

# 1 障害者総合支援法の対象疾病一覧（332疾病）

血液系疾病	代謝系疾病	
24 遺伝性鉄芽球性貧血	10 アミロイドーシス	147 シュワルツ・ヤンベル症候群
92 血栓性血小板減少性紫斑病	17 イソ吉草酸血症	148 徐波睡眠期持続性棘徐波を示すてんかん性 脳症
99 原発性免疫不全症候群	28 ウィルソン病	149 神経細胞移動異常症
113 後天性赤芽球癆	55 ガラクトース・1-リン酸ウリジルトランスフェラーゼ欠損症	150 神経軸索スフェロイド形成を伴う遺伝性びまん性白質脳症
119 骨髄異形成症候群	57 肝型糖原病	152 神経フェリチン症
120 骨髄線維症	77 筋型糖原病	153 神経有棘赤血球症
127 再生不良性貧血	83 グルコーストランスポーター1欠損症	154 進行性核上性麻痺
139 自己免疫性溶血性貧血	84 グルタル酸血症1型	156 進行性多巣性白質脳症
179 先天性赤血球形成異常性貧血	85 グルタル酸血症2型	159 スタージ・ウェーバー症候群
193 ダイヤモンド・ブラックファン貧血	96 原発性高脂血症	165 正常圧水頭症
222 特発性血小板減少性紫斑病	110 高チロシン血症1型	168 脊髄空洞症
267 ファンconi貧血	111 高チロシン血症2型	169 脊髄小脳変性症(多系統萎縮症を除く。)
282 ヘパリン起因性血小板減少症	112 高チロシン血症3型	170 脊髄髄膜瘤
289 発作性夜間ヘモグロビン尿症	140 シトステロール血症	171 脊髄性筋萎縮症
	142 脂肪萎縮症	175 先天性核上性球麻痺
免疫系疾病	186 先天性葉酸吸収不全	177 先天性筋無力症候群
4 IgG4関連疾病	204 タンジール病	180 先天性大脳白質形成不全症
51 家族性地中海熱	235 尿素サイクル異常症	184 先天性ミオパチー
53 化膿性無菌性関節炎・壊疽性膿皮症・アクネ症候群	237 脳髄黄色腫症	185 先天性無痛無汗症
60 関節リウマチ	269 フェニルケトン尿症	187 前頭側頭葉変性症
71 巨細胞性動脈炎	270 複合カルボキシラーゼ欠損症	188 早期ミオクローニ-脳症
80 クリオピリン関連周期熱症候群	272 副腎白質ジストロフィー	195 大脳皮質基底核変性症
91 結節性多発動脈炎	277 プロピオン酸血症	198 多系統萎縮症
101 顕微鏡的多発血管炎	283 ヘモクロマトーシス	201 多発性硬化症/視神経脊髄炎
102 高IgD症候群	290 ポルフィリン症	218 禿頭と変形性脊椎症を伴う常染色体劣性白質脳症
104 好酸球性多発血管炎性肉芽腫症	302 無βリポタンパク血症	221 特発性基底核石灰化症
105 好酸球性副鼻腔炎	303 メーブルシロップ尿症	228 ドラベ症候群
115 抗リン脂質抗体症候群	304 メチルマロン酸血症	232 難治頭回部分発作重積型急性脳炎
129 再発性多発軟骨炎	306 メンクス病	238 脳表ヘモジエリン沈着症
134 シェーグレン症候群	319 リジン尿性蛋白不耐症	241 パーキンソン病
138 自己免疫性出血病XIII	327 レシチンコレステロールアシルトランスフェラーゼ欠損症	248 ハンチントン病
166 成人スチル病		250 PCDH19関連症候群
172 全身型若年性特発性関節炎	神経・筋疾病	252 非ジストロフィー性ミオトニー症候群
173 全身性エリテマトーデス	1 アイカルティ症候群	253 皮質下梗塞と白質脳症を伴う常染色体優性 脳動脈症
197 高安動脈炎	2 アイザックス症候群	257 ビッカースタッフ脳幹脳炎
200 多発血管炎性肉芽腫症	5 亜急性硬化性全脳炎	268 封入体筋炎
215 TNF受容体関連周期性症候群	8 アトピー性脊髄炎	276 プリオン病
229 中條・西村症候群	12 有馬症候群	281 バスレムミオパチー
242 バージャー病	14 アレキサクター病	284 バリー症候群
260 皮膚筋炎/多発性筋炎	15 アンジェルマン症候群	286 ベルオキシソーム病(副腎白質ジストロフィーを除く。)
274 ブラウ症候群	21 遺伝性ジストニア	287 片側巨脳症
280 ペーチェット病	22 遺伝性周期性四肢麻痺	288 片側痙攣・片麻痺・てんかん症候群
	29 ウエスト症候群	291 マリネスコ・シェーグレン症候群
内分泌系疾病	32 ウルリッヒ病	293 慢性炎症性脱髄性多発神経炎/多巣性運動ニューロパチー
6 アジソン病	33 HTLV-1 関連脊髄症	298 ミオクローニ-欠伸てんかん
31 ウォルフラム症候群	40 遠位型ミオパチー	299 ミオクローニ-脱力発作を伴うてんかん
35 ADH分泌異常症	44 大田原症候群	300 ミトコンドリア病
50 下垂体前葉機能低下症	48 海馬硬化を伴う内側側頭葉てんかん	305 メビウス症候群
63 偽性副甲状腺機能低下症	59 環状20番染色体症候群	308 もやもや病
79 クッシング病	64 ギャロウェイ・モフト症候群	313 遊走性焦点発作を伴う乳児てんかん
108 甲状腺ホルモン不応症	65 急性壊死性脳症	315 ライソゾーム病
121 ゴナドトロピン分泌亢進症	67 球脊髄性筋萎縮症	316 ラスマッセン脳炎
167 成長ホルモン分泌亢進症	76 筋萎縮性側索硬化症	318 ランドウ・クレフナー症候群
182 先天性副腎低形成症	78 筋ジストロフィー	329 レット症候群
183 先天性副腎皮質酵素欠損症	86 クロウ・深瀬症候群	330 レノックス・ガスター症候群
211 中隔視神経形成異常症/ドモルシア症候群	89 痙攣重積型(二相性)急性脳症	
214 TSH分泌亢進症	93 限局性皮質異形成	視覚系疾病
255 ビタミンD依存性くる病/骨軟化症	97 原発性側索硬化症	7 アッシュャー症候群
271 副甲状腺機能低下症	136 自己食空胞性ミオパチー	41 円錐角膜
273 副腎皮質刺激ホルモン不応症	144 シャルコー・マリー・トゥース病	43 黄斑ジストロフィー
278 PRL分泌亢進症(高プロラクチン血症)	145 重症筋無力症	56 加齢黄斑変性
		62 眼皮膚白皮症

