategorija, kai rezultatas suvokiamas kaip **reti susitikimai** (6), paaiškino daugel šeim išsakyt problem . Šie reti susitikimai vardyti kaip inicijuojami tiek pa i šeim , tiek ir specialist .

Šeim nuomon s apie socialin darbuotoj Lietuvoje buvo siejamos su trumpalaik informacine pagalba. Šeimos nepasakojo apie ilg laik juos pasiekiam pagalb ar socialinius darbuotojus kaip atvejo vadovus. Socialiniai darbuotojai buvo matomi kaip svarb s specialistai, kurie gal t gyvendinti daugel statymais nustatyt veikl , ta iau šeim pamin ti kontaktai su šiais

specialistais buvo tiek reti, jog šeimos vargiai gal jo juos apskritai prisiminti.

Apibendrinimas

Šeim subjektyvios nuomon s apie valstybin paramos sistem tyrimas atskleid , jog, joms susid rus su sunkumais, parama vertinama kaip nepakankama. Šeim nuomone, ryšiai tarp medicinos, švietimo ir socialinio sektori yra silpni, lengvai pažeidžiami. Kiekvienas sektorius buvo matomas grei iau kaip veikiantis pavieniui nei priklausantis sistemai. Šeimos pateik „savo“ b d , kaip bendrauja šiuose sektoriuose – prisirišant prie „savo“ specialisto. D l šios priežasties, užuot ieškojusios ir kit specialist konsultacijos, šeimos labiau linkusios lankytis pas vienintel „savo“ specialist , nes taip „saugiau“.

Nebuvo tik tasi, kad tyrime paaišk s toks svarbus dalykas, jog kai kurios šeimos niekada nesutiko socialini darbuotoj . Dar daugiau – socialinio sektoriaus interviu r m si šeim sivaizdavimu *kas, jei socialinis darbuotojas b t* . Šeimos pasakojo, kad sistemoje egzistuoja poreikis atstovauti vaiko interesams. Šeimos nemin jo socialinio darbuotojo kaip svarbiausio sistemos profesionalo, ta iau, remiantis j sivaizdavimu, tarpininkavimo funkcijos, vadovavimas atvejui ir palaikymas sunkioje situacijoje gal t b ti socialinio darbuotojo veiklos sfera.

Tyrimo rezultatai atskleid , kad socialinio darbuotojo nebuvim sistemoje šeimos suvokia kaip šeimos suskaldym vaik , turint negal , ir mam , kovojan i d l vaiko interes . Goffman, Jones ir kt. (cit. Carter ir Feld, 2004) tok fenomen apib dina kaip neigiam socialin d mesingum .

Atskleisti tyrimo duomenys kelia r pest d l šeim siekio apibendrinti savo išgyvenimus – bent kart išgyvenusios neigiam patirt , jos pasakoja bendr ja prasme, jog visas sektorius yra blogas (ypa tai stipriai buvo išreikšta kalbant apie medicinos sektori). Taip pat ir šeim pasisakymai, jog jos netiki egzistuojan ios situacijos pager jimu ateityje.

Dauguma šeim nuomoni buvo pozityvios kalbant apie švietimo sistemos personal . Labiausiai patenkintos buvo tos šeimos, kuri vaikai lanko integruotas klases kartu su „sveikaisiais“. Esmin problema, kuri min jo šeimos – tai tinkamos mokyklos su inkliuzine aplinka suradimas. Šeimos teig , kad pedagogin je sistemoje svarbiausia – motyvuotas personalas. Remiantis šeim nuomon mis, darbuotojai suvokiami kaip pats svarbiausias paramos faktorius, kuris net padeda nepasteb ti nepritaikytos mokyklos aplinkos. Taip pat šeimos priskiria personalui vaiko *saugios nišos* k r jo vaidmen .

Lyginant su kitais sektoriais, pedagoginis buvo matomas kaip atviriausias bendradarbiavimui.

Nuomoni analizė parodė, jog socialinio darbo praktinė veikla šeimos supranta kaip labai siaurą ir neefektyvią. Dauguma subjektyvių nuomonių atskleidė, jog socialinė parama sistemoje dažniau teikiama kitam specialistui: gydytojui, kineziterapeutui, pedagogui. Prie šių specialistų šeimos linkusios prisirišti.

Kalbama apie paramą socialiniame sektoriuje, šeimos minimos tik pavienius atvejus. Kalbant apie kitus sektorius – medicinos ir švietimo – jų poveikslas buvo aiškus, o socialinio sektoriaus joms buvo sudėtinga aiškiai sivaizduoti.

Šeimos pasakojo, jog buriasi savipagalbos ar paramos grupes socialinei pagalbai, kurios neužtikrina socialiniai darbuotojai. Todėl vienas „populiariausi“ minimali socialinio darbo modeliai buvo „iš l p l pas“ dalijantis informacija tarp šeimų.

