Barn och ungdomar med rörelsehinder
- deras uppfattningar om roller, relationer och aktiviteter
Barn och ungdomar med rörelsehindrade uppfattningar om roller, relationer och aktiviteter

av

Lisa Skär

Akademisk avhandling som för avläggande av filosofie doktorsexamen vid Luleå tekniska universitet officiellt försvaras vid Institutionen för hälsovetenskap i Boden Torsdagen den 5 december 2002, klockan 10.00 i Aulan

Fakultetsopponent:
Professor Erland Hjelmqvist
Institutionen för psykologi
Göteborgs universitet

LULEÅ TEKNISKA UNIVERSITET
ABSTRACT

The general aim of this thesis was to describe how children and adolescents with restricted mobility perceived their roles, relations and activities in relation to peers and adults in different settings. The thesis includes six sub-studies, which are based on interviews, observations and field notes with children and adolescents with restricted mobility aged from 6 to 19 years.

Using Bronfenbrenner's theory "the Ecology of Human Development" as the main theoretical framework, the ambition was to understand the children and adolescents’ social world from their perspective. The principal finding was the lack of peers in the children and adolescents’ social network. Furthermore, this tendency of isolation from peers was found to increase during the transition from childhood to adolescence. Their relationships to peers were strained and activities and surroundings in which social contacts could develop were limited. The relationships with peers were also characterised by social barriers in the form of attitudes that resulted in social isolation from the group of persons the disabled children and adolescents most wished to be with. When relations to peers were limited, the disabled children’s social life was restricted to adults. The results further showed that the children and adolescents’ roles and relations often were significantly different from their peers. The children and adolescents’ arrived at a concept of themselves that differed from the way others conceptually saw them. Furthermore, the children and adolescents saw themselves as regular members of their peer group, but the other members of the peer group saw them as different from themselves. Relationships to friends of the same age either were confined or were nonexistent. Relationships to adults were often characterised as ambivalent or asymmetric, i.e. the adults were helpful and supportive while over protective and dominant at the same time. The thesis revealed that, despite the many obstacles facing them, the children and adolescents with restricted mobility had a positive view of their future.

Keyword: Children and adolescents with disability, roles, relations, activity, social environment.
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LISA SKÄR
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The general aim of this thesis was to describe how children and adolescents with restricted mobility perceived their roles, relations and activities in relation to peers and adults in different settings. The thesis includes six sub-studies, which are based on interviews, observations and field notes with children and adolescents with restricted mobility aged from 6 to 19 years.

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Till Jonas
FÖRORD


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Rörelsehinder är en sammanfattande benämning som beskriver avvikeler i rörelsemönstret till följd av medfödda skador (som till exempel cerebral pares, ryggnärsbräck, led- och muskel sjukdomar osv.), eller skador som uppkommer senare och därmed ger upphov till vissa svårigheter i vardagen (Rabe et al., 1996). Svårigheter som kan påverka ett barn både psykiskt och socialt, men hur barnet påverkas beror på ett komplicerat samspel mellan kroppsliga, psykologiska och sociala faktorer (Carlsson, Hjelmqvist, & Lundberg, 2000).


(tankar hos ett barn i rullstol)
BAKGRUND

Barnets sociala nätverk
Människan utvecklas inte i ett vakuum utan genom att inta vissa roller, innehåva relationer och delta i social samvaro i aktiviteter och genom kontakter med olika sociala miljöer. Socialt nätverk är ett begrepp som beskriver ett relationssystem av människor. Det sociala nätverket återspeglar till exempel mönster av relationer i ett bostadsområde eller i en skolklass, men kan även beskriva vilka människor en viss individ själv upplever som viktiga i sitt liv. Det sociala nätverkets betydelse för barnets utveckling och hälsa har studerats av flera forskare (se t ex Belle, 1989; Svedhem, 1991; Craig, 2000), och resultaten visar samstämmigt att barnets utveckling på många olika sätt är beroende och påverkad av andra människor.

Historiskt sett har nätverk som begrepp sitt ursprung inom traditionen kring psykodrama och den socialantropologiska forskningen. Under 1930-talet uppmärksammades betydelsen av en ökad förståelse för omgivningsfaktorer och nätverkets påverkan på individen. Mead (1934) beskrev hur människans identitet utveckling påverkades av hennes roller och relationer till andra. Lewin (1951) vidareutvecklade Meads tankar och såg människan som ett komplext energifält där en mängd krafter av olika slag verkade. Detta fält kom att kallas ”Life space” och var produkten av interaktionen mellan individens personlighet och närmiljön. Även de processer som ägde rum mellan människor i olika grupper och gruppernas strukturer studerades eftersom det ansågs att det inte var tillräckligt att fokusera enbart på individ och gruppen utan det sociala nätverket måste ses i ett större perspektiv, det vill säga i ett samhällsperspektiv för att kunna kartlägga den sociala strukturen (Moreno, 1953).


Barn och lek


Barn, vänskap och kamratrelationer


I de allra flesta barngrupper uppstår en social struktur och en rangordning enligt Hartup (1995), vilket kan beskrivas med att det enskilda barnet får en viss position i gruppen som är beroende av hur han/hon är omyckt och vilket

rörelsehinder istället dra sig ur sociala relationer och förlora möjligheter till kamratrelationer. Miljöer där ungdomar vistas som till exempel diskotek, caféer, fritidsgårdar, sporthallar osv. kan för ungdomar med rörelsehinder vara otillgängliga miljöer och därmed fungera som hinder för att träffa jämnåriga och likasinnade. Detta medför att umgången med jämnåriga reduceras och som en följd därav också möjligheterna att etablera vänkapsrelationer eller behålla dem. En fråga att söka svar på är därför vilka relationer har rörelsehindrade barn och ungdomar med jämnåriga?

Barn med rörelsehinder och hjälpmedel


Trots den utveckling av hjälpmedel som finns idag har flera forskare uppmärksammat problem som barn med rörelsehinder möter i sin fysiska och sociala miljö när deras hjälpmedel inte fungerar. I den fysiska miljön kan barnet hindras tillträde på grund av bristande tillgänglighet som kan skapas av trånga och ovänliga platser eller att de hjälpmedel de använder inte fungerar i en viss miljö (Prohansky & Fabian, 1987; Bell et al., 1990). Men också platser speciellt skapade

TEORETISKA PERSPEKTIV


Det utvecklingsekologiska perspektivet
utvecklingsekologiska modellen från 1979 kommer dock att fokuseras i föreliggande avhandling.


Genom att beakta såväl mer närliggande som mer avlägsna miljöfaktorers betydelse, karaktäriserar Bronfenbrenner den utvecklingsekologiska modellens syn på människans utveckling som "Development in context". Utvecklingen påverkas inte endast av barnets närmiljö, utan också av barnets fjärrmiljö och av samhället, det vill säga i ett både mikro- och makrobetonat perspektiv. Bronfenbrenner analyserar miljön i systemtermer, vilket bland annat innebär att de olika miljöerna ses som sammanhängande strukturer med ömsesidig påverkan mellan systemets delar men där olika miljöer också betraktas som speciella system, vilka kan beskrivas som en serie sammanhängande strukturer där den ena rymmer inuti den andra, ungefär som ryska dockor av varierande storlek. Se figur 1 nedan.
Längst inne i denna struktur finns barnet och de olika närmiljöerna (settings), det vill säga miljöer som barnet själv deltar och agerar i, som exempelvis familjen, kamratkretsen osv. Dessa miljöer beskriver Bronfenbrenner som mikrosystem där ett nätverk av relationer utvecklas mellan mikrosystemets olika komponenter; barnet självt, övriga medlemmar i mikrosystemet och fysiska objekt. Relationer som antas ha en direkt inverkan på barnets utveckling, kan exempelvis vara dyaden mor-barn, dyaden far-barn, triaden mor-far-barn. Allt medan barnet växer kommer det sedan successivt att ingå i flera mikrosystem utanför familjen, så som till exempel skola, fritidsverksamheter, olika kamratgrupper osv. Medlemskapet i dessa mikrosystem innebär också relationer till andra personer utanför familjen som till exempel barn-kamrat och barn-lärare osv. och har betydelse för barnets utveckling.

Bronfenbrenner säger vidare att varje mikrosystem karaktäriseras av tre aspekter: roller, relationer och aktiviteter samt vissa fysiska och materiella förhållanden som utvecklas i systemet. Roller och relationer är begrepp som till sin natur är sociala, medan aktiviteter också kan utföras i ensamhet. Aktiviteter kan innehålla växlande engagemang av såväl andra som av barnet självt, det vill säga engagemang genom ensamaktiviteter eller aktiviteter som utförs tillsammans med andra eller

Lika väl som aktiviteter tillsammans med andra främjar utvecklingen menar Bronfenbrenner att utvecklingen främjas av interaktioner med människor som innehar varierande roller och genom deltagande i en ständig utvidgad rollrepertoar. Rollerna kan vara av två slag- dels sådana som barnet självt försätts i och dels sådana som barnet möter och observerar hos andra. För barnet tar utvecklingen av roller sin början inom familjen, till exempel utvecklas barnrollen i relation till föräldrarna och syskonrollen i förhållande till syskon. Allteftersom barnet växer etableras sedan relationer till andra människor i andra mikrosystem och nya roller utvecklas, exempelvis rollen som kamrat, skolelev och så vidare. Interaktionerna i dessa olika sociala sammanhang i olika mikrosystem, lär barnet att skapa och behålla roller till andra och att bli accepterad av individer i nya mikrosystem (exempelvis kamratgruppen, skolklassen osv.). Rollerna lär också barnet att anpassa det egna beteendet i förhållande till andra människor och bemästra olika sociala situationer. För när barnet utvecklar en förståelse för det som sker med det och runtomkring, kan barnet också förstå en del av det sociala sammanhang som det befinner sig i. Barnet kan dock komma att möta roller som de uppfattar som motstridiga i olika mikrosystem, det vill säga ett barn som i hemmet lärt sig att ta egna initiativ, vara aktivt och klara sig på egen hand få problem med anpassningen om det i skolan möts av förväntningar som säger att det inte ska göra något på egen hand utan invänta instruktioner. Den stimulans barnet möter i hemmet motverkas då av de helt andra kraven som finns i skolan.

Den tredje aspekten rör de relationer som utvecklas i ett mikrosystem och som uppstår när en person lägger märke till en annan eller deltar i den personens aktiviteter. "A relation obtains whenever one person in a setting pays attention to or

Mikrosystemen är i sin tur relaterade till större system (meso- och exosystem) och alla ingår de i det övergripande makrosystemet som består av samhället och som kännetecknas av mönster av värderingar, traditioner, ekonomiska förhållanden, livs- och trossystem, ideologier osv. Mesosystemet innehåller relationerna mellan två eller fler mikrosystem där barnet ingår, som till exempel hemmet, kamratgruppen, skolan osv. ”The mesosystem comprises the interrelations among two or more settings in which the developing person actively participates” (1979, s. 25). I mesosystemet är barnet den person som förenar de olika mikrosystemen men det kan även ske av andra människor som deltar aktivt i barnets närmiljöer. Ett mesosystem kan således beskrivas som ett system av mikrosystem och uppstår varje gång en person förflyttar sig till nya miljöer (settings). Gemensamt för ett mesosystem är att barnet är medlem i samtliga ingående mikrosystem och vad som sker i ett mikrosystem blir då inte betydelselöst för vad som sker i andra mikrosystem. Hur ett barn utvecklas tillsammans med kamraterna beror därför inte enbart på vad som sker i mikrosystemet kamratgruppen utan även vilket stöd och vilken uppmuntran barnet får i hemmet för att delta i kamratgruppen, samt vilken kontakt som finns mellan hemmet och kamratgruppen.
Utanför de närmiljöer där barnet är aktivt och agerar finns förhållanden och faktorer som genom interaktioner med och påverkan av andra än barnet ger indirekta konsekvenser för barnets utveckling. Dessa förhållanden och faktorer bildar ett nytt system som Bronfenbrenner i sin modell kallar exosystem. "An exosystem has been defined as consisting of one or more settings that do not involve the developing persons as an active participant but in which events occur that affect, or are affected by, what happens in that setting." (Bronfenbrenner, 1979, s. 237). I exosystemet utvecklas processer av betydelse för personer, som direkt har med barnet att göra, och dels genom att direkt påverka förhållanden i barnets närmiljö. Påverkan kan också ske i omvänd riktning, det vill säga från barnets närmiljö till exosystemet. Ett exempel som kan belysa det hela är att exosystemet innefattar förhållanden som föräldrarnas sociala nätverk och relationer. Det vill säga faktorer som indirekt kan antas påverka barnets utveckling genom att exempelvis stödja eller försvåra för föräldrarna i sin roll som förälder. Även arenor som barnet aldrig besöker kan få liknande konsekvenser för den verklighet barnet möter. Det kan till exempel gälla skolstyrelser, kommunstyrelser och andra offentliga organ som har ansvar för att fatta beslut som i sin tur kan återverka ner på barnets direkta närmiljöer som till exempel skolan.

Sammanfattningsvis kan sägas att i den utvecklingsekologiska modellen ses barnets utveckling som en produkt av samspelet mellan individen själv och den omgivande miljön. Samspelet med miljön sker genom de aktiviteter, roller och relationer som barnet möter och aktivt deltar i. Den utvecklingsekologiska modellen vidgar miljöbegreppet och anlägger ett systemperspektiv på interaktion vilket innebär att individen ses som en del av ett system, en miljöstruktur som samtidigt rymmer flera mikrosystem. Med miljö avses inte endast den omedelbara närmiljö i vilken barnet ingår utan också mera övergripande miljöstrukturer på samhällsnivå.

Den sociala modellen

och individen fick själva ta ansvar för att övervinna de fysiska och sociala hinder som fanns i miljön. Detta synsätt väckte stark kritik från flera handikappforskare i bland annat England (UPIAS, 1976) som menade att även om det finns en medicinsk aspekt på funktionshinder är det i huvudsak miljöernas utforming som skapar handikapp och återspeglar hur människor med funktionshinder upplever sin situation.

I den sociala modellen betraktas handikapp som något som är skapat av samhället det vill säga, ett handikapp uppstår till följd av att det i samhället finns en rad barriärer som utesätter människor med funktionshinder från möjligheter att utföra sociala aktiviteter (Oliver, 1996). När miljöer blir otillgängliga kan det antas påverka barns utveckling på ett negativt sätt. Sådana barriärer kan vara fysiska hinder av olika slag, till exempel om det inte finns tillgänglighet till byggnader, offentliga lokaler och transportmedel. Som en konsekvens av den otillgängliga fysiska miljön uppstår även sociala hinder i form av uteslutning från gemenskap i olika sociala grupper. Den sociala modellen handlar också om mänskliga rättigheter, det vill säga en person med funktionshinder ska ha samma rättigheter till ett delaktigt liv i samhället som alla andra.