66	急性網膜壊死
128	サイトメガロウイルス角膜内皮炎
159	スタージ・ウェーバー症候群
285	ペルーシド角膜辺縁変性症
181	先天性風疹症候群
211	中隔視神経形成異常症/ドモルシア症候群
307	網膜色素変性症
326	レーベル遺伝性視神経症
<b>聴覚・平衡機能系疾病</b>	
7	アッシャー症候群
126	鯔耳腎症候群
181	先天性風疹症候群
209	遅発性内リンパ水腫
226	特発性両側性感音難聴
227	突発性難聴
312	優性遺伝形式をとる遺伝性難聴
320	両側性小耳症・外耳道閉鎖症
328	劣性遺伝形式をとる遺伝性難聴
<b>循環器系疾病</b>	
38	エプスタイン病
61	完全大血管転位症
72	巨大静脈奇形(頸部口腔咽頭びまん性病変)
73	巨大動脈奇形(頸部顔面又は四肢病変)
81	クリッペル・トレノネー・ウェーバー症候群
109	拘束型心筋症
130	左心低形成症候群
132	三尖弁閉鎖症
146	修正大血管転位症
157	心室中隔欠損を伴う肺動脈閉鎖症
158	心室中隔欠損を伴わない肺動脈閉鎖症
181	先天性風疹症候群
189	総動脈幹遺残症
205	単心室症
219	特発性拡張型心筋症
254	肥大型心筋症
266	ファロー四徴症
321	両大血管右室起始症
322	リンパ管腫症/ゴーム病
<b>呼吸器系疾病</b>	
75	巨大リンパ管奇形(頸部顔面病変)
131	サルコイドーシス
143	若年性肺気腫
174	先天性横隔膜ヘルニア
220	特発性間質性肺炎
243	肺静脈閉塞症/肺毛細血管腫症
244	肺動脈性肺高血圧症
245	肺胞蛋白症(自己免疫性又は先天性)
246	肺胞低換気症候群
261	びまん性汎細気管支炎
262	肥満低換気症候群
279	閉塞性細気管支炎
294	慢性血栓性肺高血圧症
317	ランゲルハンス細胞組織球症
322	リンパ管腫症/ゴーム病
323	リンパ管筋腫症
<b>消化器系疾病</b>	
23	遺伝性膵炎
49	潰瘍性大腸炎
74	巨大膀胱短小結腸腸管蠕動不全症
87	クローン病
88	クローンカイト・カナダ症候群