Baigiant galima sakyti, jog šeimoms požiūriu valstybinėje sistemoje labai menkai jaučiamas suderinamumas tarp sektorių. Šeimos dažniausiai kalbėjo apie egzistuojančias problemas koordinuojant išteklius ir juos pasiekiant. Nuomonės apie socialinį darbą buvo siejamos tik su informavimu, tačiau ir jis vertintas neigiamai.

Ypatingos reikšmės socialiniam darbuotojui sistemoje šeimos nesuteikė. Dar daugiau, jos minimos sunkumus, su kuriais susiduria šeimos kalbėjo apie egzistuojantį ilgalaikį paramos poreikį. Šeimoms sivaizdavimu, socialinis darbuotojas galėtų būti specialistas, ilgą laiką palaikantis ryšius su šeima. Labiausiai šeimoms minimali specialisto poreikis iškyla lankantis medicinos sektoriuje, pavyzdžiui, svarbu, kad kas lankytų vaiką, stebėtų jo pokyčius ir atstovautų ne galumo ir darbingumo nustatymo komisijose.

Negatyviausia šeimoms nuomonė buvo apie naujai išleidžiamus statymus. Šeimos teigė nesuprantančios naujų statymų arba nežinančios, kaip juos susirasti. Šeimos pasakojo, jog jaučiasi atskirtos nuo teisinės resursų bazės. Dėl šios priežasties, kalbama apie socialinį darbuotoją, šeimos teigė, jog tarpininkavimas tarp šeimoms ir statymų būtų svarbiausia parama.

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SUBJECTIVE REPRESENTATIONS OF FAMILIES WHO HAVE A CHILD WITH SEVERE DISABILITY ON THE PLACE OF SOCIAL WORK HELP WITHIN THE LAWFUL SOCIAL SUPPORT SYSTEM

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This article reviews the representations of families who are raising children with severe disability with social worker help in the lawful support system. This system consists of medical, social and educational sectors that are organized by the government of the Republic of Lithuania. Social work has a short history in Lithuania. Therefore, the study concerns the entire lawful support system with a particular focus on social work.

The researchers are orientated towards revealing the *subjective representations of families* rather than to present *objective* results; in other words their lived experiences of receiving support. Families coping with severe disability reported that the support received was insufficient. The main problems mentioned were that there was not enough cooperation between medical, educational and social sectors. The most positively represented sector was educational and the least being within the medical sector. The educational system was represented as the most open in collaboration with families compared to other sectors. Problems mentioned in the medical sector were the negative attitudes towards “different” children, often attributing labels to them and not sharing information with their parents. Families did not give any special prominence to the social worker operating in the system. However, families represented a great need for longitudinal supervision and in this role they imagined that the most appropriate professional for such long-lasting interactions could be a social worker.

Keywords: *social work, support system, disability, family.*

Background

Two new phenomena relating to social integration were evident in Lithuania after regaining independence in 1990: social work and new disability understanding. Bu inskas (2009) writes that in this period transformations affected all areas of everyday life. These changes were not only discursive but based also on new legislation.

The main law serving as a background for changing social attitudes towards disability was *Ne gali j socialin s integracijos statymas*¹ released in 2005. This law opened new possibilities for people with disabilities. In enacting this law Lithuania approached a more interpretative paradigm in disability meaning. Disability was perceived more broadly than previously; this new perspective on disability involved not only biological but also social aspects. The new law created new terms, and portrayed a functioning system of social integration with three main constituents of a lawful support system: Medical, Social and

Educational, all being guaranteed by the state. The Ministry of Social Security and Labour² states that passing this law was a “*Legal act of our disability model conforming to European context*”³. Gudžinskien and Jurgutien (2010, p. 21) mention the most essential point of the new law was a newly evaluated disability concept and a revealing of the possibilities for people with disability.

Data from the Ministry of Social Security and Labour show that the number of children with disabilities is growing each year in Lithuania. Therefore, increasing the need for support is imperative. Research by Guscia, Harries, Kirby, Nettelbeck, and Taplin, (2006,) showed that people who suffer from multiple disabilities, need the most intensive support. Kreivinien (2007, 2011) and Vai ekauskait (2009) state that

² www.socmin.lt

³ This law was important in the creation of a longitudinal idea of social support construction. It was said that disability has to be perceived in perspective of life circle emphasizing not only treatment possibilities, but as *new level* in the context of quality of life.

¹ The Law on Social Integration of the Disabled.

support is essential as people with disabilities are more vulnerable because of social changes in society. These authors (Kreiviniene, Vaiškauskaitė, 2010) write that the situation in families where there is a disabled person is complicated; therefore, support must be orientated towards rebuilding stability and harmony.

Families caring for a disabled person are involved in meeting many specialists, but the social worker, in principle, could be the closest in providing support within this multi-professional system (Kreiviniene, 2011).

The role of the social worker from the position of families has not been investigated enough as a new phenomenon. The majority of research seeks to “objectivise” the research results in a quantitative methodology, therefore, the “subjective” or qualitative experiences of respondents remain hidden.