När det gäller barn med funktionshinder har flera forskare uppmärksammat miljöns betydelse för delaktighet. Prellwitz m fl. (2001) fann till exempel att lekplatser sällan var konstruerade så att barn med rörelsehinder själva kunde leka där utan istället blev beroende av hjälp från någon vuxen. Risken med att en vuxen alltid finns med och ”hjälper till” kan medföra att barn med rörelsehinder gradvis socialiseras in i rollen som svag och ständigt hjälpbehövande där handikappet blir en fråga om barnets tillkortakommanden medan hindren i lekmiljön inte ifrågasätts (Oliver, 1996). Integriering av barn med rörelsehinder i den ordinarie skolan är ett annat exempel där skolmiljöns tillgänglighet påverkar graden av aktivitet och delaktighet. Eftersom begreppet integriering används i
betydelsen att föra in ett barn i en viss miljö, blir de problem som uppstår personliga med individuella anpassningar av framförallt den fysiska miljön som följd. Sett utifrån den sociala modellen måste därför den individuella behandlingen kompletteras med en social handling där organisationen av skolans aktiviteter, lärarens undervisningsstil samt hur assistans utformas som influerar möjligheten till delaktighet ses över för att också ge barnet en kollektiv tillhörighet (Hemmingsson, 2002).

Symbolisk interaktionism
Roller och relationers betydelse för barnets utveckling har även studerats inom den symboliska interaktionismen av bland annat George Herbert Mead som var en av inspiratörerna för Urie Bronfenbrenner när han utvecklade sin utvecklingsekologiska modell (1979). Symbolisk interaktionism beskriver nära relationers och delaktighetens betydelse i olika sociala sammanhang för barnets utveckling varför det är angeläget att återspegla detta perspektiv i föreliggande avhandlings teoretiska referensram.


Språket är enligt Mead (1934) inte något som ett barn har med sig vid födelsen utan något som utvecklas i det sociala livet människor emellan. Språket utvecklar symboliseringsförmågan och beskrivs genom att orden i sig själva inte innehåller någon mening, inte heller anses en enskild individ ge dem mening utan den skapas först när två eller fler individer använder språket för kommunikation. Genom språket utvecklas även det Mead kallar ”rollövertagande” vilket beskrivs ske i situationer när barnet skickar ut symboler med hjälp av språket (skrik, skratt osv.) och dess vårdare är benägen att besvara dem på olika sätt, exempelvis genom att härma barnets ”språkliga uttryck”. Detta rollövertagande ger i sin tur upphov till att objekt i omvärlden blir meningsbärande, det Mead kallar symboler och som han beskriver som den väsentligaste substansen i människans reflekterande. Om ett barn blir berövad mångfalden av rollövertaganden berövas det också förmågan att utveckla ett jagmedvetande.
Den personliga utvecklingen sker enligt Mead (1934) genom sociala processer där roller och relationer utvecklas och vidmakthålls genom interaktionen med andra. Interaktionens betydelse beskrivs som central både när det gäller medvetande om omvärlden och medvetandet om det egna jaget. När medvetandet riktas mot individen själv och resulterar i en jagbild liknar Mead (1934) det med att människan kan vara objekt för sig själv med sig själv som subjekt, vilket gör att människan ses som både objekt och subjekt, en process Mead kallar ”I” and ”me”. Identiiten ses därigenom som ett resultat av hur barnet uppfattar sig själv och hur barnet upplever att det uppfattats av andra. Utvecklingen av identiteten påverkas även av barnets sociala kontext där ”signifikanta andra” (betydelsefulla personer) formar barnets personlighet. Dessa signifikanta andra är till en början barnets närmaste, mamma, pappa etc., men allt medan barnet växer blir fler personer i barnets närhet de signifikanta andra, till exempel vänner, klasskamrater osv. Barnets personlighet formas dels i denna intima krets av barnets signifikanta andra men för att barnet skall utveckla sin identitet behövs också personer utanför familjen och närmaste kretsen av vänner.

Stigma och stigmatisering


Enligt Goffmans begrepp stigmatisering är det främst det etablerade samhällets stämpling eller stigmatisering av avvikaren som orsakar en persons fortsatta utveckling mot en avvikande identitet. Möten som leder till att stigmatiserande etiketter utvecklas hos en person medför att sociala relationer begränsas och kan på sikt leda till att en negativ identitet utvecklas där de förväntningar andra har på en kan komma att börja motsvaras. Förväntningarna leder till att en person med funktionshinder kan börja se sig själv med fokus på funktionshindret istället för den person som de är.

Kan de olika teoretiska perspektiven kombineras?

För att kompleterra den utvecklingsekologiska modellens svagheter har andra teoretiska perspektiv som belyser miljön på olika sätt använts i föreliggande avhandling. Dels genom den sociala modellen för att belysa miljön ur ett handikapp perspektiv eftersom den sociala modellen beskriver hur en otilgänglig miljö bidrar till att göra en person handikappad och utesluten från social gemenskap. Dels genom perspektivet stigma och stigmatisering som beskriver hur den sociala miljön kan komma att påverka en person som har ett avvikande beteende ("ett stigma" som till exempel ett funktionshinder). Det interaktionistiska perspektivet (Mead, 1934), som beskriver roller och nära
relationers betydelse för barnets utveckling i olika sociala sammanhang låg till grund för den utvecklingsekologiska modellens utveckling varför det var angeläget att även belysa detta teoretiska perspektiv för att erhålla en större förståelse av den sociala miljöns betydelse för barns utveckling genom roller och relationer.

Sammanfattningsvis kan alltså konstateras att det finns skillnader men också likheter mellan den utvecklingsekologiska modellen, den sociala modellen, symbolisk interaktionism och stigmatisering. Trots dessa skillnader/likheter kan användandet av olika teoretiska perspektiv komplettera varandra genom att utgöra strukturer eller mallar där olika aspekter av empirin passar in (Holme & Solvang, 1997).
SYFTE OCH FRÅGESTÄLLNINGAR


Det övergripande syftet med föreliggande avhandling var att beskriva hur barn och ungdomar med rörelsehinder själva uppfattar sina roller, relationer och aktiviteter med jämnåriga och vuxna i olika miljöer.

Studie I
Syftet med denna studie var att jämföra det sociala nätverket (med speciellt fokus på roller, relationer och aktiviteter) hos barn och ungdomar med rörelsehinder, med det sociala nätverket hos en grupp barn och ungdomar utan rörelsehinder.

Studie II
Syftet var att få förståelse för om hur barn med rörelsehinder uppfattar sina tekniska hjälpmedel i leksituationer.

Studie III
Syftet med denna studie var att beskriva hur barn med rörelsehinder själva uppfattar sina tekniska hjälpmedel och om de tror att deras tekniska hjälpmedel hjälper eller hindrar dem i interaktionen till andra, huvudsakligen kamraterna.

Studie IV
Syftet var att erhålla kunskap och förståelse för hur barn med rörelsehinder leker i olika leksituationer.

Studie V
Syftet var att beskriva hur barn och ungdomar med rörelsehinder uppfattar sin assistent med fokus på roller och relationer de har visavi varandra.

Studie VI
Syftet med denna studie var att beskriva vad det innebär att växa upp med ett funktionshinder, med speciellt fokus på rörelsehindrade ungdomars sociala roller och relationer till kamrater och vuxna.
METOD

Insamlingen av det empiriska materialet har skett genom intervjuer, observationer och fältanteckningar för att sedan bearbetats med de kvalitativa analysmetoderna innehållsanalys och med inspiration av grounded theory. De olika delarbetena (studie I-VI) kan karakteriseras som empirinära, det vill säga verklighetsnära i den mening att det funnits en närhet till informanterna i deras naturliga miljöer och att utgångspunkten för datainsamlingen varit ett infiränperspektiv där barnens och ungdomarnas egna röster har fått höras.

Ett kvalitativt perspektiv

Historiskt har den kvalitativa och kvantitativa forskningen framställts som oförenliga medan man idag belyser fördelar med att komplettera kvalitativ forskning med kvantitativa data (jfr t ex. Alvesson och Sköldberg, 1994). Föreliggande avhandling har i huvudsak använt den kvalitativa ansatsen, men i en studie (I) har kvalitativa och kvantitativa data kombinerats för att därmed nyttja metodernas kompletterande funktion i ett förtydligande syfte. Metodernas sätt att komplettera varandra kan beskrivas genom att kvalitativ forskning tillåter forskaren att studera utvalda frågeområden mer detaljerat (Patton, 1990) medan kvantitativ forskning är mer formaliserad och strukturerad (Holme & Solvang, 1997).


Den kvalitativa forskningen har sin styrka i att den visar på totalsituationen där en helhetsbild möjliggör en ökad förståelse för sociala processer och sociala sammanhang (Denzin & Lincoln, 1994). Den närhet kvalitativa

Ett kvantitativt perspektiv


Den grundläggande likheten mellan kvalitativ och kvantitativ forskning är således att de har gemensamma syften, det vill säga båda angreppssättet är inriktade på att ge en bättre kunskap om det samhälle vi lever i och hur enskilda människor, grupper och institutioner handlar och påverkar varandra. Utöver detta är det nog skillnaderna som framträder tydligast. Vid en kvalitativ ansats kommer skillnaden till uttryck i att forskaren tolkar eller har uppfattningar av information som står i förgrunden, till exempel genom att tolka referensramar, motiv, sociala processer och sociala sammanhang när insamlad data ska analyseras. Medan den kvantitativa ansatsen innebär att undersökningen ofta inkluderar standardiserade mätmetoder, slumpmässiga urval och statistiska beräkningsmetoder. Den kvantitativa
forskningen strävar också efter att förklara samband, påvisa samband och förutsäga.

Undersökningsgrupper
Urvalet av undersökningspersoner har stor betydelse för resultatet av en undersökning. Ett felaktigt urval kan medföra att undersökningens syfte ej blir besvarat. Kvalitativ forskning strävar efter ett ökat informationsvärde och att skapa en grund för djupare och mer fullständiga uppfattningar om det fenomen som studeras, urvalet bör därför ske systematiskt utifrån vissa medvetet formulerade kriterier (Holme & Solvang, 1997).

I föreliggande avhandling har ett urvalsriterium för samtliga artiklar (I-VI) varit barn och/eller ungdomar med rörelsehinder. Ett annat urvalsriterium var att rörelsehindret även skulle ha medfört att barnet/ungdomen använt något förflyttningshjälpmedel som till exempel, elektrisk rullstol, manuell rullstol, rollator eller kryckor. Ytterligare ett urvalsriterium var att barnen och ungdomarna skulle ha god kommunikationsförmåga för att kunna medverka vid intervjuerna. För studie V fanns ytterligare ett specifikt urvalsriterium, det vill säga att alla undersökningspersoner skulle ha hjälp av en personlig assistent eller elevassisten, hela dagen eller delar av dagen.

Åldersintervallet för de undersökningspersoner som söktes var barn mellan 6 och 12 år och ungdomar mellan 13 och 19 år. Anledningen till att detta åldersintervall valdes är att barn yngre än 6 år kan ha svårt att berätta och beskriva erfarenheter och upplevelser (Doverborg & Pramling, 2000). Ungdomar äldre än 19 år är på väg in i vuxenvärlden och var därför inte relevanta undersökningspersoner utifrån avhandlingens syfte.

För att erhålla undersökningspersoner som motsvarade ovanstående urvalsriterier gjordes urvalet från en klinisk population (barn och ungdomar som var inskrivna vid barn och ungdomshabiliteringen i norra Sverige) vilket medförde att rörelsehindret kom att relateras till en medicinsk diagnos (ryggmärgsbräck, cerebral pares, muskel dystrofi, reumatisk sjukdom och polio syndrom). Urvalet från en klinisk population och med de kriterier som ställdes medförde att antalet barn och ungdomar som motsvarade de ställda kraven blev relativt litet. Därför kom flera barn/ungdomar att ingå i flera studier vilket kan ha påverkat avhandlingens resultat både positivt och negativt. Positivt genom att barnen/ungdomarna lärt känna författaren väl och känt en trygghet när de har berättat om mer känsliga ämnen och därigenom delgett författaren ett större omfång av sina erfarenheter och upplevelser. Resultaten kan dock ha påverkats i en negativ riktning när relationen till barnen/ungdomarna kan ha utvecklat ett beroendeförhållande till författaren där barnen/ungdomarna kan ha haft svårt att själva avgöra om de ville delta eller inte. Författaren har därför varit mycket noga med att informera barnen och ungdomarna om vad deltagandet inneburit och

I studie I fanns en jämförande grupp barn och ungdomar utan rörelsehinder som matchades utifrån ålder (födda samma år och månad) och kön med de rörelsehindrade barnen och ungdomarna. De jämförande barnen/ungdomarna gick på fyra olika skolor av samma storlek som den undersökande gruppen, dock inte i samma skolor. Urvalet av jämförelsegruppens barn och ungdomar skedde med hjälp av ansvarig rektor på respektive skolor.

Nedan följer en översikt (tabell I) av de olika artiklarnas undersökningsgrupper, datainsamlingsmetoder och dataanalys.

Tabell I, Översikt över deltagare, datainsamling och analysmetod i de sex olika studierna.

<table>
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<tr>
<th>Studie</th>
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<td>Instrumentet &quot;Mitt sociala nätverk&quot; tillsammans med intervjuer</td>
<td>Sammanställning av instrumentets nätverkskarta och en kvalitativ analys av svaren på intervjufrågorna</td>
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<td>Studie II</td>
<td>8 barn med rörelsehinder</td>
<td>Intervju</td>
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<td>Studie III</td>
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<td>Studie IV</td>
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<td>13 barn/ungdomar med rörelsehinder</td>
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<td>Intervju</td>
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Intervju


Att intervjua barn skiljer sig från att intervjua vuxna eftersom barns sätt att tänka och uppfatta världen är annorlunda och därmed kan ge andra svar och belysa viktiga perspektiv ur nya synvinklar (Hemmingsson, 2000). Frågor som rör barn bör därför i möjligaste mån ge barnet möjlighet till egna beskrivningar av upplevelser och erfarenheter och barnens rätt att komma till tals bör utgå från principen om barnets bästa (Barnombudsmannen, 1999).