95	原発性硬化性胆管炎
98	原発性胆汁性肝硬変
100	顕微鏡的大腸炎
103	好酸球性消化管疾患
137	自己免疫性肝炎
190	総排泄腔遺残
191	総排泄腔外反症
207	短腸症候群
208	胆道閉鎖症
213	腸管神経節細胞僅少症
225	特発性門脈圧亢進症
234	乳幼児肝巨大血管腫
240	嚢胞性線維症
247	バッド・キアリ症候群
259	非特異性多発性小腸潰瘍症
264	ヒルシュスプルング病(全結腸型又は小腸型)
296	慢性膵炎
297	慢性特発性偽性腸閉塞症
322	リンパ管腫症/ゴーム病
<b>皮膚・結合組織疾病</b>	
36	エーラス・ダンロス症候群
45	オクシビタル・ホーン症候群
52	家族性良性慢性天疱瘡
62	眼皮膚白皮症
70	強皮症
90	結節性硬化症
94	原発性局所多汗症
125	混合性結合組織病
135	色素性乾皮症
151	神経線維腫症
160	スティーヴンス・ジョンソン症候群
176	先天性魚鱗癬
206	弾性線維性仮性黄色腫
212	中毒性表皮壊死症
217	天疱瘡
223	特発性後天性全身性無汗症
239	膿疱性乾癬
263	表皮水疱症
292	マルファン症候群
310	薬剤性過敏症候群
324	類天疱瘡(後天性表皮水疱症を含む。)
<b>骨・関節系疾病</b>	
42	黄色軟骨骨化症
69	強直性脊椎炎
107	後縦軟骨骨化症
114	広範脊柱管狭窄症
118	骨形成不全症
155	進行性骨化性線維異形成症
199	タナトフォリック骨異形成症
216	低ホスファターゼ症
224	特発性大腿骨頭壊死症
231	軟骨無形成症
249	汎発性特発性骨増殖症
256	ビタミンD抵抗性くる病/骨軟化症
295	慢性再発性多発性骨髄炎
322	リンパ管腫症/ゴーム病
332	肋骨異常を伴う先天性側弯症
<b>腎・泌尿器系疾病</b>	
3	IgA腎症
13	アルポート症候群
18	一次性ネフローゼ症候群