Foucault (quoted from Cannella, 1999) notes that for ages people with disabilities were not consulted as their representations were considered meaningless. There are very few scientific studies that analyse the views of families raising children with disabilities or of disabled people themselves into the area of lawful support systems (see Ališauskienė, 2007; Ališauskienė, Ališauskas, Gerulaitis, Melien et al., 2008; Navaitis, 2007; Skerytė-Kazlauskienė, Barkauskienė, 2010). There was little analysis of the family’s view towards the social work intervention in the system (see Butkevičienė, Majerienė, Harrison, 2006).

Research orientated towards an analysis of social work support for disabled families demonstrates that there are diverse opinions. For example, Varažinskienė (2009, 129) states that legislation regulating social work practice in a system is still developing and that social work lacks an historical background in supporting practice. Research presented by Butkevičienė, Majerienė and Harrison (2006) showed that families in disability situations face many problems from within the supporting system. Research by Makštutytė and Naujanienė (2008) revealed that social workers apply clinical models in their practice. Research made by Ivanauskienė and Varažinskienė (2007) brought to light that an understanding of the purpose of the social work profession in society is barely formed. Bitinas, Guogis, Migun and Važgytė (2010) state their research revealed many practical issues that social workers face in their practice. On the contrary,

Prakapas (2007, 14), based on an analysis of the legislative discourse, states that there have already been many positive improvements implemented in social work practice.

In developing supportive practices for families raising children with disabilities, it is crucial to be aware of both “objective” research, and also to listen to the “subjective” opinions given by families, i. e., there is a need to give voice to the families as “service users” and to represent the lawful support system including social work practice from their own perspective.

Research questions of the study:

What are families’ subjective representations on lawful support from medical, educational and social sectors?

How do families perceive support from social workers in the system?

The **aim of this study** was – to analyse the representations of families who experience situations of severe disability⁴ within lawful support focusing on social work Intervention.

Conceptualization of representations

The view on representations gives a personal character to the research aim. The main point in the empirical part was analysing the subjective representations of perceived lawful support as a social reality in the *sense of family* (quoted from Gabb, 2009, 37).

Souza-Filho and Beldarrain-Durendagui (2009, 772) write that particular goals can be used in analysing the data for e.g., revealing the need for a change in practise. An analysis of representations on lawful support is seen as *mediums of exchange and instruments of exchange* (Moscovici, quoted from Gillespie, 2008, 377) in dealing with system.

The original concept of *representation* used by Durkheim (quoted from Gillespie, 2008, 375), was expanded later to include the tradition of *social representation* by Moscovici (ibid, 375). Before Moscovici, Lévy-Bruhl (1927) presented similar ideas by speaking of “collective soul”, Vygotski (1962) was writing about collective representations, and Piaget (1932) mentioned the term of social representation (Orfali, 2002, 399).

⁴ Based on law of ministers of health, social security and labour, and education and science of the Republic of Lithuania (2005-03-23, No. Nr. V-188/A1-84/ISAK-487) of the assessing criteria and order of disability level.

In this study, the way to understand the concept of representation is closest to Gillespie's (2008) term *alternative representations*. He developed the concept whilst analysing Moscovici's concept of social representations and addressed the feature of subjectivity to the concept. On this basis, representations on lawful support are analyzed as subjective representations given by families to professionals and the support system.

Subjective representations of families are perceived as how they attribute views to professionals (in using categorization *they all, they are* etc.) and the plurality of contexts given to the lawful support content. In evaluating supporting contexts, families invoke representations of professionals' personal qualities, models of work, perceptions of the child and other qualitative aspects attributing to the subjective conceptualization.

Understanding of severe disability

There was an ethical dilemma in conceptualizing *severe disability*. The research idea was to reveal the representations of families that used medical, social and educational services; therefore one of the sampling criteria was based on the child's medical factors. (diagnosis). Viluckien (2008, 51) writes that the main problem with the shift of paradigms lies in contrasting biological and social aspects of disability.

Therefore, this study uses the term of *severe disability* as a social *construction* (Bruner, quoted from Swartz, 2009) of the concrete situation as a meaning, i.e. for this research. However defining severe disability in both social and biological aspects allows for the perception of seeing the families situation as multi-faceted.

Nowadays the majority of researchers in Lithuania similarly conceptualize *disability* (Ruškus, 2001; Kreivinien and Vai ekauskait, 2010; Ališauskas, Ališauskien, Gerulaitis, Melien, Miltenien et al., 2009 and others) – with the orientation being not only towards the medical factors, but with a broader perspective – as a construct drawn from the interaction of the person with the environment. Viluckien (2010, 116) even suggests the use of Bury's concept of *biographical disruption*, when disability causes changes that greatly impact on everyday life.

The ideas invoked by Morrow, Quine, and Craig (2006, 529) stated that children with severe

disability may encounter biological, physiological and behavioural difficulties, such as uncoordinated swallowing, gastro-oesophageal reflux and chronic lung diseases which may lead to a significant morbidity and mortality. Additionally disability was posited as an interpretative understanding and regarded as an interaction between a person with disability and their environment (Ruškus, 2001). Such representations open the possibility to approach the "true subjective sense of the family's view" towards the lawful support system.