Intervjuer med barn bör ta sin utgångspunkt i en för barnet och forskaren gemensam referensram, där forskaren möter barnet i dess vardag. Interaktionen kräver en sensitivitet och öppenhet av forskaren (Doverborg & Pramling, 2000). Arbetssättet vid datainsamlingen i de olika artiklarna har därför varit att försöka möta barnen och ungdomarna i för dem invanda och trygga miljöer som hemmet och skolan. Författaren har sedan tagit del av deras erfarenheter och upplevelser genom att be dem fritt berätta eller beskriva en situation eller händelse. Detta har medfört att intervjuerna fått karaktären av ett vardagligt samtal (Kvale, 1997). Barn är ofta lättpåverkade i en intervjusituation och har en naturlig följsamhet när de talar med vuxna. Följsamheten innebär att barnet anstränger sig för att motsvara vad det tror att den vuxne vill ha ut av samtalen. Följsamheten är dock mindre ju yngre barnet är men desto större ju fler år barnet gått i skolan, eftersom barnet i skolan lärt sig att det förväntas ett rätt svar på en fråga. För att uppnå tillförlitlighet i intervjuer med barn bör forskaren försöka nå fram till det som Piaget (1975) betraktar som barnets genuina svar. Piaget menar att om flera liknande frågor om samma sak ställs till barnet kan forskaren lättare fånga barnets sätt att tänka och inte de ”klyschor" som barn har lärt sig av vuxna. Frågeställningarna i de olika studierna (studie I-VI) utgick från ”breda”
frågeområden där barnen och ungdomarna själva hade möjlighet att fritt välja vad de ville berätta dessutom fanns alltid möjlighet för barnen/ungdomarna att väcka frågor som för dem kändes angelägna i det aktuella ämnet.

Observation

Osystematiska observationer används ofta i syfte att inhämta så mycket information som möjligt kring ett visst problemområde. Allt kan dock inte registreras även om forskaren är en skicklig observatör. För att erhålla så mycket information som möjligt bör forskaren förbereda sig genom att ta del av kunskap i ämnet både teoretiskt och empiriskt. I och med den ökade kunskapen kan forskaren anpassa sina observationer därefter för att erhålla maximal information om det aktuella problemområde som studeras. Vid själva observationssituationen har forskaren inte något observationsschema utan bygger på att data samlas in genom direkt observation av en situation eller interaktion som forskaren ser i ett naturligt sammanhang. När datainsamling sker i naturliga sammanhang istället för i artificiellt skapade sammanhang (t ex. laboratorieexperiment) kan forskaren studera det som ”normalt” inträffar om inte den naturliga miljön störs. Fördelen med osystematisk observation är således att den är flexibel och att forskaren kan alltefter vad hon/han observerar inriktar sig på vissa företeelser i sitt naturliga sammanhang. Det som kännetecknat naturliga sammanhang i studie III och IV, har varit skolmiljöer där leksituationer studerats. För att inte ”störa” dessa naturliga miljöer som skulle observeras etablerade författaren vid upprepade intervjuer en nära relation till barnen innan observationerna genomfördes. Att vara medveten om att miljöer och sammanhang kan påverkas av forskaren medför att forskaren bör ställa sig frågan, ”i vilken utsträckning det som studeras påverkas av forskarens närhet och av det faktum att situationen studeras”. Närheten innebär en nackdel eftersom observatören genom sin närvaro mer eller mindre påverkar det

Observation som datainsamlingsmetod ställer större etiska krav på både forskaren och metoden eftersom en observationssituation kan innebära att oönskad information om undersökningspersonen framkommer. I föreliggande avhandling ställdes frågor till barnen som kunde verifierade de data som samlades in och det fanns även möjlighet för barnen att ge sin bild av den händelse/situation som hade studerats om de tyckte att forskaren hade uppfattat situationen fel.

Fältanteckningar
Fältanteckningar ses ofta som ett komplement till andra datainsamlings metoder, till exempel intervjuer och observationer. Anteckningarna ger ofta en mer eller mindre kronologisk bild av händelseförloppet. De refererar till handlingar, personer och interna samtal i forskargruppen. För att kunna använda anteckningarna som en del av data är det viktigt att dessa är så konkreta som möjligt och återspeglar den situation där de är hämtade (Denscombe, 1998). Fältanteckningar i det aktuella fallet kom därför att innehålla information om klimatet och atmosfären under intervjun, ledtrådar om intentioner bakom påståenden och kommentarer för att kunna komplettera en ofullständig bild av företeelser, handlingar och relationer i olika leksituationer.


Instrumentet, ”Mitt sociala nätverk”
För att samla in data till studie I användes delar av instrumentet ”Mitt sociala nätverk” (Aresik-Ram & Elf, 1997). Detta instrument är ett nyutvecklat svenskt bedömningsinstrument utgivet av Psykologiförlaget i Sverige och utformat för att analysera det sociala nätverket utifrån både psykologiska och sociala aspekter hos barn från sju år upp till tonåren. Instrumentet innehåller en nätverkskarta där barnet inom sex olika grupper (familjen, släkten, grannar, skolan, kamrater/vänner och professionella) får ange viktiga/betydelsefulla personer de har i sin närhet. Nätverkskarten kompletteras sedan med en intervju med utgångspunkt i ett frågeformulär bestående av sex olika frågeområden för att ge
en helhetsbild av hur barnet uppfattar interaktionerna i sitt sociala nätverk. Det sjätte frågeområdet valdes dock bort eftersom det handlade om konflikter och rekommenderades att endast användas i kliniska sammanhang. Sammanlagt fick barnen svara på 28 frågor.

Frågeområde 1 (intensitet) berör vilken känsla barnet har gentemot sina nätverkmedlemmar, samtidigt som det ger en bild av om det finns personer som barnen uppfattar positivt eller negativt i nätverket. Frågeområde 2 (praktiskt stöd) och 3 (känslomässigt stöd) berör frågor om vilka nätverksmedlemmar barnet upplever att han/hon får praktiskt respektive känslomässigt stöd från och vilka personer barnet själv ger det till. Frågeområde 4 (feedback) berör vilka personer barnet upplever ge positiv respektive negativ bekräftelse. Det 5: e frågeområdet (multiplexitet) avser om interaktionen mellan den tillfrågade (barnet) och nätverksmedlemmarna sker utifrån mer än ett innehåll, det vill säga om barnet gör flera olika betydelsefulla aktiviteter med de personer som interaktionen avser.

Användandet av instrumentet "Mitt sociala nätverk" medförde att författaren med hjälp av instrumentets frågeområden och nätverkskarta kunde erhålla rik information om barnens och ungdomarnas sociala nätverk. Frågeomrädena innehöll frågor som var konstruerade för att samtala kring känsliga ämnen som till exempel om barnet hade någon bästa vän eller inte. Författaren ställde samtliga frågor till barnet för att inga frågor skulle kunna missförstås och därmed lämnas obesvarade eller med svaret "vet ej". Frågorna var viktiga att få svar på för att bättre kunna förstå barnens och ungdomarnas relationer till jämnåriga men hade kanske inte gett en tydlig bild av deras sociala liv om inte en jämförande grupp barn och ungdomar ingått i studien.

Analys och tolkning av data
I föreliggande avhandling har kvalitativ innehållsanalys och grounded theory använts för analys och tolkning av data. Att använda kvalitativ innehållsanalys i studie I och III baseras på antagandet att metoden ger möjlighet att på ett systematiskt sätt beskriva resultatet av intervjuer och observationer utifrån ett textnära barnperspektiv där barnens egna uppfattningar och erfarenheter varit i fokus. Metoden gjorde det också möjligt att analysera data insamlat med instrumentet "Mitt sociala nätverk" (studie I). Metoden kan dock ses innehålla en begränsning eftersom den inte förespråkar tolkning av samband mellan data.

Valet av att använda grounded theory för analys av studierna II, IV–VI utgår från att roller, relationer och aktiviteter uppstår och utvecklas vid interaktionen med andra människor och att interaktionerna har en mening för de inblandade. Grounded theory är sällan använd fullt ut, det vill säga genom att generera en teori och även i denna avhandling, i studierna II, IV–VI, har metoden använts mer som en inspirationskälla och som en hjälp vid analys av data.
Kvalitativ innehållsanalys


Nästa steg i den kvalitativa innehållsanalysen är att läsa texterna och koderna igen och försöka förstå innebörden i undersökningspersonernas berättelser varvid nya kodar från texterna kan abstraheras. De koder som skapats blir sedan utgångspunkten för forskaren vid utvecklingen av kategorier som kan beskrivas som tematiskt sammansatta enheter för att öka kunskapen om det problemområde som studeras. I studie III ställde författaren följande frågor för varje hjälpmedel för att utveckla kategorierna: Hur upplever barnet sitt tekniska hjälpmedel?, Hur upplever barnet med rörelsehinder att andra barn agerar när de har ett hjälpmedel?, och Vilka är fördelarna respektive nackdelarna med hjälpm laden? Skapandet av kategorier speglar följaktligen forskarens tolkning av innebörden i data vilket i studie III var att alla hjälpmedel beskrivs ha ett statusvärde för barnen. Verktyget vid kategoriseringen är forskningsfrågan i studiens syfte varför den kvalitativa innehållsanalysen kan beskrivas som en interaktiv process mellan datamaterialet, forskningsfrågan och teoretiska reflektioner. Kodningen avslutas således med att
texterna åter igen läses igenom för att kontrollera de meningsbärande enheterna verkligt passar de skapade kategorierna (Patton, 1990).

Grounded theory


Denna mix av induktion och deduktion, som Glaser (1978) kallar ”*constant comparison*”, sker genom ett växelvis arbete mellan urval, datainsamling, analys och bearbetning av litteratur. I de traditionella kvalitativa undersökningar som till exempel innehållsanalys utgår arbetssättet från väl åtskilda steg där datainsamling till exempel sker åtskilt från analys. Genom att i grounded theory jämföra olika former av data kommer forskaren att se vad som är viktigt i det insamlade datamaterialet och teorin kommer på detta sätt att generas från data samtidigt som den är grundad i data. Skillnaden mellan att arbeta utifrån grounded theory eller att arbeta antigen induktivt eller deduktivt är att när man följer grounded theory är tanken att generera en ny substantiv/praktiskt användbar teori. Att arbeta utifrån grounded theory är ofta både komplicerat och svårt och därför stannar många forskare halvägs och använder sig av grounded theory inspirerad metod. Så har också skett i denna avhandling.

Den öppna kodningen är en inledande fas och börjar med att datamaterialet läses igenom som en helhet. Vid denna första genomläsning av data ställdes också den övergripande frågan ”Vad är det som sker”? Analysen fortsätter sedan med att det empiriska materialet systematiseras och de textavsnitt man finner kodas och jämförs med varandra (constant comparison) för att upptäcka mönster. Dessa mönster omformuleras sedan till koder som nedtecknas i marginen vilka i studie IV benämndes ”att initiera lek”, ”att vara utanför”, ”att ha assistenten med i leken” osv. Därefter sammanförs koderna till teman som sorterats vidare i olika större grupper så att ett större mönster kan börja framträdja och bilda ett antal kategorier. Kategorierna i studie IV fick namnen ”Lek med kamrater”, ”Leka ensam” och ”Leka med vuxna”. Dessa kategorier ses först som preliminära.

Nästa steg i analysprocessen är den axila kodningen som har till syfte att upptäcka relationer mellan kategorier, samt att bestämma kategoriernas egenskaper. De valda kategorierna utvecklas vidare genom att förfinas men också genom att underkategorier utvecklas. Forskaren försöker nu se samband mellan de olika kategorierna och underkategorierna genom att arbeta både deduktivt och indukttivt. Analysarbetet innebär dels att dra slutsatser om enskilda företeelser och följa bevisandets väg men också att studera materialet med utgångspunkt i upptäckandets väg. I studie IV var denna fas av analysprocessen fokuserad på vilka orsaker som gav upphov till olika typer av lekar, vilka interaktionsprocesser som barnen beskrev i olika leksituationer och vilka konsekvenser barnen upplevde av att leka en viss typ av lek.

Analysarbetet avslutas sedan med selektiv kodning där forskaren relaterar de funna kategorierna med varandra och söker efter en huvudkategori som kan definieras som central, det vill säga att den är relaterad till de andra kategorierna och dess egenskaper. I studie IV identifierades det centrala fenomenet ”Hur jag leker”, som den huvudkategori som var tillräckligt abstrakt för att kunna beskriva barnens berättelser. Huvudkategorin återspeglade datamaterialet och visade på så sätt på dess stabilitet, relation till andra kategorier och var det mest generella som kunde sägas om forskningsområdet (Glaser, 1992).
Vetenskaplig stringens

Validitet

Reliabilitet

Bedömning utifrån rimlighet och inre logik

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Även om inte Patel och Tibelius (1987) begrepp för de olika kvalitetskriterierna har använts i avhandlingens olika studier har vissa av dessa kriterier uppfyllts. **Tillämpligheten** betyder val av datainsamlingsteknik och undersökningsgrupp i förhållande till frågeställningen och den tänkta undersökningsuppläggning. Valet måste uppvisa största möjliga användbarhet för att forskaren ska erhålla önskad information och har i föreliggande avhandling erhållits genom ett noggrant urvals- och observeringsförfarande av undersökningspersonerna i samtliga studier (I-VI). Undersökningsgrupperna har även intyjats och observerats vid ett flertal tillfällen och resultaten av empirin diskuterats med forskarkollegor. Undersökningsgrupperna finns även noggrant beskrivna i de olika artiklarna för att läsaren själv ska kunna bedöma tillämpligheten. **Överensstämmelse** handlar om samstämmigheten mellan de underliggande fenomenen i termer av tilldelade egenskaper och den information forskaren söker. Kvalitativa studier bör innehålla en tydlig beskrivning av utförande-processen samt av de teoretiska referensramen för att läsaren själv ska kunna bedöma trovärdigheten, vilket finns tydligt beskrevet i föreliggande avhandlings sex olika artiklar. **Pålitligheten** kan förklaras med bekräftelsebarhet och kan jämföras med den kvantitativa forskningens krav på objektivitet. Pålitligheten innebär att undersökningen måste säkerställa att resultatet verkligen kommer från empirin och inte från forskarens förutfattade menningar, det vill säga forskningen får inte störa den verklighet den beskriver. Ett sätt att säkerställa pålitligheten i de olika artiklarna har varit att även låta andra forskare bedöma styrkan i analysen och slutsatserna genom att titta på insamlade empiriska data. **Noggrannheten** har sedan återspeglats i de olika artiklarnas resultat genom tydliga exempel med citat från barnens och ungdomarnas berättelser återgivna från empirin.


Forskarens roll och inflytande
Inom all forskning är forskarens inflytande på resultatet en central fråga som ofta tar sig till uttryck i en strävan att minska forskarens inverkan på data. De livserfarenheter och den kunskap forskaren har, utgör hans/hennes förförståelse. Holme och Solvang (1997) beskriver antagandet att forskaren inte påverkar data men i realiteten kan detta vara en svår uppgift eftersom forskaren gör urval,


Författaren till föreliggande avhandling förberedde sig innan datainsamling med intervjuer genom att ta del av kunskap inom ämnet och om metod och genomförde provintervjuer. Vid analys och tolkning av data valde författaren i studie I och III en utgångspunkt i barnens upplevelser och erfarenheter tillsammans med den egna förförståelse i beteendevetenskap eftersom de olika artiklarna förväntades ge kunskap gällande barn med rörelsehinder och deras sociala nätverk och betydelsen av att använda hjälpmedel.

företeelse som skall studeras och därigenom stimulera framväxten av relevanta begrepp och hur idéer skall relateras med varandra. Författaren till föreliggande avhandling har sina teoretiska kunskaper inom beteendevetenskap och det är därför inte säkert att andra forskare med andra teoretiska kunskaper hade fått samma resultat. Den induktiva utgångspunkten har dock inneburit att författaren, trots sin förförrståelse, så långt som möjligt varit trogen mot datamaterialets empiri.