19	一次性膜性増殖性糸球体腎炎
58	間質性膀胱炎(ハンナ型)
64	ギャロウェイ・モワト症候群
68	急速進行性糸球体腎炎
106	抗糸球体基底膜腎炎
126	鯔耳腎症候群
141	紫斑病性腎炎
178	先天性腎性尿崩症
190	総排泄腔遺残
191	総排泄腔外反症
202	多発性嚢胞腎
258	非典型型溶血性尿毒症症候群
<b>染色体または遺伝子に由来する性染色体異常</b>	
9	アペール症候群
11	アラジール症候群
16	アントレー・ピクスラー症候群
20	1p36欠失症候群
25	VATER症候群
26	ウィーバー症候群
27	ウィリアムズ症候群
30	ウェルナー症候群
34	ATR-X症候群
37	エプスタイン症候群
39	エマヌエル症候群
46	オスラー病
47	カーニー複合
54	歌舞伎症候群
82	クルーゾン症候群
116	コケイン症候群
117	コストロ症候群
122	5p欠失症候群
123	コフィン・シリス症候群
124	コフィン・ローリー症候群
133	CFC症候群
161	スミス・マギニス症候群
163	脆弱X症候群
164	脆弱X症候群関連疾病
192	ソトス症候群
194	第14番染色体父親性ダイソミー症候群
196	ダウン症候群
203	多脾症候群
210	チャージ症候群
230	那須・ハコラ病
233	22q11.2欠失症候群
236	ヌーナン症候群
251	肥厚性皮膚骨膜炎症
265	ファイファー症候群
275	ブラダー・ウィリ症候群
301	無脾症候群
309	モワット・ウィルソン症候群
311	ヤング・シンブソン症候群
314	4p欠失症候群
325	ルビンシュタイン・テイビ症候群
331	ロスモンド・トムソン症候群
<b>クモル</b>	
162	スモン

一部の疾病については複数の疾病群に属します。  
「障害者総合支援法における障害者支援区分 難病患者に対する認定マニュアル」参考

#### IV 研究成果の刊行に関する一覧表

研究成果の刊行に関する一覧表

雑誌

発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
Fukatsu, R, Imahashi, K, Nakajima, Y, Ito, T, Horigome, M, Haruna, Y, Noda, T, Itoyama, Y	Research on Utilization of National Employment Welfare Service by Persons with Intractable Diseases in Japan.	LIFE ; International Journal of Health and Life-Sciences,		印刷中	2016

## Research on Utilization of National Employment Welfare Service by Persons with Intractable Diseases in Japan

Reiko Fukatsu<sup>a</sup>, Kumiko Imahashi<sup>a</sup>, Yasoichi Nakajima<sup>a</sup>, Tateo Ito<sup>b</sup>, Mariko Horigome<sup>c</sup>, Yuichiro Haruna<sup>d</sup>, Tatsuya Noda<sup>e</sup>, Yasuto Itoyama<sup>f</sup>

<sup>a</sup> National Rehabilitation Center for Persons with Disabilities, Namiki4-1, Tokorozawa, Saitama, Japan

<sup>b</sup> Japan Patients Association

<sup>c</sup> Tokyo Colony Welfare Corp.

<sup>d</sup> National Institute of Vocational Rehabilitation

<sup>e</sup> Nara Medical University

<sup>f</sup> International University of Health and Welfare

### Abstract

With the revision of the Services and Supports for Persons with Disabilities Act in 2013 to provide welfare service to patients with Intractable Diseases (IDs) and the enactment of a new act for these patients in 2015, employment support (ES) service for them has become an important issue in Japan because of the chronicity of many of the diseases. The objective of this research is to examine utilization of the ES welfare services, and to identify care expected from ES service providers and their current efforts. A questionnaire was mailed to every registered provider in Japan (12,483 locations). Among 6,053 respondents, 16 percent reported patients with IDs using their services, and that among them, 74 percent had a certificate of person of disabilities, which is not required under the current Act. As for the reasons for reporting non-utilization, the percentage of “absence of inquiry” was 77 percent, while that of “needed medical care,” “insufficient staff/facilities” and “lack of appropriate work” were all less than 3 percent. The result shows that dissemination of the ES service is still insufficient, and patients with IDs, their families, support providers and medical professionals need to be familiarized with the service in detail

## **Perceptions and Support Needs of Individuals with Intractable Diseases Regarding a Range of Work-Related Issues**

Kumiko Imahashi<sup>a</sup>, Reiko Fukatsu<sup>a</sup>, Yasoichi Nakajima<sup>a</sup>, Megumi Nakamura<sup>a</sup>, Tateo Ito<sup>b</sup>, Mariko Horigome<sup>c</sup>, Yuichiro Haruna<sup>d</sup>, Tatsuya Noda<sup>e</sup>, Yasuto Itoyama<sup>f</sup>

<sup>a</sup> National Rehabilitation Center for Persons with Disabilities, Namiki4-1, Tokorozawa, Saitama, Japan

<sup>b</sup> Japan Patients Association

<sup>c</sup> Tokyo Colony Welfare Corp.