Sampling the respondents

Ten families⁵ raising children with cerebral palsy were sampled for this research. As far as the Law on Social Integration of the Disabled (2005) sees support via social, medical and educational sectors, the selection was based on the following criteria:

- Family raising a child with cerebral palsy (families with children suffering from complex disability).
- Age of child from 4–15 years.
- Full family: mother, father and at least two children. One child suffers from cerebral palsy, the second and following children do not have a disability. The approach of having the *full family* was formed in order to have as homogenous group as possible.
- Child with disability attends educational institution.

Research process and data analysis

Empirical data were gathered through semi-structured in-depth qualitative interviews with families. Each interview lasted from one hour to three; four of the families were met repeatedly in order to gather additional results. Families were coded giving a number from 001 to 010. Interviews were conducted with each family every two weeks. The themes of the interviews embraced three sectors of a system: medical, social, and educational. In interviews, families were asked to speak freely about all dimensions of the support system.

Rigorous qualitative content analysis was applied to the empirical data. Open coding was used. Elo and Kyngäs (2008, 109) describe open

⁵ The respondents were from the following cities: Biržai, Elektrai, Klaipėda, Palanga, Kaunas, Mažeikiai, Vilkaviškis, Plungė, Kupiškis and Telšiai.

coding as putting notes and headings in the text while reading it. Later headings were systemized into categories. The researcher made notes on the ideas and themes mentioned by the families after each interview. These were newly discussed with the family in the days following and categories were constructed.

It was decided not to achieve an *uncoloured* content analysis with *naked words* that can lose the whole picture of the experienced phenomena (Angelique and Culley; Brabant and Mooney; Krippendorff; Milburn, Carney and Martinez, all quoted from Baker and Stahl, 2004). Therefore phrases given by the families were analysed as to their meanings. Such a *phrasal*

analysis was more beneficial to get the picture of the lawful support schema in Lithuania as represented by the families. Phrases were counted and the number was given in brackets (for example (5) shows the number of cases that had similar experiences or even used the same words).

Participants were involved in constructing categories, subcategories and first-level subcategories. First level subcategories of the research were subsumed into subcategories: professionals, representations towards the child, applied model of work, and result of intervention. Families constructed subcategories to medical, educational and social categories (see Table).

Table

Empirical data analysis branches in categories of medical, educational, and social sectors

| Subcategories | First level subcategories of medical sector | First level subcategories of educational sector | First level subcategories of social sector |
|---|---|---|--|
| Support providers: professionals | cold-blooded | supportive | misunderstanding (but helping) |
| | passive neglecters | | |
| | chemical interventors | not-satisfying | Title |
| | side takers | methodologists | Professionals |
| Support providing: attitude towards child | labelling | orientated towards the child's strength | Empathic |
| | experimental | | |
| | unequal equality | orientated towards the child's weakness | Burden |
| | adjusting | as burden | expecting poor |
| Support providing: applied model of work | supportive | individual | red taping |
| | puzzled | | Informational |
| | limitations | | None |
| | clear medical | | "you need" (needy) |
| | other | | |
| Support providing: result of intervention | positive | seen as development of child | word of mouth |
| | negative | | not-satisfactory |
| | neutral | limited representation | rare meetings |

Research credibility

Kimberlin and Winterstein (2008) mention that credibility can be constructed by researchers and grounded in descriptions. Research credibility was constructed on the researchers' decision on:

- **Sampling the respondents.** Families were gathered very carefully taking into account all mentioned criteria: similarities of their social situations, the child's diagnosis, social participation of the child.
- **Participation of families.** Habermas (quoted from Moilanen, 2000, 384) writes that in gathering feedback it is meaningful to

construct unforced dialogue so that participants can evaluate and strengthen their arguments. Therefore, after each interview there were a few organized additional meetings with each family in order to ascertain their "true meaning" and they participated in creating categories.

Research results

The research results will be presented for each sector of the system individually (categories): medical, educational and social. These categories are analysed through four subcategories: representations of professionals, representations of professionals towards the child,

applied model of work and the result of the intervention.

Lawful support provided by medical sector Medics

Describing *medics*, families shared first level subcategories: ***cold-blooded***, ***passive neglecters***, ***chemical interventors***, ***side takers***.

The common feature of all the families participating in the interviews pointed towards specific medical *personalities* who were working in particular institutions. Families tended to create a generally-negative representation of the whole medical sector. Medical professionals described as ***cold-blooded*** (5) were mentioned by half of the families.

A very similar first level subcategory was raised picturing medics as ***passive neglecters*** (3). Families represented medics as having no empathy in understanding special needs. Also families pointed to the experienced exclusion just because they were in a hospital with a *different* child. In the case of family 007 they recalled that: *Medics seeing a disabled child would tend to neglect them.*

Medics as ***chemical interventors*** (8) occurred in almost all families. This first level subcategory portrayed all medics as suggesting that the only means for improving the situation was to take drugs. Families represented that a child's disability is incurable and a child must be accepted as a personality with a disability. Family number 004 stated: *As much as we met doctors, they suggested only chemical interventions.* Family number 010 said: *We do not acknowledge chemical treatment.* All parents mentioned they were afraid of *chemical intervention* because they had previous unsuccessful experiences.