Etiska överväganden
Forskning där människor är deltagare kräver goda etiska regler enligt MFR (Medicinska forskningsrådet, 2000) och bör innehålla dessa fyra grundläggande etiska principer: 1) respekten för personer (autonomiprinципen), 2) godhetsprincipen, 3) principen att inte skada och slutligen, 4) rättviseprincipen. Dessa krav innebär att forskaren måste respektera den individuella människans personliga integritet och att forskningen skall leda fram till kunskaper som är värdefulla forskningsmässigt vilket kan beskrivas med att göra gott och inte skada. Undersökningspersonerna har också rätt att bli behandlade lika, det vill säga urvalet av undersökningspersoner bör ske på ett etiskt godtagbart sätt och inte särskilja eller välja bort personer om de uppfyller forskarens krav på urvalskriterier.

För att tillgodose dessa etiska regler är ”informerat samtycke” en viktig faktor, det vill säga att forskaren ska inhämta informerat och frivilligt samtycke om medverkan från varje undersökningsperson. Det grundläggande kravet på god information innebär därmed att undersökningspersonerna informeras på ett sätt och med ett språk som de förstår. Informationen bör innehålla studiens syfte, hur data kommer att samlas in, den förväntade nytta av studien och slutligen att deltagandet är frivilligt och inte särskilja eller välja bort personer om de uppfyller forskarens krav på urvalsriter.

Vid forskning med barn, som inte själv kan ge informerat samtycke är det således ett stort ansvar för forskaren att söka se till undersökningspersonens egna intressen och respektera signaler som visar att undersökningspersonen själv inte vill delta. I föreliggande avhandling har detta skett genom att författaren varit lyhörd för
signaler som kunnat tyda på att barnet/ungdomen inte varit villig att svara på vissa frågor eller velat avbryta sin medverkan. Detta kan exemplifieras genom situationer när barnen/ungdomarna inte velat lämna något svar på en fråga genom att tystna eller genom kroppsspråket sänd ut signaler som till exempel att de ej längre velat ha ögonkontakt med författaren. Inget barn/ungdom har dock velat avbryta sin medverkan men har ibland velat undvika att svara på vissa frågor om till exempel relationer till kamrater av det motsatta könet osv.

Underlaget för denna avhandling är litet och det geografska området undersökningspersonerna representerar begränsat varför det av integritetsskäl ibland funnits flickor i de olika artiklarna som benämnts som pojkar och vice versa, dock endast där denna variabel inte haft någon relevans. Data som innehållt förtroligheter och som undersökningspersonerna inte velat ska framkomma i avhandlingen har inte heller analyserats. Den etiska bedömningen har varit att det eventuella besvär som barnen och ungdomarna kunde uppleva i samband med datainsamlingen skulle vara mindre än den kunskap som denna avhandling förväntas medföra.

RESULTAT

Studie I
Det visade sig att det fanns en omfattande forskning om barns och ungdomars sociala nätverk, men få studier om hur ett socialt nätverk ser ut för barn och ungdomar med rörelsehinder. De fåtal studier som fanns visade att barn med funktionshinder ofta var isolerade från kamrater och att barnen ofta kände sig ensamma och sorgsna. Utgångspunkt för denna studie var därför att jämföra det sociala nätverket (med speciellt fokus på roller, relationer och aktiviteter) hos barn och ungdomar med rörelsehinder, med det sociala nätverket hos en grupp barn och ungdomar utan rörelsehinder.

Resultatet visade att barnen och ungdomarna med rörelsehinder hade färre antal kamrater i sina sociala nätverk till skillnad från den jämförande gruppen och att skillnaden var större bland ungdomarna. Kamratkontakterna saknades dels på fritiden och i olika utemiljöer nära hemmet och dels i skolan. Orsakerna berodde till viss del på att flera fysiska miljöer (sporthallar, biografer, diskotek osv.) var otillgängliga och därmed begränsade eller hindrade barnen och ungdomarna med rörelsehinder att utföra och delta i olika aktiviteter. Att kamraterna saknades i skolan beskrevs bero på att det fanns sociala hinder i form av uteslutning från kamratgruppen och att barnen/ungdomarna valde att umgås med den assistent som ständigt fanns vid deras sida för att ge praktiskt och socialt stöd. Vid en närmare granskning av relationernas art (till kamrater) kunde konstateras att de få relationer som beskrevs inte alltid var ömsesidiga, till exempel när
barnen/ungdomarna med rörelsehinder fyllde år och bjöd sina kamrater till födelsedagsfest, var det få som kom.

Nätverksskaran visade att barnen och ungdomarna med rörelsehinder hade fler relationer i sektorerna familjen och släkten än den jämförande gruppen. De olika familjemedlemmarna gav barnen och ungdomarna med rörelsehinder känslosmässigt och praktiskt stöd och det fanns alltid någon i familjen som brydde sig om dem. Hos den jämförande gruppen återfanns liknande resultat men med en skillnad, att även kamraterna gav känslosmässigt och praktiskt stöd. Relationer till andra vuxna som barnen och ungdomarna med rörelsehinder hade var till de professionella, det vill säga assisterter, lärare, läkare, sjukgymnaster, arbetsterapeuter osv. vilket den jämförande gruppen saknade.

Studie II
Denna explorativa studie kom att fungera som en pilotstudie till artiklarna III, IV och V. Syftet var att få förståelse för om hur barn med rörelsehinder uppfattar sina tekniska hjälpmedel i leksituationer. Resultatet visade att barn med rörelsehinder inte hade erfarenhet av att deras tekniska hjälpmedel var något hinder i själva leken. Däremot var det flera miljöer (fysiska och sociala) som innehöll barriärer som försvårade deras möjligheter att leka. Resultatet presenteras i följande tre kategorier, 1) Relationen till tekniska hjälpmedel, 2) Relationen till lekmiljön, och slutligen 3) Relationen till assistenter/föraldrar.

Den första kategorin, Relationen till tekniska hjälpmedel beskriver en individuell relation där barnen uppfattade sina hjälpmedel på olika sätt. De yngre barnen (mellan 6 och 9 år) beskrev sina hjälpmedel (t ex. orthoserna) som en naturlig del i deras liv och som något som tillhörde deras kropp och var förutsättningen för dagliga aktiviteter. Medan de äldre barnen (mellan 10 och 11 år) reflekterade över att de var i behov av hjälpmedel för att kunna förflytta sig och att det var något som andra barn inte hade. De äldre barnen beskrev också att hjälpmedlen hindrade dem i deras sociala relationer till jämnåriga eftersom de inte kunde delta i alla aktiviteter som andra barn inte hade. De äldre barnen beskrev också att hjälpmedlen hindrade dem i deras sociala relationer till jämnåriga eftersom de inte kunde delta i alla aktiviteter som andra barn gjorde.

Den andra kategorin, relationen till lekmiljön, delades in i två undergrupper en innemiljö och en utemiljö. Barnens relation till innemiljön beskrevs som harmonisk och utan hinder. Lekaktiviteterna som barnen utförde var ofta stillsamma som till exempel att lyssna på musik, lägga pussel, rita eller spela TV-spel. Att leka i utemiljön beskrevs som roligt men fyllt av hinder. Det var svårt för barnen att komma till lekplatsen med sin rullstol eftersom markunderlaget ofta var svårhållbart och dådet var av sand. Lekredskapen var sällan utformade så barnen själva kunde använda dem och andra barns framfart på lekplatsen kunde vara skrämmande då barnen med rörelsehinder inte kunde förflytta sig lika bra. Utemiljön innehöll även hinder beroende på årstid. Vintertid var det svårare för barnen att vistas ute eftersom framkomligheten var försämrad på grund av dåligt
plogade gångbanor. Även kylan medförde att barnen inte kunde vistas ute lika länge som andra barn eftersom de blev kalla när de satt stilla i sina rullstolar. Sommartid var det lättare att leka utomhus men det var svårt att följa med kamraterna överallt som till exempel till badstranden där det var svårt att komma fram.

Tredje kategorin, relationen till assistenter/föraldrar visar att de yngre barnen såg assistenten som en del i deras liv, ibland även som en vän eller lekammat, medan de äldre barnens ifrågasatte varför de var tvungna att ha assistent. Relationen till föräldrarna beskrevs av barnen som traditionell där pappan var den som barnen gjorde roliga saker tillsammans med, medan mamman fungerade som organisatör, det vill säga planerade barnens resa till skolan, skjutsade barnet till aktiviteter så som handikappridning eller olika fritidsaktiviteter. Barnen beskrev de vuxnas närvaro som en förutsättning för att de skulle kunna leka. Ibland behövde den vuxna bara finnas i närheten men ibland krävdes ett mer aktivt deltagande. De yngre barnen reflekterade inte så mycket över att ha de vuxna vid sin sida medan de som var äldre önskade att göra saker på egen hand utan vuxnas närvaro.

Studie III
Resultatet av studie II visade att barnen uppfattade sina hjälpmedel dels som en naturlig del av deras kropp och dels som en förutsättning för att kunna förflytta sig. Barnen berättade även att deras hjälpmedel hindrade sociala relationer till jämnåriga varför det var angeläget att erhålla fördjupade kunskaper inom detta område. Det primära syftet med studie III var därför att beskriva hur barn med rörelsehinder själva uppfattar sina tekniska hjälpmedel och om de tror att deras tekniska hjälpmedel hjälper eller hindrar dem i interaktionen med andra, huvudsakligen kamraterna. Resultatet visade att hjälpmedlen hade ett statusvärde (hög-låg status) för barnen och att statusen räknades socialt, det vill säga i förhållande till kamraterna snarare än hur användbara de olika hjälpmedlen var. Hjälpmedlets sociala värde framhölls av de rörelsehindrade barnen således i större utsträckning än den funktionella nyttan dessa hjälpmedel hade utifrån hjälpmedlets fördelar respektive nackdelar.

Elektrisk och manuell rullstol hade höga statusvärden och beskrevs som betydelsefulla hjälpmedel. Den funktionella nyttan, det vill säga möjligheten till förflytning som den elektriska och manuella rullstolen hade bland de studerade barnen kompletterades av det höga sociala statusvärdet och ledde till att barnen fick vara både autonoma och delaktiga i kamratkontakten på mer jämliga villkor. Barnen som ägde en elektrisk rullstol blev i många fall ”intressantare” i de andra barnens ögon och fick därför vara med i olika lekar.

Ortosen var det hjälpmedel som skilde sig från de andra eftersom den inte uppfattades av barnen som ett hjälpmedel utan snarare som en förstärkning av kroppen och fick därför ett neutralt statusvärde. Ortosens nackdelar beskrevs bero
på att de begränsade barnens rörlighet och framkomlighet men hade även en estetisk nackdel, det vill säga den påverkade utseendet på ett negativt sätt. Ortosen förtydligade att benen inte kunde användas i samma utsträckning som hos kamraterna och upplevdes speciellt av äldre flickor som någonting fult och något man inte ville visa sina kamrater.


Arbetsstolen som var det hjälpmedel som användes i skolmiljön fick det lägsta statusvärdet i barnens ögon. Det berodde till stor del på att den var svår att sätta sig i men hade trots allt bra sittkomfort. Den skilde också ut barnen med rörelsehindr från kamratgruppen eftersom den försvårade barnens möjligheter till förflyttnings i klassrummet och påminde barnet om dess oförmåga. Arbetsstolens låga statusvärde kan därmed förklaras genom att den skapade distans i förhållandet till kamraterna.

Studie IV

Barnens berättelser i studie II visade att deras lekar var förknippade med en rad hinder, dels miljöer som var otillgängliga men även otillgängliga lekredskap på lekplatser. För att få mer kunskap om barnens lek företogs denna studie (studie IV) där syftet var att erhålla kunskap och förståelse för hur barn med rörelsehinder leker i olika leksituationer. Denna studie resulterade i en teoretisk modell som beskriver barn med rörelsehinders lek på tre olika sätt: 1) Lek med kamrater, 2) Lek ensam, 3) Lek med vuxna. Varje kategori beskriver barnens lek, bakomliggande faktorer till en viss typ av lek och lekens karaktäristiska drag och vissa bestämda konsekvenser. Att leka med kamrater var den minst förekommande leken, medan att leka ensam var den mest förekommande leken tätt följd av leken med vuxna.

Lek med kamrater utgjordes av två slag- dels var barnen med rörelsehinder aktiva medspekare i leken och dels var de åskådare till andras lek. Lek där barnen var aktiva deltagare föranledes ofta av att det saknades en aktör i leken, vilket kan exemplifieras med att när andra barn skulle leka och det saknades en aktör tillfrågades de rörelsehindrade barnen om de ville vara med. Initiativet till leken

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kom således i huvudsak från andra än från barnen med rörelshinder. Deltagandet i dessa lekar medförde att barnen med rörelshinder ofta fick roller i leken med lägre status än de andra barnen, till exempel fick de vara lillasyster i familjeleken eller fiende i krigsleken.

I andra leksituationer beskrev barnen sig som aktiva deltagare i leken även om observationerna visade att de var åskådare till andra barns lek. Här framkom en klar diskrepans mellan vad barnen upplevde, vad de berättade på uppmaning och vad observationerna visade. Lekarna som barnen berättade om var olika regellekar så som till exempel kurragömma, fotboll eller ishockey. Regellekens karaktär gjorde det svårt för barnen med rörelshinder att delta vilket medförde att de istället blev åskådare till andra barns lek. Trots att observationerna visade att barnen stod vid sidan om och var åskådare beskrev de ett aktivt deltagande i leken.

De ovan beskrivna leksituationerna i kategorin lek med kamrater karaktäriseras som lek på andras villkor. Initiativet till leken togs av andra, eller så fick barnen med rörelshinder vara med i brist på någon annan lekkamrat. Även när de var åskådare till andra barns lek var det på andra barns villkor. Barnen med rörelshinder tillfrågades sällan om att delta i rollekar och hade inte heller någon huvudroll i dem. Lekarna styrdes av andra, dess tema och innehåll valdes av andra och det mesta av aktiviteten och kreativiteten utfördes av andra. Konsekvenserna av denna typ av lek, det vill säga lek med kamraterna var ändå att barnen med rörelshinder kände sig glada och tillfreds med att ibland få vara med.