<sup>d</sup> National Institute of Vocational Rehabilitation

<sup>e</sup> Nara Medical University

<sup>f</sup> International University of Health and Welfare

### Abstract

A number of persons with intractable diseases (IDs) experience work-related problems that could lead to job loss. The objective of this study is to obtain perceptions and support needs of individuals with IDs regarding a range of work-related issues. People aged 15 to 64 years old with one of 130 designated chronic diseases were invited to participate in the study. Data were collected through a self-report questionnaire. 3,000 questionnaires were mailed with assistance of patient organizations. The questions included demographic variables, family concerns, employment/supported employment, work accommodations, and other aspects of their lives. Among 889 respondents, 47 percent reported being unemployed due to fatigue and/or long-term treatment. Nearly half of the unemployed respondents reported that they had been unable to work despite their willingness to do so. Their common accommodation requests included flexible work hours, working at home and job/workplace modification. Only 30 percent knew of job training programs and supported work available for persons with disabilities. The results of the study are relevant for employees, employers and occupational health/human resource professionals. In order to promote sustainable work for persons with IDs, the issue of reasonable accommodations for them needs to be addressed in future research.

Key words: Intractable, Chronic Disease, Employment, Supported, Social Welfare



Reiko Fukatsu et al.

Special issue Vol. 1, Issue 1, pp. 172-179

## RESEARCH ON UTILIZATION OF NATIONAL EMPLOYMENT WELFARE SERVICE BY PERSONS WITH INTRACTABLE DISEASES IN JAPAN

**Reiko Fukatsu\***, Kumiko Imahashi, Yasoichi Nakajima  
*National Rehabilitation Center for Persons with Disabilities,  
Tokorozawa City, Saitama Pref. Japan, fukatsu-reiko@rehab.go.jp*

**Tateo Ito**

*Japan Patients Association, Shinjuku Ward, Tokyo, Japan*

**Mariko Horigome**

*Tokyo Colony Welfare Corp., Toshima Ward, Tokyo, Japan*

**Yuichiro Haruna**

*National Institute of Vocational Rehabilitation, Chiba City, Chiba Pref., Japan*

**Tatsuya Noda**

*Nara Medical University, Kashihara City, Nara Pref., Japan*

**Yasuto Itoyama**

*International University of Health and Welfare, Ohtawara City, Tochigi Pref., Japan*

---

### Abstract

*Abstract—With the revision of the Services and Supports for Persons with Disabilities Act in 2013 to provide welfare service to patients with Intractable Diseases (IDs) and the enactment of a new act for these patients in 2015, employment support (ES) service for them has become an important issue in Japan because of the chronicity of many of the diseases. The objective of this research is to examine utilization of the ES welfare services, and to identify care expected from ES service providers and their current efforts. A questionnaire was mailed to every registered provider in Japan (12,483 locations). Among 6,053 respondents, 16 percent reported patients with IDs using their services, and that among them, 74 percent had a certificate of person of*



*utilization, the percentage of “absence of inquiry” was 77 percent, while that of “needed medical care,” “insufficient staff/facilities” and “lack of appropriate work” were all less than 3 percent. The result shows that dissemination of the ES service is still insufficient, and patients with IDs, their families, support providers and medical professionals need to be familiarized with the service in details.*