The first level subcategory of medics as ***side takers*** (9) reflected the understanding of families that during each contact the medic seemed to be taking someone's side. For example, doctors tend to stress the responsibility of the parents. Family number 007 mention that: *The doctor said I CAN prescribe if YOU want it <...>. Such sayings terrorized me... If I WANT IT – I am not a medic...*

Attitude towards the child

The *attitude towards the child* was split into the first level subcategories: ***labelling***, ***experimental***, ***unequal equality***, and ***adjusting***.

The attitude towards the child as ***labelling*** (10) was illustrated by Family number 010: *We felt discarded there...absolutely.* Labelling was not only put on the child. Families mentioned that the attitude towards a child inherently spread to the whole family - that *the whole family were disabled*. So, when parents were saying how the doctor observed the child, they quite commonly used the word *we* instead of *he*, *she* as if the whole family experienced the common stereotyping label leading to neglect.

Families were greatly disappointed by meeting an ***experimental attitude*** (5) from professionals. Instead of receiving advice they felt as if they were participating in an experiment. Family number 010 stated: *The child was in the role of an experimental guinea-pig <...> various medical trials caused crippled legs <...> and the disintegration of teeth.*

The ***unequal equality*** due to families means facing indifferent medics. Families represented that medics, being members of a disability commission, tend to demonstrate high power relationships over their patients. Family number 003 said: *When we come to get the invalidity <...> we have to be prepared for disregard, waiting, and sitting...*

The end of first level subcategory was ***adjusting*** (6). Family number 007 mentioned about the doctor's words: *"Mother, don't give your child's diagnosis prominence, nothing can be changed now be happy he is in such a family" <...> I think the doctor meant not in an asocial family <...> and that I must sit and watch his death-throes.* The family was saying that the doctor represented the dying child as some *thing* that can be replaced.

Applied model of work

The *applied model of work* was shared into the first level subcategories: ***supportive***, ***puzzled***, ***limitations***, ***clear medical***, and ***other***.

The ***supportive*** model (3) was described by families as facing a concrete doctor with the following features: experienced specialist, and open to collaboration with parents. The best doctors were named as those who gave the family space but were able, in critical situations, to provide expert help if required. Speaking about the supportive model, some of the families noted that the effort given by professionals far outweighed the final result and had more importance for them. Family number 010 said: *I*

talk with and consult with my neurologist. She accepts that I read up on and care about the drugs. She by no means trusts me and knows that I am observing my child.

The Puzzled model (9) was represented in speaking of treatment that was not understood by the families, organized inefficiently, or not understood by doctors themselves. The families pointed out that there cannot be any more considerable heartbreak than seeing their own child severely sick. *Mothers* were speaking of their feelings of hopelessness occurring in situations when they saw that the doctors were puzzled and didn't understanding what treatment to apply.

Another first level subcategory was called the **limitations** model (10). This model is very closely related to the expressed doctor's representation towards the child. All families mentioned this model's prevalence. In Family number 008: For example *if a doctor does not have the dimensional perception that a child is too long for the bed and yet <...> we slept together with a child in such small beds for two nights.* The mother felt that she was treated also like a child as a deprived person just because of the severe disability of her child.

Another first level subcategory represented by families was the **clear medical** (9) model. This model should not be mixed up with the clinical-corrective model having negative features. On the contrary, the majority of families saw this as a positive way of working.

Families were satisfied with meeting sophisticated experts who shared information with them. Families highly *evaluated* doctors who conceived their complicated situations and who made all necessary arrangements to help them and their child: *wrote all needed papers.*

The medical model called **other** (10) was described as: insensitive, bribery-required, initiated by parents. Family number 008 stated that: *Treatment is organized from the ceiling <...> in the same way that disability is diagnosed.* Families expressed the view that a diagnosis of *severe disability* overshadows any other health problems. Doctors were represented as insensitive as they did not take into account the essential parental expert knowledge about a child's condition.

Result of intervention

The *result of intervention* was split into first level subcategories: **positive**, **negative** and **neutral**.

Families who represented interventions as delivering a **positive result** (8) were more often using the words *our doctor* or were speaking about a particular clinic or sanatorium where successful interventions had been made.

A **Negative result** (7) of interventions was also mentioned by the majority of families. Treatment was represented as negative when families met within an unfriendly environment in medical institutions where they experienced a shocking lack of communication, poor supervision and disrespectfulness.

Interventions as a **neutral result** (4) were mentioned by about half of the families. A neutral result was related to a family's point of view that they could not define the result achieved in one or another institution. Family number 002 said: *It is difficult to say... he is a bit different, a bit stronger, can hold his head a bit... understand... we think he understands.*

Lawful support provided by educational sector Educators

Whilst analysing the lawful support in the education sector, the *educators* were split into first level subcategories: **supportive educators**, **non-satisfying educators** and **educators as methodologists**.