Faktorer som gav upphov till kategorin, Lek ensam, berodde ofta på att det saknades kamrater att leka med eller att barnet föredrog att leka ensam på grund av negativa erfarenheter från tidigare leksituationer med kamrater. De negativa erfarenheterna kunde exemplifieras i form av besvikelser när kamraterna inte ville leka med dem eller ens tog notis om dem trots att de befann sig i närheten av en grupp lekande barn. Kategorin, leka ensam, representerades av alla barnen och ensamleken förekom i hemmet, skolan eller dess närhet. Lekarna som barnen beskrev var typiska pojk- och flicklekar, det vill säga lek med bilar eller dockor. Det karaktäristiska för denna typ av lek kan beskrivas som att barnen med rörelshinder ofta valde att leka ensamma eftersom det saknades kamrater att leka med. Även när barnen med rörelshinder tog initiativ till lek var det sällan som någon kamrat ville leka med dem och observationerna visade tydligt att barnen ofta var utanför leken. Konsekvenserna av att leka ensam var att barnen ändå tyckte om dessa lekar, men samtidigt beskrev de känslor av övergivenhet och utanförskap.

Lek med vuxna speglas av faktorer där den vuxne, ofta assistenten, tog initiativ till lek. Initiativet kom från den vuxne när barnet inte hade någon kamrat att leka med i skolan eller fritiden och den vuxne ersatte på så vis kamraterna. Vissa lekars

Studie V
Som det framkom i studie II var de vuxna (assistenter/föräldrar) många gånger förutsättningen för att barnen skulle kunna vara deltagare i aktiviteter. Den ständiga närvaron av vuxna gav en bild av att assistenten kunde antas vara en nyckelperson i barnens liv varför det kändes viktigt att närmare studera hur assistentens närvaro påverkade barnen. Resultaten visade att det var både svårt och tidskrävande för barnen och ungdomarna att etablera en relation till sin assistent. Relationerna till/från assistenten både var och inte var ömsesidiga och det fanns relationer som upplevdes ambivalenta.

Samtliga barn och ungdomar hade lång erfarenhet av att ha en personlig- eller en elevassistent. Alla barn/ungdomar hade även fått byta till nya assistenter vid ett flertal tillfällen och erfarenheterna hos samtliga var att assistenterna är utbytbara. Att ständigt byta assistent medförde att barnen/ungdomarna gång på gång fick berätta ”allt” om sig själva för en ny och okänd person, vilket uppfattades som ett intrång i deras integritet. Relationen som barnen hade till sin assistent upplevdes därför inte alltid som ömsesidig.

För flera av barnen och ungdomarna var erfarenheten vidare att assistenten upplevdes ha rollen som en mamma/pappa, både i förhållande till barnen/ungdomarna och i förhållande till deras kamrater. Assistenten i denna roll medförde hinder i relationen till kamraterna eftersom assistenten ofta övertog leken och bestämde hur och vad barnen skulle leka eller för ungdomarnas del vad de skulle göra. När assistenten hade denna roll (rollen som mamma/pappa) uppkom situationer som inte uppskattades av barnen och ungdomarna.

I följande kategori (Den professionella assistenten), upplevdes assistenten som ett stöd i praktiska situationer och visade ungdomarna respekt och lyhördhet för
ders önskemål och synpunkter. När assistenten var professionell kände sig barnen och ungdomarna mer likvärdiga sina kamrater. Speciellt för ungdomarna var detta viktigt eftersom de eftersträvade en likhet med kamraterna när de sökte sin egen identitet.


Studie VI

I huvudkategorin (Vem är jag) berättade samtliga ungdomar att funktionshindret hade lite betydelse för vem de själva uppfattade att de är och att de i sin självpresentation beskrev att de identifierade sig med andra ungdomar i gruppen tonåringar. När ungdomarna däremot skulle berätta om sina erfarenheter kring hur de uppfattade att andra betraktade dem hade funktionshindret ofta en avgörande betydelse, det vill säga deras erfarenheter var att de ofta blev sedda med fokus på sitt funktionshindre och inte som den person de är. Ungdomarnas erfarenheter visade att även tillgängligheten i olika miljöer (både fysiska och sociala) påverkade hur de uppfattade sig själva och hur de blev betraktade av andra. I fysiska miljöer där tillgängligheten var god (till exempel i hemmet) såg ungdomarna sig som vanliga ungdomar. Medan däremot fysiska miljöer med dålig tillgänglighet (till exempel olika utemiljöer som skolgårdar) medförde att ungdomarna ofta kände sig annorlunda när de inte kunde delta i aktiviteter och gemenskap.

Den första underkategorin (Relationer till kamrater) ger en beskrivning av både spända och bristfälliga relationer med kamrater. Ungdomarna ansåg att orsaken var funktionshindret som hindrade dem i relationerna och att funktionshindret gjorde att kamraterna såg dem som annorlunda. För att exemplifiera detta berättade ungdomarna att det inte alltid kunde vistas i samma miljöer som kamraterna eftersom miljön var svårframkomlig med de tekniska hjälpmedel de använde på grund av olika hinder så som sand eller ojämnt markunderlag osv. Ungdomarna berättade också att de fort blev trötta när de utövade aktiviteter och var tvungna att gå hem långt före kamraterna vilket medförde att de inte hade så många erfarenheter av aktiviteter tillsammans med kamrater utanför skoltid. Relationerna till jämnåriga innehöll även sociala barriärer i form av attityder vilket medförde att ungdomarna redan från tidig skolålder känt sig uteslutna från kamratgruppen.

Följande underkategori (Relationer till vuxna) beskriver ungdomarnas erfarenheter av relationer till vuxna, huvudsakligen till föräldrar och assistenter men också till lärare. Relationen till föräldrar skedde huvudsakligen i hemmiljön där ungdomarna var i behov av praktisk hjälp på grund av sitt funktionshindre. Relationen till mamman beskrevs ofta som emotionellt nära eftersom hon förutom att hon var ett praktiskt stöd även fanns till hands känslomässigt. Ungdomarnas relation till föräldrarna beskrevs även innehålla en asymmetri där föräldrarna bestämde och kontrollerade ungdomarna vilket uppfattades av ungdomarna som ett hinder i utvecklingen av självständigheten. Ungdomarnas relation till assistenten beskrevs som ambivalent, det vill säga ibland upplevdes relationen ömsesidig och ibland inte. När ungdomarna upplevde att relationen var ömsesidigt kändes det positivt och en sådan relation återfanns fram för allt under skoltid när assistenten var ett praktiskt stöd eller när assistenten hade rollen som kamrat och deltog i olika aktiviteter. När däremot assistenten bestämde över ungdomarna i rollen som mamma/pappa kände sig ungdomarna kräkta eftersom
de nu var ungdomar och ville utvecklas till självbestämmande oberoende individer. Relationen till läraren i skolan var däremot näst intill obehintlig eftersom ungdomarna ofta var hävats åt till assistenten. Få av ungdomarna hade erfarenhet av att läraren pratade direkt till dem, eftersom lärare ofta pratade till dem genom assistenten. Ungdomarna exemplifierade detta med situationer när de försökt tâlta läraren med blivit ignorerade och/eller åter hävats åt till assistenten vilket uppfattades som kränkande.


DISKUSSION

Det övergripande syftet med denna avhandling var att beskriva hur barn och ungdomar med rörelsehinder själva uppfattade sina roller, relationer och aktiviteter med jämnåriga och vuxna i olika miljöer. Med utgångspunkt i den utvecklingsekologiska modellen (Bronfenbrenner, 1979) och därmed antagandet om att barns roller, relationer och aktiviteter varierar beroende på den speciella miljö (både fysisk och social) som barnet befinner sig i, visade resultatet att de rörelsehindrade barnens och ungdomarnas roller, relationer och aktiviteter ofta var av annan karaktär än hos jämnåriga. Skillnaden orsakades dels av att antalet jämnåriga i barnens, men framför allt i ungdomarnas sociala nätverk var begränsade till följd av att flera miljöer där jämnåriga vistades var otillgängliga. Dels av att bristfälliga kontakter med jämnåriga ledde till en social isolering från den kamratgrupp de egentligen ville tillhöra. Att berövas relationer med jämnåriga kan påverka möjligheten att utveckla och träna sig i olika roller och kan medförö brister i en kommande rollrepertoar. Vilka roller ett barn upplever att det tilldelas, vilket bemötande rollen upplevs ge och hur rollen upplevs av barnet, kan enligt Mead (1934) påverka utvecklingen av identiteten, det vill säga vilka roller ett barn upplever att det tilldelas påverkar vem barnet uppfattar att det är och vem barnet kommer att bli och vilken social värld barnet kommer att tillhöra.
Nedan kommer barnens och ungdomarnas uppfattningar av sina roller, relationer och aktiviteter i olika miljöer att diskuteras var för sig.

Roller
För att bli en del av en social gemenskap behöver ett barn i takt med att det växer och blir äldre utveckla en rad kompetenser, det vill säga träna sig i olika nya roller som utvecklar barnet vid en viss tidpunkt, i en viss miljö. Dessa nya kompetenser kan barnet sedan ta med sig till andra miljöer för att utveckla nya eller vidareutveckla ömsesidiga roller (Mead, 1934). Av resultaten i föreliggande avhandling framgår att barnen och ungdomarna med rörelsehinder upplevde att de tilldelades och utvecklade olika roller i olika miljöer och att miljöns tillgänglighet var en bidragande orsak till vilka roller som utvecklades. I hemmet utvecklade de rörelsehindrade barnen och ungdomarna roller som andra barn/ungdomar, det vill säga de ingick i relationer som var ömsesidiga och de hade roller som barn i en familj i förhållande till sina föräldrar, roller som syskon i förhållande till yngre och/eller äldre syskon osv. Rollerna var önskade och gav barnet/ungdomen en positiv identitetsroll när de själva och andra uppfattade dem som barn eller ungdomar i en familj och som barn/ungdomar i förhållande till jämnåriga. Familjens betydelse för att barn och ungdomar ska utveckla önskade roller betonas av flera forskare (jmf. Pettit et al., 2000) och hemmet beskrivs ofta som en viktig miljö där barn med stöd av vuxna kan utveckla önskade roller vars erfarenheter de sedan kan ta med sig vid utvecklandet av roller i andra miljöer.

motsvarar de förväntningar som andra har på dem och en avvikareroll är då under utveckling. Huruvida barnet eller ungdomen identifierar sig som en person med "mindre förmåga att erhålla liknande/samma roller som jämnåriga" är emellertid en fråga om barnets tolkning av situationen. Kanske kan barn redan från sex till tio års ålder ha "ett speciellt perspektiv på vad det innebär att kunna något" (Gustavsson, 1998, s 84). Att vara innehavare av liknande/samma roller som jämnåriga återspeglas i resultatet i den aktuella avhandlingen när de rörelsehindrade barnen berättade att om de bara gavs möjlighet till deltagande i lek i samma miljöer som kamraterna skulle de också klara av att inneha liknande/samma roller. De rörelsehindrade ungdomarnas berättelser var liknande när de önskade ingå i framtida roller som till exempel pojkvän/flickvän.


Relationer
Relationer är en annan aspekt av Bronfenbrenners teori och i likhet med roller utvecklas relationer i olika miljöer. Resultatet av denna avhandling visade att flera miljöer där jämnåriga vistades (lekplatser, sporthallar, diskotek, caféer osv.) var miljöer de rörelsehindrade barnen/ungdomarna sällan besökte till följd av fysiska barriärer. När miljöerna inte var tillgängliga fanns inte heller möjligheter till att utveckla relationer till jämnåriga. Att inte kunna delta i olika miljöer kan enligt den sociala modellen (Oliver, 1996) medföra en uteslutning från den sociala gemenskapen där relationer utvecklas. Kanske var det just därför barnen och ungdomarna med rörelsehinder hade så få relationer till jämnåriga och beskrev relationerna som bristfälliga, spända och ambivalenta, en slutsats som även andra


De undersökta barnen och ungdomarna var relaterade till vuxna i flera miljöer, det vill säga till vuxna både i hemmet, i skolan och under fritiden. I hemmet fanns föräldrarna, i skolan hade barnen/ungdomarna relationer till assistenter och på fritiden beskrevs relationer till släktingar och assistenten. Barnen/ungdomarna beskrev sina relationer till vuxna både som ömsesidiga, ambivalenta och asymmetriska. De ömsesidiga relationerna återfanns framför allt i hemmet till föräldrarna och släktingar men också till assistenten i vissa skolsituationer. Ömsesidiga relationer upplevdes positiva och utvecklades när barnet/ungdomen visades respekt och när det fanns möjlighet till självständighet. Att relationer är ömsesidiga anses viktigt för individens utveckling och förbereder även till att kunna skapa relationer längre fram i livet (Bronfenbrenner, 1979).


Ungdomarnas relationer till vuxna (föräldrarna och assistenten) var även asymmetriska, det vill säga relationer där den ena har mer makt än den andra. När de vuxna inte lämnade utrymme för spontana aktiviteter eller inflytande till självständighet kände sig ungdomarna kontrollerade av de vuxna och relationerna beskrevs asymmetriska. Barron (1997) beskriver just hur utvecklingen av självständighet kan påverkas för ungdomar med funktionshinder som är i behov av en noggrann planering av det dagliga livet. Om vuxna som planerar det dagliga livet för funktionshindrade barn och ungdomar inte tar hänsyn till att skapa utrymme för att utveckla självständighet kan det medföra oro för konflikter och upplevelser av besvikelser. Just oro för konflikter var vad de intervjuede ungdomarna med rörelsehinder i denna avhandling beskrev om de inte kände sig tacksamma och nöjda med den hjälp de fick av de vuxna, samtidigt som de ville vara som andra ungdomar och själva bestämma över sina liv. Bronfenbrenner (1979) anser dock att det är utvecklande för barn och ungdomar att ha erfarenheter av olika typer av relationer och att erhålla erfarenheter av relationer med olika makt. Visserligen är alla barn-vuxenrelationer i viss mån asymmetriska i den meningen att vuxna har mer att säga till om än barn, men när vuxna (t ex. elevassistenten i skolan) bestämmer över barn/ungdomar och sällan frågar efter deras synpunkter kan det hindra utvecklingen av självständighet och oberoende och barnen kan uppleva att de saknar kontroll över sina liv och känna sig bundna när de försöker att frigöra sig från föräldrarna och bli självständiga (jmf. även Johnson, 1995; Sathananthan & David, 1997; Blomqvist et al., 1998).
Aktiviteter


Resultatet visade att barnen/ungdomarna i hemmet tillsammans med familjen eller ensamma utövade en mängd olika aktiviteter. Barnen beskrev att de lekte kreativa lekar eller typiska pojk- och flicklekar, det vill säga lekte med bilar eller dockor, ensamma eller tillsammans med sina syskon, föräldrar och släktingar. Ungdomarnas erfarenheter av aktiviteter i hemmet var att de ofta utövade stillsamma ensamma aktiviteter som att läsa, lyssna på musik eller se på TV. Tillsammans med familjen gjorde också barnen och ungdomarna utflykter och resor. De beskrivna aktiviteterna saknade dock relationer till jämnåriga men det kan tänkas att familjen och den närmaste släkten i viss mån kan kompensera avsaknaden av jämnåriga i aktivitetsomgivningen inom hemmet, men de vuxna kan aldrig ersätta samspelet med andra barn (Hartup, 1995). För ungdomar som berövas det normala omgändet med jämnåriga kamrater kan brister i deras referensram uppstå eftersom det är i kamratgruppen ungdomar utvecklar och formar sin sociala värld och sin framtida identitet (Smith, 2000).