### **Keywords**

Intractable diseases, employment support

---

## **1. Introduction**

Many of intractable diseases (IDs) have become chronic in nature in recent years because of a range of technological advances in medicine, which has made it possible for patients with these diseases to lead relatively active social life. As a result, employment support service for them has become an important issue in Japan, and in order to address this issue, IDs have been defined as a disease, cause of which has not yet been detected, for which there is no established therapy and which is chronic and poses not only financial problems, but also a heavy burden on the patients' family including potential psychological burdens (“Definition of Nanbyo,”n.d.), and 130 specific diseases (see Table 1) have been designated as IDs. Having given the status of persons with disabilities to patients with IDs by the revision of the Services and Supports for Persons with Disabilities Act (SSPDA) in 2013 (“Act for Establishment,” 2013) and enacted a new act for these patients in 2015(“Healthcare Act,”2014), their utilization of National Employment Welfare Service (NEWS) is expected to increase hereafter. Few researches on the utilization of NEWS in this area, however, have been conducted in the past. Support needs of patients with IDs and their families vary because long-term treatments are needed for many of the diseases, and patients' mental and physical functions do not remain fixed and rather undergo drastic changes. Although a comprehensive support system to ensure their life-long treatments and to support their social life has not been established yet, it is an urgent issue to propose and promote measures required to realize an inclusive society where they are able to lead a life with dignity in a community through social participation in the form of employment including one under an employment support (ES) scheme of social welfare. The objective of this research is to





examine utilization of NEWS by these patients, and to identify care expected from ES service providers and their current efforts.

**Table 1.** Representative Designated 130 Intractable Diseases by Classifications

Classifications	Representative Diseases
Blood disease:	Idiopathic thrombocytopenic purpura Myelofibrosis, etc.
Immunological disease:	Systemic lupus erythematosus Aortitis syndrome, etc.
Endocrine disease:	Syndrome of abnormal secretion of prolactin Addison's disease, etc.
Metabolic disease:	Amyloidosis Primary hyperlipidemia, etc.
Neuromuscular disease:	Spinocerebellar degeneration Moyamoya disease, etc.
Visual disease:	Retinitis pigmentosa Optic neuropathy, etc.
Auditory/ disequilibrium disease:	Idiopathic bilateral sensorineural hearing loss Ménière's disease, etc.
Circulatory disease:	Restrictive cardiomyopathy Idiopathic cardiomyopathy, etc.
Respiratory disease:	Early-onset chronic obstructive pulmonary disease Alveolar hypoventilation syndrome, etc.
Digestive disease:	Crohn's disease Ulcerative colitis, etc.
Skin and connective disease:	Neurofibromatosis Scleroderma, etc.
Bone and joint disease:	Ossification of posterior longitudinal ligament Idiopathic osteonecrosis of the femoral head, etc.
Kidney/urology disease:	Polycystickidney



	IgA nephropathy, etc.
Others:	SMON

## 2. Methods

There are three types of NEWS providers in Japan. One type is specialized in transition support for employment (TSE), and there are 2,655 of them. Another type, called Type A, is specialized in continued employment support (CES) for people who are able to work more than 19 days under a labor contract based on the Labor Contract Act (“Difference Between,”2015, February 12), and there are 1,725 of them. The last type, called Type B, is specialized in CES for those who are unable to work more than 19 days under the labor contract (“Difference Between,2015,” February 12), and there are 8,103 of them. While the use of a TSE provider is limited for two years since the main objective of the training provided there is to get employment, there is no time limitation for the use of a Type A or Type B provider. An exhaustive survey of all registered NEWS providers in Japan was conducted, and a self-reporting questionnaire, which was customized according to their specialties, was mailed to 12,483 locations. All the response data were collected at National Rehabilitation Center for Persons with Disabilities (NRCPD) to be aggregated. This research was conducted according to the ethical guidelines for epidemiology research developed and implemented on April 1st, 2002 by Health, Labour and Welfare Ministry (HLWM) and Ministry of Education, Culture, Sports, Science and Technology (MEXT) of Japan.

## 3. Results

The overall response rate to the questionnaire was approximately 50 percent, and of 6,053 responses, 960 ES service providers (148 TSE service providers, 185 Type A service providers and 625 Type B service providers), which account for 16 percent, reported the utilization by patients with IDs as of the response date. Of those users, 74 percent have been issued the disability certificate (physical disability certificate, 44 percent; intellectual disability certificate (medical rehabilitation handbook), 21 percent and mental disability certificate, 9%). 94 IDs were reported in the responses, and the diseases that were reported most frequently were