A definition of the **supportive** (8) educator was mainly based on the representations describing professionals who were capable of creating a *safety niche* for children. Families conceived how it is complicated for an educator to work with a child. Therefore they highly valued educators were able to make the child happy in the school environment. Families said they were orientated towards creating trustful relationships with educators.

A totally different situation was found if the educator was represented as **non-satisfying** (4). Family number 002 said: *I am not very satisfied with the nurse <...> she always complains when the child has dirtied his nappies and says they don't have time to change them.*

Educators as **methodologists** (4) were described by nearly half of the families. If in the medical sector information was the main supportive mechanism, then in the educational sector information on methodology was the least

important thing for families. Family number 003 stated: *I go there, communicate, stay <...> I show the teachers how I calm her down, persuade her to do an activity, and show the teachers what activity could be organized for her.*

Families perceived the education sector as *safer* if the educator was working on the child's life skills development. If the educator was perceived as communicative and willing to share information with parents, they were highly valued. The same assessment was noticed if the educator tried to collaborate with or asked the parents' opinion.

Attitude towards the child

The *attitude towards the child* was split into first level subcategories: ***orientated towards the child's strength***, ***orientated towards the child's weakness***, and ***burden***.

Despite severe disability when educators use the ***attitude as orientated towards the child's strength*** (5) families said they tend to *forget* about the diagnosis and limitations and focus on the child's strengths. Family number 007 noted: *They tell me that my child, is orientated, communicative <...> other children like him very much <...>. No problems, no tears.*

Families heard appraisal in the words of the educators: *see what a socialised child you are raising, everybody likes him.* The biggest fear for parents was to see the child alone and neglected. Therefore, when educators gave an evaluation that a child's status, despite his/her disability, is closer to *normality* than to *invalidity*, parents felt relief and realised – the child is developing.

Carpenter (2005, 180) writes that such inclusive strategies help family members to feel involved, acknowledged and valued.

Families also represented the opposite perceptions – ***orientated towards the child's weakness*** (4). Instead of supporting the family and organizing an individual education programme fitting this child's capabilities, educators *take responsibility to share* what best could be done in their situation. Family number 003 said: *The head of the kindergarten suggested I withdraw the child.*

An attitude towards a child as a ***burden*** (3) was mentioned by one third of families. Family number 003 mentioned: *They got the jitters from my daughter as she is too severe...* McLaughlin *et al.*, (2006) write about such a labelling process existing in many countries in the

educational sphere. The most important point is that labelling unfortunately leads to attaching negative stereotypes, expectations and exclusion.

Applied model of work

Due to representations given by families, *model of work* was apportioned only one - the ***individual*** (9). Kluth, Biklen, English-Sand, and Smukler (2007) write that quite often even inclusive education is faced with a range of obstacles, including educational segregation, inappropriate curricula, lack of appropriate support and services, and social rejections.

Almost all the families mentioned the uniqueness of their children, therefore a need for an individual model emerges (9). However, three families mentioned that sometimes individuality means segregation. Family number 006 said: *The government began teaching her sign language after my writing <...> so I can say we started to communicate with the child only when she started to go to school.*

The family spoke of the situation when having the only child with hearing problems in a small city means the child needs an individual learning programme in order to communicate in everyday life. The problem mentioned by parents was that there was no specialist who could teach a child and other family members. That meant up until the child was seven or eight years the family had to invent their own *communication signs*.

Result of intervention

The *result of intervention* was split into first level subcategories: ***development*** and ***limited representation***. When the result was perceived as a constant development, families expressed satisfaction with educators and the institution. When the result was developed on a limited representation towards the person with disabilities, it cumulated in more stress for families and created a sense of dissatisfaction.

The result of longitudinal interventions by educators was very important for parents. Seeing the ***developmental results*** (4) families mentioned a few of the main aspects as: inclusion, increased the child's abilities, and self-sufficiency. Family number 004 stated: *The last year that he spent in normal school; he was one among healthy children so the unbelievable jump forward is clearly seen.*

When the result was perceived as ***limited representation*** (3) to the person with disability it

was perceived as closing all doors for development. Families mentioned that in visiting educational institutions such cases were expected to fail. Family number 003 mentioned: *At the age of seven she had to go to school. The situation is dramatic and complicated.* This family didn't have the possibility to take the child to a school 200 kilometres away from home, therefore the situation of seeking education they called *complicated* and *dramatic*.

Lawful support provided by social sector

Social workers

This part of the research was absolutely not expected in its results. Families raising children with severe disability should have met a social worker during the 5–14 years of seeking help. However it was a great surprise when during the interviews almost all families said that they never met with a social worker. Some of the families could not explain what sphere of specialist s/he should be (3), and it was astonishing to hear that a social worker is a *specialist* who entertains (3) parents with some activities when there is *nothing to do*.