Avhandlingens resultat visade även att barnen och ungdomarna med rörelsehinder hade få erfarenheter av aktiviteter tillsammans med jämnåriga i andra miljöer utanför hemmet, som till exempel fritidsmiljöer. Barnen hade få erfarenheter av aktiviteter tillsammans med jämnåriga i fritidsmiljöer och berättade att det var svårt att leka på lekplatsen till följd den otillgängliga miljön och de otillgängliga lekredskapen, men även bristen på lekkamrater bidrog till mindre deltagande i aktivitet. Ungdomarnas erfarenheter visade att miljöer där jämnåriga vistades och utövade aktiviteter så som caféer, sporthallar, diskotek osv. var miljöer de sällan besökte eftersom de innehöll fysiska barriärer och därmed också fungerade som hinder för deltagande i aktiviteter. Detta medförde en social isolering från den kamratgrupp ungdomarna med rörelsehinder egentligen ville tillhöra och utöva aktiviteter tillsammans med. Att inte delta i aktiviteter tillsammans med jämnåriga kan innebära att barn/ungdomar får färre tillfällen att utveckla för åldern anpassade sociala beteenden (Spirito et al., 1991; Ellerton et al., 1996). Hur en sådan uteslutning från kamratgruppens sociala gemenskap återspeglas i den värld som barn och ungdomar med rörelsehinder befinner sig i och hur den kommer att påverka dem, hjälpa dem eller hindra dem att finna sin väg i livet har vi för närvarande lite kunskap om. Betydligt mer forskning behövs
för att undersöka och analysera aktivisternas betydelse under deras väg från barndom till vuxen ålder.


I den aktuella avhandlingens resultat tycks det finnas ett samband mellan de aktiviteter barn och ungdomar med rörelsehinder företar sig, de relationer de har till jämnåriga/vuxna och den möjlighet som finns för att besöka miljöer där aktiviteter äger rum. En förklaring till att barnen och ungdomarna med
rörelsehinder i den aktuella avhandlingen utövade färre aktiviteter tillsammans med jämnåriga än icke funktionshindrade barn kan tolkas som ett resultat av att flera miljöer där jämnåriga vistades innehöll fysiska barriärer som hindrade de rörelsehindrade barnen att besöka dessa miljöer. Avhandlingens resultat stödjer således det som forskare i andra länder kommit fram till (Missiuna & Pollock, 1991; Stevens et al., 1996; Mulderij, 1997), det vill säga att barn och ungdomar med funktionshinder har svåra delta i aktiviteter tillsammans med jämnåriga än barn/ungdomar utan funktionshinder och det på grund av olika sociala och fysiska hinder. Om resultaten ses utifrån den sociala modellen av Oliver (1996), är det miljöernas utformning som stänger ute barn med funktionshinder från deltagande i aktivitet. När miljöer är konstruerade så att barn och ungdomar med funktionshinder inte kan utföra aktiviteter på egen hand utan istället blir beroende av hjälp från någon vuxen blir funktionshindret en fråga om den enskilde individens tillkortakommande medan fysiska och sociala miljöers tillgänglighet inte ifrågasätts. När möjligheten att delta i aktiviteter inte finns eller om deltagandet kräver ständigt hjälp av vuxna kan det leda till att olika färdergheter aldrig förvärvas och att en känsla av bristande kompetens och dåligt självförtroende utvecklas hos barn och ungdomar med funktionshinder (Missiuna & Pollock, 1991).

Sammanfattande slutsatser

Sammanfattningsvis kan konstateras att barnens och framför allt ungdomarnas erfarenheter visade att de hade färre kamrater, att deras sociala nätverk innehöll få jämnåriga och att deras roller och relationer var av annan karaktär än hos jämnåriga. När kontakter med jämnåriga saknades återstod ett socialt liv tillsammans med vuxna som föräldrar, släktingar och professionella (assistenten).
IMPLIKATIONER

Vad kan man då göra för att hjälpa dessa barn och ungdomar att utveckla önskade roller, ömsesidiga relationer och möjligheter till deltagande i aktivitet?

De vuxna som finns i hemmet bör ses som viktiga personer med uppgift att fungera som länk till andra sociala miljöer, till exempel fritidsmiljöer där barnet kan ges möjlighet till aktiviteter och sociala interaktioner tillsammans med jämnåriga. Hur den sociala miljön för barn med rörelsehinder ska organiseras på fritiden är till stor del en normativ fråga och det borde ses som en utmaning för fritidsverksamheter att skapa arenor där barn oavsett om de har ett funktionshinder eller ej, kan mötas och ges tillfällen till interaktioner med jämnåriga. Men också professionella som arbetar med miljö och tillgänglighet (t ex. arbetsterapeut) kan genom att analysera barnets olika fysiska miljöer identifiera tillgängligheten och därigenom se till att de hjälpmedel barnen använder fungerar adekvat i de miljöer och aktiviteter som barnet önskar och därigenom hjälper barnet att nå de fysiska miljöerna där kamraterna finns (Stout, 1988; Case-Smith et al., 1996).

Att fysiska miljöer är otillgängliga beror till stor del också på de fördomar och sociala barriärer som finns i samhället idag, det vill säga samhällets syn på funktionshinder som utgår från den individuella handikappmodellen. Skolgång tillsammans med andra barn borde erbjuda delaktighet i en rad aktiviteter eftersom sociala interaktioner i sig innefattar en utvecklingspotential. Integrering i skolan måste därför ha till uppgift att se skillnader som en tillgång och inte som ett problem eller utifrån Barnes et al. (1999) beskrivning, det handlar om att se värdet i en grupp där alla får vara olika och där alla har en plats i gruppen. Skolmiljön bör även organisera på ett sådant sätt att funktionshinder inte skiljer barn åt utan istället främjar det sociala samspelet barn emellan. Socialt samspele borde kunna skapas genom att barn i skolan under ledning av vuxna, ges större ansvar för att barn och ungdomar med rörelsehinder tas med i lek och social gemenskap.

Professionella (t ex. sjuksköterskor, sjukgymnaster, arbetsterapeuter och elev- eller personliga assistenter) som arbetar med rörelsehindrade barn måste vara medvetna om det sociala nätverkets betydelse för dessa barn. För assistenter som ska stödja barn och ungdomar med funktionshinder i olika praktiska och sociala situationer är det viktigt att det finns en kunskap om vad det innebär för barn och ungdomar att ständigt vara i sällskap med en vuxen och vilket stöd som assistentarbetet innebär för att utveckla barnets möjligheter till social gemenskap i kamratgruppen. För flera av de professionella finns möjlighet att inom ramen för sitt arbete stödja och hjälpa dessa barn och ungdomar att etablera viktiga kamratkontakter och en möjlighet att utveckla en grupptillhörighet. Detta kan ske till exempel genom att sammankalla barn och ungdomar med likartade
funktionshinder och ge dem möjligheter att träffas inom habiliteringens regi. Detta förekommer inom ett flertal barnhabiliteringskliniker i Sverige idag, där man arbetar med så kallade ”kompisveckor”. Sjuksköterskan, sjukgymnasten och arbetsterapeuten har inom dessa ”kompisveckor” en viktig uppgift att i samarbete med skolans personal, elev- eller den personlig assistenten och föräldrarna, hjälpa barnen att utveckla och bygga upp sin sociala kompetens för att bli aktivare i sina sociala kontakter med jämnåriga kamrater också utanför gruppen rörelsehindrade (Bradley, 1994; Giangreco et al, 1993).
REFERENSER


Artikel I
Disability and social network. A comparison between children and adolescent with and without restricted mobility.

Lisa Skär, R.N., PhD student & Maare Tamm, PhD.
Luleå University of Technology, Department of Health Sciences
Hedenbrovägen
S-961 36 Boden, Sweden

ABSTRACT
The purpose of this study was to compare the social network (with particular emphasis on roles, relationships and activities) of school children and adolescents with restricted mobility (investigated group) with the social network of non-disabled school children and adolescents (comparison group). The group investigated consisted of 23 children and adolescents aged 7 to 19 years from northern Sweden. The results were compared with a group of 23 children and adolescents matched for age and gender from the same area. The children and adolescents were individually interviewed using the instrument “My social network.” The results showed that children and adolescents with restricted mobility had considerably fewer peers in their social network. Furthermore, these differences were greater among the adolescents. A plausible interpretation of these results is that there is a clear association between the number of peer relationships, accessibility to different surroundings and the possibility to perform various activities. How a social network that consists of members of the same age group affects children with restricted mobility is discussed according to Bronfenbrenner’s ecological theory and the perspective of Oliver’s (1996) social model of disability.

Key Words: social network, peers, children, adolescents, disability, relationships
INTRODUCTION
In this article we studied the social network of children and adolescents with restricted mobility and their perceptions of important relationships in their lives. Research on children with physical disabilities has shown that these persons have difficulty in making or keeping friends and are seldom spontaneously initiated in the play of other children (Missiuna and Pollock, 1991; Mulderij, 1996, 1997; Tamm & Skär, 2000). Children with physical disabilities are often excluded from peer groups in a variety of settings, including school and different types of leisure activity (Missiuna & Pollock, 1991, Mulderij, 1997; Prellwitz & Tamm, 2000). Furthermore, there is evidence that children with restricted mobility have limited possibilities to visit new settings because of the physical and psychosocial barriers imposed by these settings (Butler, 1984; Campos & Barenthal, 1987; Diamond et al., 1993). These barriers are partly due to the construction of mobility aids, which has made it difficult to use the aids in all settings, but they are also related to the fact that children with severe motor dysfunction are simply not accepted by their peers.

Moreno (1953), founder of the theories of psychodrama, socio-drama and sociometry, was one of the first to use the term 'social network'. However, already earlier, Kurt Lewin and George Herbert Mead had noted the importance of increased understanding of environmental factors and their influence on the social network of individuals. In the 1930s, Lewin (1951) developed his field theory, a theory that emphasised the influences of the immediate environment on the behaviour of the individual. Mead (1934) showed that a large part of a person's identity is formed by his or her roles in society and upheld through interaction with others.

During the 1970s, many researchers studied the interaction between environmental and interpersonal processes. Inspired by both Lewin and Mead, Urie Bronfenbrenner (1979) developed a model of the ecological environment (The ecology of human development). According to Bronfenbrenner, the child's primary environment is his or her family, which forms part of a microsystem, which includes the complex of relationships between the developing person and the immediate environment. Other microsystems of the child could include the child's day-care centre, school, recreation centre, peer groups and other groups in the child's social network. The older the child, the more complex becomes the child's microsystem. For the child's development, contact and communication with important persons in different microsystems are extremely important. This contact can be in the form of performing activities together, talking with each other and passing on important information to persons in other microsystems. If these contacts exist, this can give the child important links when entering new settings, which is especially intensive during the teenage process of liberation. During adolescence, the adolescent establishes social relationships in new contexts, i.e. new social networks are created. Through these networks, teenagers
gain access to relationships outside the nuclear family and their immediate circle of friends. The adolescent is perhaps in a stage of development when it is most evident that the creation of a social network is of crucial importance to future development (cf. Svedhem, 1991).

Bronfenbrenner’s model focuses on how “ordinary” children and adolescents (i.e. persons without disabilities) interact with other persons (e.g., friends, peers, teachers and family members) in numerous environments (i.e. different Microsystems) and how such interactions (or lack of them) influence these persons. The problems that children and adolescents with disabilities encounter are slightly different from those of persons without disabilities. Michael Oliver (1996) recently developed a social model of disability. His model is similar to Bronfenbrenner’s in that it, too, describes the individual’s interaction with other persons in different environments. However, it differs from Bronfenbrenner’s in that the model focuses on disabled people. According to this model, it is society that disables physically impaired people. It is the immediate environment that makes it difficult for individuals, such as disabled children and adolescents, to get about in their surroundings. It is these inaccessible settings that restrict the activities of persons with physical disabilities, especially persons with profound disabilities. Transportation problems can prevent the disabled persons from going out as often as they would like. Thus, the model asserts that society and its organisations take little account of persons with disabilities, excluding them from participation in the mainstream of social activities.

Today, there is fairly extensive research that concentrates on two aspects of children’s social network: one aspect describes the importance of the social network to children’s development and health while the other addresses children’s mental ill-health and social adaptation. Findings concerning the first aspect indicate how important it is that the social network should contain other persons (other adults, siblings and friends) that the child can turn to for practical and emotional support as well as general feedback. It also shows that the social network is important for the child’s health and well being (Furman & Buhrmester, 1985; Bö, 1989; Cochran & Bö, 1989; Cassidy & Asher, 1992). Research within the other area, i.e. research on children’s mental ill health and social adaptation (Svedhem & Swaling, 1989; Svedhem, 1991) indicates that children with behavioural problems (children who are aggressively extroverts and/or show much anxiety) have a fragmented and/or sparse social network. The implication is that these children not only have fewer adults and groups (e.g., family, relatives, friends, schoolmates and neighbours) in their social network but also that the networks contain a smaller number of connecting links between the different groups.

With mental ill health as a starting point, the psychologists Aresik-Ram and Elf developed an instrument they called ”My social network” (Aresik-Ram & Elf,
To date, the instrument has been used only in a therapeutic context (i.e. it has not been used as a tool in research), with the purpose of systematically setting children’s situations in a network perspective. Another purpose of the tool is to use structured conversations with children to contribute to knowledge of how they perceive important relationships in their lives.

There are few studies on the social network of children with restricted mobility. In one of the few published studies Ellerton et al. (1996) found that children with spina bifida became socially isolated from friends, which the authors felt was related to limitations of movement that was caused by their functional disability. This forced social isolation meant that the children experienced loneliness and a condition related to emotional or mental stress. In contrast, there are several studies on children with chronic illnesses (cystic fibrosis, asthma and cardiology) and their social networks (Zeltzer et al., 1980; Spirito et al., 1991; Ellerton et al., 1996). The results of these studies are consistent in showing that chronic illness can result in a sparser social network and a profound limitation on contacts with friends. These children in general also had a smaller number of friends in their social network in comparison with healthy children. With this background, the primary purpose of this study was to use Aresik-Ram and Elf’s instrument to compare the social network (with particular emphasis on roles, relationships and activities) of children and adolescents with restricted mobility with the social network of non-disabled children and adolescents.

METHOD
Subjects
Totally, 23 children (11 girls and 12 boys) with restricted mobility (target group), integrated in ordinary schools, participated in the study. They ranged in age from 7 to 19 years. The child with restricted mobility was defined as a person unable to move without a wheelchair, walking frame or other walking device. In setting this criterion, the selected children came to represent the following medical diagnoses: spina bifida, cerebral palsy, muscular dystrophy and polio syndrome. In addition, the children were required to have the capacity to respond to questions in the interview. These inclusion criteria, restricted mobility and good verbal communication skills, placed a limitation on the number of children that could take part in the study. Thus, we studied all children and adolescents with restricted mobility for all residents of two adjacent medium-sized municipalities in the north of Sweden during the year of 2000 and 2001.