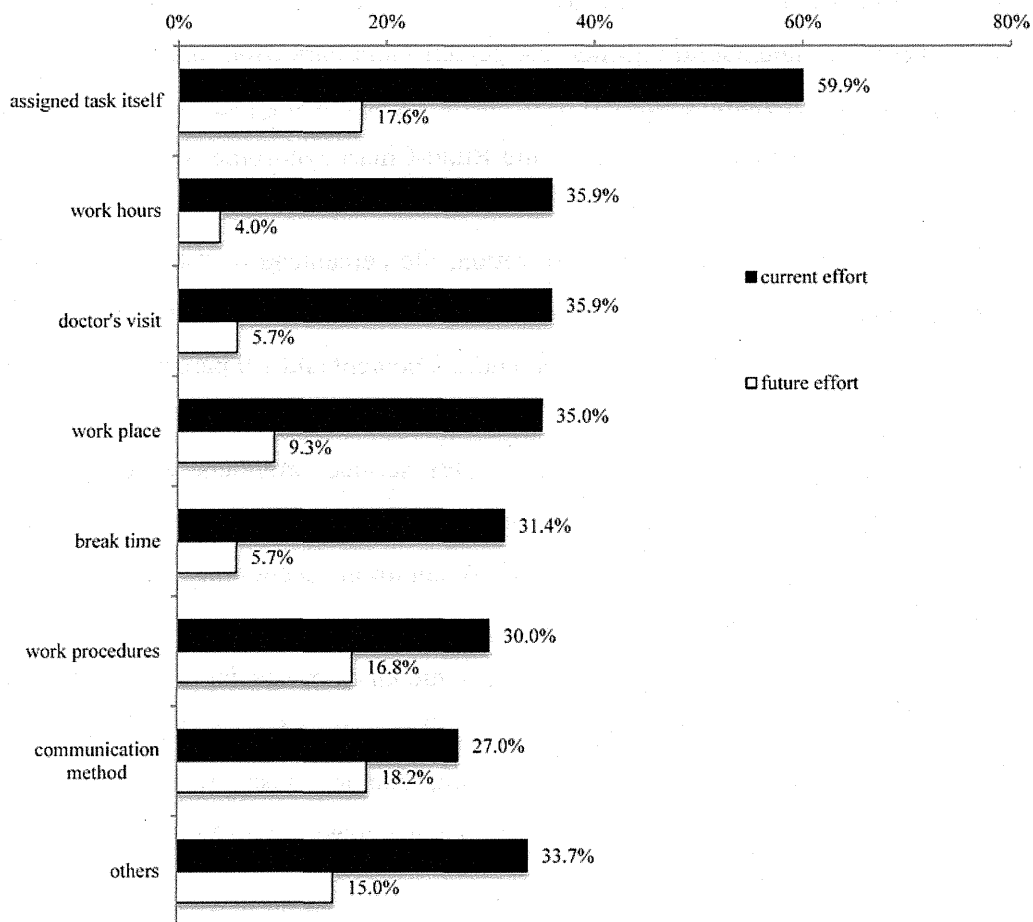


spinocerebellar degeneration (11.3 percent), moyamoya disease (8.3 percent), retinitis pigmentosa (7.8 percent), rheumatoid arthritis (5.4 percent) and Parkinson disease (4.9 percent). 37 IDs including Creutzfeldt-Jakob disease (CJD), sub acute sclera singpanence halite's (SSPE), Addison's disease, autoimmune hepatitis (AIH) and Budd-Chiari syndrome were not reported at all.

As for the reasons for reporting non-utilization, the percentage of "absence of inquiry" was as high as 77 percent, while that of "needed medical care," "insufficient staff/facilities" and "lack of appropriate work" were as low as 1.5 percent, 2.2 percent and 1.0 percent, respectively.

The average days of the use of the services was 17.5 days per month, and the average monthly wage at the Type A CES and Type B CES service providers were JPY 66,212 (approximately USD 538) and JPY 14,851 (approximately USD 121), respectively. As for the type of work they are assigned, light labor is most common, accounting for 55.4 percent, followed by computer operation and cleaning tasks.

68 percent of the respondents reported having some kinds of special care for the patients with IDs. While special care regarding assigned task itself was most frequently reported, special cares regarding work hours, work place, break time, doctor's visit, work procedure and communication method were also reported at comparable level (see Figure 1).