The *social workers* were split into the following first level subcategories: *misunderstanding* (but helping), *title*, and *professional*.

The social worker as *misunderstanding* (3) was mentioned by families who were confused in giving a picture of social workers they had met. Constructing the social worker's image, some of the families did not know what a social worker was, therefore, were often confused describing the social workers, and the descriptions clearly showed that families are speaking about a *social worker* who is definitely not a social worker. Family number 002 said: *Good workers. Come to do massage from the third floor to the first <...> really devoted to work.*

When families did not know how to describe the social worker, they started to recount general ideas, like a social worker *does something*, but we *don't know what*.

A social worker was described as only a *title* (8) due to the representations by families. They described the situation that they had never met a social worker and could not say for what this specialist was needed.

Another interesting finding in this research was that the majority of the families mentioned that they had never met a social worker, but later speaking of sanatoriums some of

them were describing the social worker. It shows that families did not see the social worker as a support provider. Two family cases gave representations of an unprofessional social worker. Family number 006 said: *When there is nothing to do, we go to the social worker and drink coffee.*

Families perceived the social worker's role simplified to coffee drinking or *chatting*. Therefore families represented the social worker as some kind of general specialist, a person with whom you can spend your spare time in the sanatorium and nothing more. Families did not even expect any lawful support. Such ideas seemed impossible for families to understand. The social worker was perceived too simply, as if for creating just friendship relationships. For this reason the social worker was perceived as a weak specialist.

Social sphere workers as *professionals* (10) were named as social workers and specialists who took care of disability affairs in governmental or nongovernmental institutions. Professionals who came together and worked in NGO's were evaluated positively, however the governmental sector were valued negatively. Of governmental organizations, families mentioned the general representation that the system does not take care of *such* families.

Attitude towards the child

First level subcategory *attitude towards the child* was split due to the representations given by families: *empathic*, *burden*, *expecting poor*. In all the lawful support systems the same attitude towards the child as a burden was repeatedly indicated.

Two families mentioned examples that were categorized into the *empathic* (2) attitude towards the child. One family mentioned that an empathic view was applied not only for the child, but supportively for the whole family. Family number 007 said: *The social worker taught me how to love from the heart, have a wish, and delve deeply into myself and not to give up on the child). Just fight, fight and everything will be okay.*

An empathic attitude was perceived if the social worker *understood* how difficult the situation was and gave a professional consultation demonstrating their view towards the child – *not to leave*.

The attitude of a child being perceived as a *burden* (9) was met by almost all the families. It had a direct relationship with the next

representation where not only the child, but rather the whole family was perceived as having an expectation of poor support.

Families said they met these attitudes in governmental institutions. A child was perceived as a burden putting his/her family into a beggar's position. Families said that wheelchairs were not adapted for special needs therefore; families felt they had to rely on charity from abroad or construct the wheelchairs themselves.

There was an attitude towards the whole family as *expecting poor results* (7) and this was also met in governmental institutions. Family number 001: *We got twice as much money when she stayed at home with me. Now she's started to go to school, so they cut the allowance by half because I don't keep her at home.* Such examples show that there is an expectation from government that *mothers* should stay at home with the child.

Families thought that attitudes towards the child in the social sector were more unsupportive than helpful. The majority of families indicated that lawful support was essential but that they faced difficulties in getting this because they felt as if they were raising additional problems for specialists by asking for some benefits.

Applied model of work

The *applied model of work* was split into four first level subcategories: *red taping*, *informational*, *none*, and *you need*.

The *red taping* (2) model contained representations by families describing some documents that the social worker was constantly filling in. Families thought that such red tape caused delays in accessing lawful support because the social worker needed more information about the child. It transpired that social workers were using their position in order to conduct surveys or for other purposes, but definitely not for accessing support for the child on the basis of the information gathered.

The *informational model* (5) was mentioned by all the families who said they had met a social worker or could describe this professional. Families said that the information model can hold both positive and negative aspects. In some cases families described the social worker as a passive agent giving answers and showing no initiative him/herself. It was quite common practise for families to organise themselves according to the *informational* model in mutual help groups. Authors Mitchell and Sloper (2002,

74) write that recent research shows families feel that governmental institutions are more likely to withhold information than to share it.

A fascinating finding in this research was to find that families tend to look for information amongst other families instead of asking a professional social worker. Families tended to implement the informational role of social workers themselves (4). Families reflected that the main role of the social worker was to provide help for those who need it. One family mentioned (number 001) that *if the social sector were strong, perhaps parents wouldn't communicate so often.* It shows that the family thinks that the weakness of the lawful support system forced them to meet parents in NGO's and deal with their questions together.

Another first level subcategory of the used model was *none* (8). Family number 001 stated: *All social benefits were arranged by our neurologist <...>.* Such a model was described when families could not say anything about the social worker's model or that they had never met him/her.

The model: *you need* (9) was represented by the majority of families, even if they did not meet the social workers. The *you need* model makes families feel as if they are always begging for something or are always in debt. Family number 001 (3): *It would be really great to have some person who would say that you have rights for this and this <...> otherwise you don't know.*

The research results showed that the *you need* model made families seek information from all possible sources. Families felt deprived in their situation and had to spend all their spare time in analysing new laws.