The comparison group was made up of 23 schoolchildren with no physical disabilities. The children in the two groups (investigated and comparison) were matched on age (born in the same year and month) and gender. Children and adolescents in the comparison group attended ordinary schools of the same size and in the same two municipalities in Northern Sweden as those in the investigated group.
The children in the two groups were further divided into two age groups: age group 1 consisted of 10 children aged 7-12 years (mean age 9.92 years), and age group 2 was made up of 13 adolescents aged 13-19 years (mean age 17.42 years). This division was made because the development of more intense relationships with peers typifies adolescent years, which, in turn, influences the size and quality of their social network.

The children with restricted mobility were selected with the assistance of the chief physician in charge of the Children’s Rehabilitation Centre. For the comparison group, the headmaster of the schools in the two municipalities selected the children on the basis of the criteria described above. After the selection process, the chief physician and the headmaster sent a letter to the parents of the selected children requesting permission to interview their child. The purpose of the study was presented in the letter, where each participant was informed that they were guaranteed confidentiality and could withdraw from the study at any time. The parents of the children that accepted the invitation to participate in the study then contacted the researcher in order to set up an appointment for the interview. The project was approved by the ethics group at the Department of Health Sciences, Luleå University of Technology.

**Instrument**

All components of the Aresik-Ram and Elf instrument were used, except the section on conflicts, which is used only in clinical settings. The instrument was designed to analyse the social network of children aged from 7 years up to the late teens (Aresik-Ram & Elf, 1997). The instrument was developed within a clinical and therapeutic context and has been used to evaluate therapeutic conversations. The instrument consists of a network map listing all persons the child/adolescent knows, placing them in six sectors (family, relatives, schoolmates, friends, neighbours and professionals). In addition to the network map, the instrument comprises five question domains: intensity, practical support, emotional support, feedback and multiplexity. In the area of intensity the questions concern how important the child/adolescent perceives different persons in his or her social network. In the domains practical and emotional support, the questions address which network members the children/adolescents perceive themselves as receiving practical and emotional support from, and to which members the children give practical and emotional support. The feedback domain deals with which persons the child/adolescent feels give positive or negative reinforcement. Multiplexity refers to whether the interaction between the interviewed person (child/adolescent) and network members takes place based on more than one content, i.e. does the child carry out several significant activities with the persons in question?
Administrative procedure
All children and adolescents were individually interviewed at school by the first author following the result sheets for the instrument. The interviews, which took between 1 and 1.5 hours, started by asking the children/adolescents to list which people they knew best and met almost daily. At this time, the respondents were also asked to draw a social network map. The respondents were told that they could name as many people as they wished. Next, they were questioned about how they perceived important relationships to the people in their social networks, following the interview instruments five question domains comprising 28 questions.

RESULTS
The results are presented as a function of age groups (children and adolescents) in the investigated and comparison group but not in regard to gender because there were no significant differences. An initial overview is provided of the structure of the social network and the network members in the six sectors of the network map. These data are depicted separately for children (Figure 1) and adolescents (Figure 2). As indicated in Figure 1, the structure of the social network differs between disabled and non-disabled children. For children with restricted mobility, the number of network members (n = 154) is smaller as compared with non-disabled children (n = 218). For disabled children, 72 (46.8%) network members were children and 82 (53.2%) were adults; for the non-disabled children, 132 (60.6%) network members were children and 86 (39.4%) were adults. The pattern of the results indicates that the proportion of children in the social network is smaller for children with restricted mobility, whereas the proportion of adults is comparable between groups. The largest differences between disabled and non-disabled children are in the sectors schoolmates, friends and neighbours.

Figur 1. The number of network members in the six different sectors in the network map for the children.
As in children, the adolescents with restricted mobility have a smaller social network \((n = 177)\) than the comparison group \((n = 283)\) (Figure 2). For the adolescents with restricted mobility, 72 (40.7%) network members were adolescents and 105 (59.3%) were adults; for the comparison group, 174 (61.5%) network members were adolescents and 109 (38.5%) were adults. These results correspond to those in children; i.e. adolescents with restricted mobility have fewer peer contacts but about the same number of adult contacts as non-disabled adolescents. The largest differences between the investigated and comparison group are in the sectors of schoolmates, friends and neighbours, differences that are more pronounced in the adolescents as compared with younger children.

![Figure 2. The number of network members in the six different sectors in the network map for the adolescents.](image)

Below, the results for each of the five question domains (intensity, practical support, emotional support, feedback and multiplexity) are presented separately for children and adolescents.

**Intensity**

The results from the domain *intensity* show which persons the participants perceive as important. Important persons were described through relationships in a positive (e.g., a close friend giving practical or emotional support) or negative way (e.g., a person the participant was angry or disappointed with). Table I presents persons with whom children and adolescents perceive as important in their life.
Table I. The number of children and adolescents who perceived which members of the six different sectors in the network map were important to the child/adolescent.

<table>
<thead>
<tr>
<th>Age group 1 (7-12 yrs)</th>
<th>Relatives</th>
<th>Schoolmates</th>
<th>Friends</th>
<th>Neighbours</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>With restricted mobility</td>
<td>9</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Comparison group</td>
<td>8</td>
<td>5</td>
<td>9</td>
<td>10</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age group 2 (13-19 yrs)</th>
<th>Relatives</th>
<th>Schoolmates</th>
<th>Friends</th>
<th>Neighbours</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>With restricted mobility</td>
<td>12</td>
<td>6</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Comparison group</td>
<td>12</td>
<td>3</td>
<td>5</td>
<td>12</td>
<td>3</td>
</tr>
</tbody>
</table>

The data in Table I indicate that the important persons for children and adolescents (with and without restricted mobility) are within the family. However, the table also shows that children and adolescents with restricted mobility have fewer important persons in the schoolmates and friends sectors.

One of the questions asked concerned whether the child had a best friend. The children’s responses to this question are listed in Table II.
Table II. The number of children and adolescents in both age and comparison groups who have a best friend.

<table>
<thead>
<tr>
<th>Group</th>
<th>n</th>
<th>Have a best friend</th>
<th>Have no best friend</th>
<th>A child as a best friend</th>
<th>An adult as a best friend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group 1 (7-12 yrs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With restricted mobility</td>
<td>10</td>
<td>9</td>
<td>1</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Comparison group</td>
<td>10</td>
<td>10</td>
<td></td>
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<tr>
<td>Age group 2 (13-19 yrs)</td>
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<td></td>
</tr>
<tr>
<td>With restricted mobility</td>
<td>13</td>
<td>8</td>
<td>5</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Comparison group</td>
<td>13</td>
<td>13</td>
<td></td>
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</tbody>
</table>

The table indicates a difference between the target and comparison group, with the greater difference existing in the adolescents. In the investigated group there were children and adolescents who did not have a best friend, whereas all those in the comparison group had a best friend. Another difference between the groups was that children and adolescents in the investigated group had adults (parents or the assistant) who served the role of best friend. Such a relationship was not observed in the comparison group, where everyone had a person of the same peer group as a best friend. Another question about relationships concerned the people the participants invited to their birthday party. Half of the children and adolescents with restricted mobility stated that they generally do not have birthday parties because they have no friends to invite. If they did invite people to their party, they reported feeling uncertain as to whether anyone would come. "I don't invite anyone because I don't know whether anyone would come." "I usually invite everyone I know but nobody comes." The other half of the children and adolescents with restricted mobility usually had a party on their birthday, where some of them invited their friends of the same age while others invited only adults (e.g., family members, relatives or the assistant). All the participants in the comparison group invited peers to their birthday party.

To the question regarding with whom they would like to make a long journey, the children and adolescents with restricted mobility replied that most of all they would like to travel with someone in the family (a parent or sibling) or a close relative (a grandmother or cousin). For some of the adolescents, even the assistant was a possible travelling companion. In the comparison group, half the children would prefer to travel with their best friend while the remaining half would favour someone in the family; if given the opportunity, all of the adolescents in this group would choose their best friend as a travelling companion.
Practical support
Within the domain practical support, the results show from which sectors in the network map the children could either receive or give practical support. Practical support is defined as different kinds of help in practical situations (e.g., assistance with housework or homework). The results are presented in Table III.

Table III. The number of children and adolescents who perceived practical support from members of the six different sectors in the network map.

<table>
<thead>
<tr>
<th></th>
<th>Family</th>
<th>Relatives</th>
<th>Schoolmates</th>
<th>Friends</th>
<th>Neighbours</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group 1 (7-12 yrs)</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>With restricted mobility</td>
<td>10</td>
<td>10</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Comparison group</td>
<td>10</td>
<td>10</td>
<td>4</td>
<td>3</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td><strong>Age group 2 (13-19 yrs)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With restricted mobility</td>
<td>13</td>
<td>13</td>
<td>8</td>
<td>1</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Comparison group</td>
<td>13</td>
<td>13</td>
<td>4</td>
<td>1</td>
<td>13</td>
<td>2</td>
</tr>
</tbody>
</table>

The results in Table 3 indicate that all children and adolescents (with and without restricted mobility) gave or received practical support from the sector family. The children and adolescents' responses in the investigated group indicated that the father helped with household repairs while the mother helped with matters related to homework. The responses of the participants in the comparison group were similar, but with one important difference, namely, that the children in the comparison group also gave or received practical support from their friends.

Furthermore, it was not common for children with restricted mobility to help others with practical matters. Several stated that nobody ever asked for their help. "I don't know who I can help. There is never anyone who asks me." This tendency differed from the children in the comparison group; in this latter group everyone assisted others with practical things and group members frequently helped their friends.

Another question, which described the children's relationships within the area practical support, was whether they could borrow things from others. Half the children and adolescents with restricted mobility and all those in the comparison group reported that they occasionally borrowed things from others. They borrowed similar things in both groups, mostly from peers, things such as toys, books and games. Those children and adolescents in the investigated group that
did not borrow anything reported that they did not know to whom they could ask.

Emotional support
The questions regarding emotional support dealt with the network members from whom the children and adolescents perceived themselves as receiving emotional support, i.e. persons who asked how they feel or showed interest in their activities and with whom they could discuss emotional issues. These results are given in Table IV.

Table IV. The number of children and adolescents who perceived emotional support from members of the six different sectors in the network map

<table>
<thead>
<tr>
<th>Age group 1 (7-12 yrs)</th>
<th>The six different sectors in the network map:</th>
<th>n</th>
<th>Family</th>
<th>Relatives</th>
<th>Schoolmates</th>
<th>Friends</th>
<th>Neighbours</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>With restricted mobility</td>
<td>10</td>
<td>10</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison group</td>
<td>10</td>
<td>10</td>
<td>2</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age group 2 (13-19 yrs)</td>
<td>13</td>
<td>13</td>
<td>4</td>
<td>4</td>
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<td></td>
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<tr>
<td>With restricted mobility</td>
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<td>13</td>
<td>4</td>
<td>4</td>
<td>4</td>
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<td></td>
<td></td>
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<tr>
<td>Comparison group</td>
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<td>7</td>
<td>4</td>
<td>9</td>
<td>2</td>
<td></td>
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</tr>
</tbody>
</table>

As can be seen in Table IV, all the children and adolescents with restricted mobility felt that there was someone who cared especially for them (e.g., through asking how they feel or what they were doing). The emotional support was provided principally by someone in the family (parents or a sibling), but also by close relatives such as grandparents. The children and adolescents in the comparison group also felt that their friends and schoolmates gave emotional support, which was not so for the participants with restricted mobility.

Another question in this area concerned having someone the participants felt special trust towards in their social network. The participants’ responses indicated that few of the persons with restricted mobility had a confidant they could rely on. "I don't know. I don't think I have anyone to tell." Even when the participants felt afraid, most lacked someone they could confide in. "I never talk about things like that with anyone." "I have no one to whom I can discuss private matters with." Those few who said that they had a confidant reported this person to be their parent. In the comparison group everyone had someone they could confide in.
when they wanted to say something in confidence or when they were frightened. They also reported that they normally confided in their parents first, but also that their friends were always told eventually.

Feedback
The questions on feedback deal with the persons in the social network that the participants perceive to provide reinforcement, i.e. persons that create relationships where the participants become worthy of attention (e.g., by taking time to listen what the participants have to say). The results also illustrate which persons the participants give their reinforcement. These results are summarised in Table V.

Table V. The number of children and adolescents who perceived feedback from members or to which members they give feedback in the six different sectors in the network map

<table>
<thead>
<tr>
<th></th>
<th>Family</th>
<th>Relatives</th>
<th>Schoolmates</th>
<th>Friends</th>
<th>Neighbours</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age group 1 (7-12 yrs)</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>With restricted mobility</td>
<td>10</td>
<td>8</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Comparison group</td>
<td>10</td>
<td>10</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Age group 2 (13-19 yrs)</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>With restricted mobility</td>
<td>13</td>
<td>11</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Comparison group</td>
<td>13</td>
<td>13</td>
<td>3</td>
<td>5</td>
<td>12</td>
<td>1</td>
</tr>
</tbody>
</table>

The table shows that almost all of the persons with restricted mobility received reinforcement from their family. The comparison group, on the other hand, received reinforcement from persons in several network sectors, including peers. The data showed that all participants, except one child with restricted mobility, reported that they received praise from someone in their social network. The praise mainly came from the parents though it also came from the schoolteacher or the assistant. All the participants in the comparison group were also given praise by their parents, but unlike the children with restricted mobility, it was their friends who gave most approval and commendation.

Expressing admiration to someone else was done by only half of the participants with restricted mobility. The persons who received most praise were the same persons as those who gave praise (i.e. a parent, schoolteacher or assistant).
Whereas only a few of the adolescents with restricted mobility reported expressing admiration for a friend, all of the adolescents in the comparison group reported giving some form of praise.

Multiplexity
Multiplexity provides a depiction of the relationship between the participant and persons in the network map. This relationship is expressed through a description of those activities they carry out jointly. The participants' multiplex relationships are displayed in Table VI.

Table VI. The number of children and adolescents who perceived multiplex relations between members and themselves of the six different sectors in the network map

<table>
<thead>
<tr>
<th>Age group 1 (7-12 yrs)</th>
<th>Family</th>
<th>Relatives</th>
<th>Schoolmates</th>
<th>Friends</th>
<th>Neighbours</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>With restricted mobility</td>
<td>10</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Comparison group</td>
<td>10</td>
<td>9</td>
<td>10</td>
<td>8</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Age group 2 (13-19 yrs)</td>
<td>13</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>With restricted mobility</td>
<td>13</td>
<td>9</td>
<td>7</td>
<td>13</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Comparison group</td>
<td>13</td>
<td>9</td>
<td>7</td>
<td>4</td>
<td>13</td>
<td>3</td>
</tr>
</tbody>
</table>

The table shows that the participants with restricted mobility had fewer multiplex relationships as compared with the non-disabled participants. The differences in such relationships were most strongly observed in adolescents.