#### 4. Discussion

The questionnaire revealed that patients with IDs uses the services of approximately 16 percent of NEWS as of December of 2013, which is the first year of the revised SSPDA. Considering the result that majority of the reason for reporting non-utilization was “absence of inquiry,” the welfare service available to the patients with IDs might not be sufficiently publicized currently, and this is an issue that needs to be addressed. Information that NEWS service providers seek when they consider an application by a patient with IDs were as follows: disease specific issues that a provider should be aware of, physical issues that a user him/herself should be aware of, measures to be taken in case of an emergency, medication a patient is taking and prognosis. Since use of their service under medical treatment is often expected, providers



tend to seek information on issues not only they should be aware of as a service provider, but also issues the patient him/herself should be aware of regarding self-management. These kinds of information need to be provided by medical facilities. However, medical facilities often do not know the specific work the patient with IDs does at a given facility, and therefore, in order to provide needed medical information, a certain specific format needs to be prepared.

According to data counted for each disease, 94 out of 131 IDs were reported to have patients using the NEWS service providers. As for the possible reasons for 37 IDs that do not have patients using the service, small number of patients with these IDs and their progression rate too fast to make it chronic in nature can be suggested. It may be also important to publicize the availability of the NEWS service in the medical facilities specialized in these diseases as many of them are disorders of endocrine system, metabolic abnormality and digestive system disorders except for the cases of ulcerative colitis and Crohn disease.

Approximately 90 percent of patients with IDs who use the NEWS services have one of official disability certificates, and the percentage of patients without the disability certificate was only 6.6 percent. According to the SSPDA of 2013, patients with IDs are eligible for the NEWS service even he or she does not have the disability certificate, provided that the patient has a doctor's certificate for the disease. Insufficient dissemination of this eligibility criterion could account for the small percentage of patients with IDs without the disability certificate using the NEWS service.

## **5. Conclusions**

The revision of the SSPDA in 2013 should pave the way for the patients with IDs to utilize the welfare services that have been traditionally limited to persons with disabilities. As of 2013, approximately 16 percent of the NEWS providers have patients with IDs included in their users, and in the past five years, 20 percent of them had those patients included one time or another. The high percentage, nearly 80 percent, of respondents who reported "absent of inquiry" as the reason for not having patients with IDs in their users might be the result of insufficient publication of the revision of the act. Also, the high percentage, as much as 74 percent, of the NEWS users having one of three types of disability certificates might be the



indication of inadequate dissemination of the fact that a doctor's certificate is sufficient to use their services. Further effort to familiarize all the parties concerned with the services and their requirements in detail is necessary to help promote the dissemination of the measures for patients with IDs.

## 6. Acknowledgements

This study was supported by Health Labor Sciences Research Grant.

## REFERENCES

- Act for Establishment of Related Acts for Implementation of New Health Care and Welfare Measures for Persons with Disabilities to Realize Inclusive Society (chiikishakai-ni-okeru-kyosei-no-jitsugen-ni-mukete-aratana-shougaihokenhukushisesaku-wo-koujuru-tame-no-kankeihouritsu-no-seibi-ni-kansuru-houritsu-ni-tsuite).(2013).Retrieved from [http://www.mhlw.go.jp/seisakunitsuite/bunya/hukushi\\_kaigo/shougaihashukushi/sougoushien/dl/sougoushien-02.pdf](http://www.mhlw.go.jp/seisakunitsuite/bunya/hukushi_kaigo/shougaihashukushi/sougoushien/dl/sougoushien-02.pdf)
- Definition of Nanbyo. (n.d.).Retrieved from <http://www.nanbyou.or.jp/english/index.htm>
- Difference between Type A and Type B CES Support Providers (shuro-keizoku-shien-A-gata-to-B-gata-no-chigai) (2015, February 12).Retrieved from <http://www.syuro.or.jp/20150212-129/>
- Healthcare Act for Persons with Intractable Diseases (nanbyo-kanja-ni-taisuru-iryuu-tou-ni-kansuru-houritsu). (2014). Retrieved from <http://www.mhlw.go.jp/seisakunitsuite/bunya/kenkouiryuu/kenkou/nanbyou/dl/140618-01.pdf>