Representations by families showed that social workers were not recognised as having any *expertise* in making social assessments, and they were not in a strong position to contribute on an equal basis with other professionals. Representations showed that families saw the model of organized help only on the basis of parental activity. Families spoke of situations where they had to mediate between the child and professionals in institutions.

Result of intervention

The *result of intervention* was split into first level subcategories: *word of mouth*, *not-satisfactory* and *rare meetings*.

The *word of mouth* (9) was mentioned by almost all families. It means that despite almost all families having seen the main role of the social worker as a provider of information, families said they gained all the information they needed from other parents and then checked it in social care departments. Families said that self-help groups were mainly responsible for *filling in the gaps* of socially desolate families.

Other families raising older children were seen as the most important source of useful information because they had struggled with the same challenges (3).

Another first level subcategory was formulated as *unsatisfactory* (10) result. Family number 004 said: *All tools needed for such children are very expensive and we cannot afford to buy them. Some of the tools are available to use only in kindergartens.*

Families saw that the system of benefits was inequitable and created an unequal situation for each child. Children were unique and there cannot be a *general formula* for making them equal.

This research revealed that general services were perceived as too general not responsive to individual cases of children with particular severe disabilities. Some of the children used neither the general guaranteed resources nor had the possibility to get individual service.

The majority of families mentioned that more often the results of their efforts were that they were left alone in their struggle. Family number 009: *I would say that social care could send a brochure as they know about us... if the law was changed.*

The first level subcategory describing the results as *rare meetings* (6) covered some of the issues already reviewed by families. Rare meetings were supported by families, specialists or circumstances.

Families represented the idea that social work in Lithuania is seen as short-term information providing. They did not see any longitudinal supervision, or case management. Social workers were perceived as essential specialists that could implement many practises of lawful support, but the meetings were so rare that for some families it was challenging to remember these specialists.

Summing-up

The subjective representations of families in discussing lawful support were described as insufficient. It was reported that cooperation between medical, educational and social sectors is fragile. Each sector seemed to function separately rather than as a one system. The families subjective way of dealing within the sectors was to make an attachment to “their” one specialist. Therefore, instead of consulting with many professionals they preferred to visit “their” specialist with whom they felt “safe”.

The unexpected, and significant, result was that some of the families never met social workers. Consequently the responses were constructed around families’ ideas about *what if there was a social worker*. Families said that they needed in a system to stand up for their children’s rights. Families did not mention a social worker as a key professional in a system but saw them as having functions of mediation, of being able to lead the case and give support when dealing with issues. These were the roles parents ascribed to a social worker.

The research results showed that in the absence of a social worker in the system the family can be divided often leaving the mother to fight for her child’s rights Goffman and Jones *et al.*, (quoted from Carter and Feld, 2004) describe similar phenomena relating to the negative side of social concerns.

The results raised great concerns about how through just one unfavourable contact within the social support sector it is possible to make generalizations (especially those strongly reflected when speaking of the medical sector). It was also discerned that families would tend to believe that this situation would never change.

The majority of representations showed that families were satisfied with the personnel within the educational system. The most satisfied families were those whose children were attending integrated classrooms together with non-disabled children. Considerable problems occurred in finding a proper educational facility with an inclusive environment. The most important aspect of the educational system was staff motivation. Families represented personnel as the most supportive and meaningful factor in subduing unfriendly environmental factors. Also families saw personnel as the most important factor in the construction of a safety niche for the child. The educational system was represented as the most

open in collaboration with families compared to other sectors.

Representations revealed that families perceived social work practices as very narrow and unlikely to be helpful. The majority of representations showed that social support is more often performed by other professionals: medical, physiotherapist, educator in a system. Families tend to attach themselves to these professionals.

In representing the social work sector families spoke of isolated cases of support. Where the picture of the medical and educational sectors were clear, the social sector as not clear. The research results showed that families represented themselves or other parental support as a substitute system of care for social work. Therefore, the most "popular" social work model as represented was by word of mouth, sharing information among families who had disabled children.

To conclude, families feel a great lack of compatibility within a lawful support system. Families spoke of being puzzled when dealing with and coordinating resource access. Their description of social work was connected with

information providing, but even this access was evaluated negatively.

Families did not give any special prominence to social worker in the support system. Instead, they spoke of the main issues that they faced. First of all, families represented the great need for longitudinal supervision. Families imagined that such a professional in long-lasting interactions could be a social worker. Their greatest need for a care-taking person for the family was represented as a medical professional , for e.g., visiting and checking the child's achievements, mediating with the disability commission.

The most negative representations were expressed in their lack of awareness of new legislation and their inability to understand existing legislation.. Families felt they were deprived in accessing and receiving their lawful resources. Therefore, families constructed the need for a social worker to mediate on their behalf between the law and themselves.

**References attached to the original paper
(pp. 40–41)**

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