Multiplexity among children with restricted mobility entails performing several activities in conjunction with someone in the family (mother, father or sibling). These activities could be excursions to a summer cottage or a holiday trip. The comparison group performed multiple activities, mainly with peers, but also with others in their social network. Adolescents in the comparison group, for example, participated in various sports activities (e.g., football, ice hockey and basketball) several times a week. They had a strong bond with members of these groups, often spending time together outside the normal group activities (e.g., going to the cinema or discotheque).

DISCUSSION
The results of this study convincingly demonstrate that children and adolescents with restricted mobility had considerably fewer peers in their social network in comparison with non-disabled children and adolescents. Furthermore, the findings revealed that these differences tended to increase with age. The number of adults in the network map was about the same for individuals with and without restricted mobility. There are several possible explanations to account for this finding. First, previous research has shown that children and adolescents with restricted mobility are often excluded from being with peers in different settings (Missiuna & Pollock, 1991; Muldrij, 1997). Our results are consistent with this observation. It appears that children and adolescents with restricted mobility have more difficulty than their non-disabled age-mates in developing peer relationships. Our findings suggest that the reason young persons with restricted mobility have difficulty in building peer relationships is due to both physical and social barriers.

Another explanation to account for why physically disabled children and adolescents have fewer peers than non-disabled children and adolescents may be related to the surroundings where the latter individuals spend time. Especially during the adolescent years, young people tend to congregate in many different surroundings. Our results indicate that complex activities during the adolescent years are spent in a variety of settings, including sport arenas, movie theatres, discotheques and related places. In these surroundings accessibility is often severely restricted for persons with physical disabilities. In these locations we found that adolescents with restricted mobility had few contacts with members of the same age group. These data correspond with earlier research (Butler, 1984; Campos & Barenthal, 1987) and is in accordance with Oliver’s (1996) social model of disability, which asserts that it is society that is the cause of physically impaired people’s disability. If these locations were made adaptable for young people with restricted mobility, it is quite plausible that these people would develop a larger number of peer relationships in their social network.

Our overall results suggest there is interdependence between the number of peer relationships, the activities that individuals undertake and the settings in which these activities are carried out. These reciprocal relationships have not been examined within either the ecological model of Bronfenbrenner (1979) or the social model of disability of Oliver (1996). Bronfenbrenner purports that human development is facilitated through interaction with peers and participation in divergent physical and social environments. However, Bronfenbrenner says little about the specific problems that arise for persons with restricted mobility. Oliver’s model, on the other hand, focuses on physical disability and environmental problems. Yet, his model does not pertain to an individual’s interactions in these environments, but is more concentrated upon society’s central role. Future research should explore in greater detail the interdependence between peer relationships, activities that individuals enter upon and the
particular settings in which these activities are conducted. It would also be worthwhile to determine if steps taken to resolve environmental problems for persons with restricted mobility lead to an increase in their activities and the number of peer relationships. As it were now, one can ask what consequences a lack of peer relationships has on children and adolescents with restricted mobility. One can speculate that because children and adolescents with physical disabilities are often isolated and rejected (i.e. few quality peer relationships), these young people will be deprived of crucial social models. Such models are important in realizing social adjustment and social competence. Some investigations suggest that this is a realistic appraisal of the situation (Robinson & Stalker, 1998; Hartup, 2000).

When it comes to the social network's different sectors, the study revealed that children and adolescents with restricted mobility had most of their interrelationships with their family and relatives. Concerning the family, we found that it was the family members of children and adolescents with restricted mobility that gave both emotional and practical support: there was always someone in the family that showed concern for the child or adolescent's well being. Such support was also noted in the relatives of the disabled persons. With respect to support from family and relatives, our findings indicated that there were no differences between children and adolescents with and without restricted mobility. Bronfenbrenner (1979) also pointed out the importance of family and relatives, noting that the family is crucial as regards practical, everyday support. The author further proposed that it is at least of equal importance to the children's health and development to receive and give support to friends. However, our findings clearly demonstrate that disabled children and adolescents did not receive support from peers. Although we did not examine the affect that lack of support from the peer group has on physically disabled persons, we believe it is an important area for further research.

Another group of persons that disabled children and adolescents had a relationship to was professionals in health and education, including assistants, teachers, doctors, physiotherapists, occupation therapists and orthopaedic technicians. However, all these relationships involved adults and not peer groups. To have relationships with adults only may lead to the prevention of developmental progress of the children and adolescents' autonomy (Sathananthan & David, 1997; Blomqvist et al., 1998). Gaining independence from parents is an extremely important process during the adolescent years. For disabled persons, who have primarily been in the company of adults during their childhood, disengagement from parents can be a challenging process (Missiuna & Pollock, 1991; Sathananthan & David, 1997). It is common for the parents of a youngster with a physical disability to overprotect their child (Johnson, 1995): such overprotection of children with physical disabilities can, in combination with an absence of peer contacts, cause serious social problems. Having mainly adults and
only a few, if any, peers in the social network can significantly hamper the child’s possibilities to develop a sense of identity (cf. Mead, 1934; Eriksson, 1959). Bronfenbrenner (1979) also has drawn attention to how important it is that the microsystem includes a complex of relationships between the developing person and his or her social network.

Schools and neighbourhoods were the two sectors in which physically disabled participants had fewer relationships than physically non-disabled persons. Our findings demonstrated that the relationships that children and adolescents with restricted mobility have in school are chiefly with the assistants and teachers and not with classmates. The assistants in particular was the person that often gave both practical and emotion support in everyday situations. Concerning schoolwork, it was the teacher that provided feedback to the children and adolescents with physical disabilities. One interpretation for this situation is that although the disabled children and adolescents were integrated into the ordinary school system, the integration was only physical in character, without involving deeper incorporation into the social community of the school. Several researchers (e.g., Simeonsson et al., 2001; Baker & Donelly, 2001) have noted that the social integration process (defined here as promoting harmonious interaction and solidarity at all levels of society) in school today has focused solely on the physical surroundings, with social integration being largely neglected. According to Söder (1989) and Mattsson (1994), this trend to neglect, rather than enhance, social integration seems to be also true in Swedish schools. Without positive peer relationships even in school means that the disabled are shut off from schoolmates, a situation that must be construed as negative relative to personal development and high self-esteem. To improve the position for disabled school children schools need to work towards social integration by making appropriate arrangements so that peer contacts can develop and flourish naturally. In this respect, we believe that the social model of disability can be of relevance.

When we examine the relationships that the children and adolescents had with their peers more closely, we discover that not even these relationships were reciprocal. This observation is exemplified by the fact that when the children or adolescents had invited their peers to their birthday party, there were few, if any, that showed up. According to Bronfenbrenner (1979), mutual relationships and the mastery of a sophisticated set of reciprocal exchange skills play a particularly important role in the individual’s development. Such development is necessary in preparing the individual to build supportive network relationships later in life. If children and adolescents have limited opportunities to establish reciprocal relationships with peers, some important developmental experiences will be lost.

In summary, when the data are analysed, the most obvious finding is the large difference between the investigated and comparison group in the number of
peers in the social network of the two groups. The physically disabled participants had fewer peers in their social network, a tendency that became more marked with the transition from childhood to adolescence. This inclination, in turn, contributed to a condition in which physically disabled young people had more limited opportunities for various activities outside their homes. A sparsely social network yields fewer opportunities to train social roles, behaviour and proficiencies, which can affect children and adolescents’ development negatively (Bronfenbrenner, 1979). Looking at the life of these children and adolescent from the social ecology model of Bronfenbrenner (1979), the innermost circle (i.e. the microsystem) of the nuclear family seems to be particularly close, whereas the adjacent circle (i.e. the mesosystem of peers, neighbours and other acquaintances) may be less accessible. Beyond that, the exosystem of education (school system), leisure system (leisure activities) and organisations of different kinds are hardly suitable for physically disabled young people. How can one help develop the social network of physically disabled children and adolescents? Several researchers (e.g., Corohan & Bö, 1989; Belle, 1989; Robinson & Stalker, 1998) suggest that parents and other adults in close contact with these young people could function as bridge-builders to those activities that their peers engage in by, for example, helping them come into contact with other children, even if physical and social barriers exist. Parke and Bhavnagri (1989) argue that such parental facilitation of peer bonds, when carried out with the understanding of the child’s developmental needs, can result not only in a richer social network for children but also in improvements in children’s social skills. In accordance with the social model of disability, if public places and facilities (both social and physical) in which non-disabled young people spend time are made more accessible to young people with disabilities, it becomes possible to create activities and relationships on more equal terms.

Strengths and limitations of the study
The primary strength of this study is that the social network instrument (Aresik-Ram & Elf, 1997) provided rich information about the social network of children and adolescents with restricted mobility. A further strength of the study is that it included young people covering a wide lifespan (7-19 years). A third strength is that the study questions took up important themes that the children did not mention on their own accord (e.g., whether they had a best friend or someone they could confide in). A fourth strength is that the study is based on a series of questions administered directly to the children about their relationships with different categories of network members. This approach has the advantage of examining the social network from the respondents’ perspective, which we believe is particularly important in that it shows which components of the respondents’ social network that are psychologically important to them. A final strength is that the study includes an adequate comparison group.
The limitations of the study have mainly to do with issues related to sampling. The number of participants in the investigated group was unfortunately small. Furthermore, it was drawn from a clinical population and thus consisted only of children who were enrolled in the Children's Rehabilitation Clinic. Consequently, the sample is not necessarily representative of the entire population of interest (i.e. disabled young persons). Another limitation is that the social network instrument we used was developed in a clinical context and therefore lacks psychometric properties.

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REFERENCES


Artikel II
Disabled children’s perceptions of technical aids, assistance and peers in play situations

Lisa Skär RN
Doctoral Student, Department of Health Sciences, Luleå University of Technology, Boden, Sweden


Disabled children’s perceptions of technical aids, assistance and peers in play situations

The purpose of the study was to gain a deeper understanding of how children with disabilities perceive their technical aids in play situations. Transcribed interviews with eight children with disabilities were analysed according to the constant comparative method of grounded theory described by Glaser & Strauss. Three categories were found in the data, forming a model describing the child’s relations in play situations (core category): to technical aids, to assistance and to the play environment. Two of the categories included relations to adults. The children’s opportunities to play required that a parent or an assistant be present. Access to the playground also required the assistance of adults. The third category, relation to technical aids, is an individual one, as the technical aids were perceived differently by all the children. The technical aids were also seen as an extension of the child. The implications for parents and service providers are discussed.

Keywords: children with disabilities, technical aids, play, assistance.

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Introduction

For a child with motor disability, technical aids are a prerequisite for a ‘normal’ life. Technical aids give these children increased possibilities of a regular life. At the same time technical aids can be an impediment. The child with a disability cannot play like other children. To be dependent on technical aids (wheel chairs, crutches, splints and walking trolley) may create problems for children with disabilities in their psychosocial development.

From an early age the child with a motor disability has limitations in discovering the environment. This may present problems in the development of spatial perception. As children move around and explore their world, they receive information through their senses. For the disabled child the ability to explore and interact with the environment is impaired. The use of technical aids will assist children to develop their sensory and spatial capacity and thereby help the children to create an increased independence of others (1, 2).

When children with a motor disability grow up they may also face social obstacles. Studies show that children with a disability have problems making friends and they are seldom invited to spontaneous playgroups. They rarely take part in sports activities unless they are specially targeting children with disabilities (3–6). Limitations in daily activities are not only because of their disability, but also because of the technical aids, which cannot completely compensate for the impairment. This will, for example take place in the playground, which is not designed to meet the need of children with motor disabilities.

On the other hand, technical aids make children with motor handicap more independent and in charge of their environment. The use of aids make the environment more accessible and the aids make the children feel freer and this permits them to interact with other children more frequently. This interaction prevents them to develop secondary social and/or emotional handicaps (7, 8).

Our knowledge of the relationship between handicap and play is limited. Occupational therapy theorists have described how disabilities may affect a child’s play (9, 10). It is recognized that play dysfunction may impair a person’s ability to cope with new and complex situations (11) and impede the development of personal skills (12). Several studies have pointed out the impact of disability on a child’s participation in social activities (13–16). The interaction between the child with a disability and play has just started to be explored (17).

Much has been written about play. Most researchers agree that play is a complex, multifaceted behaviour that is relatively easy to observe and describe but difficult to define (18–21). No child is ever taught how to play. Long
before children have a language to express their needs or to explain their actions, they play. Whenever they have time, children will automatically play. Play is the child's natural activity. It is this intrinsic motivation that is one of the core components of play. Rubin et al. (22) have provided a generally accepted definition of play. He identifies five characteristics that separate play from other activities. The five characteristics are: (a) friends, toys and interesting material, (b) an agreement that the child decides the play, (c) minimal management from parents or other adults, (d) a comfortable and safe atmosphere and (e) planning so that the child does not get tired. Rubin et al. (22) consider that if all the five characteristics are present it will stimulate play. But play will be influenced if any of the characteristics is missing.

Play is a very important part of life for all children, including children with a disability. This study was designed to explore the perceptions and personal experiences of play for children with physical disabilities and in need of technical aids. The purpose of the study was to gain a deeper understanding of how children with disabilities perceive their technical aids and interact with them in play situations. This study is part of a larger project and can be considered as a pilot study of a relative unexplored field.

Method

Subjects

Eight children with a motor disability in age group of 6–11 years were selected to participate in the interview. Each child had a medical diagnosis and was in need of a technical aid (wheel chair, walking trolley or crutches) for his/her daily activities. The inclusion criterion were: (a) 6–12 years of age, (b) no intellectual disability, (c) good verbal communication skills, and (d) disability related to the medical diagnosis, CP, Spina Bifida or different kind of muscle disease.

The age range was selected out of consideration for the difficulty in interviewing children younger than 6 year, and beyond the age of 12 when the children reach their teens they cease typical childhood games. The ambition was to have an equal distribution among boys and girls. All the participants had to have good communication skills in order to be able to answer the questions and narrate different situations. The participants are presented in Table 1.

Table 1 Participants

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Sex</th>
<th>Diagnosis</th>
<th>Technical aids</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Boy</td>
<td>CP</td>
<td>Wheelchair</td>
</tr>
<tr>
<td>6.5</td>
<td>Girl</td>
<td>Spina Bifida</td>
<td>Splints</td>
</tr>
<tr>
<td>8</td>
<td>Boy</td>
<td>Spina Bifida</td>
<td>Splints</td>
</tr>
<tr>
<td>8</td>
<td>Girl</td>
<td>St. P. Polio</td>
<td>Crutches</td>
</tr>
<tr>
<td>8</td>
<td>Boy</td>
<td>Spina Bifida</td>
<td>Splints</td>
</tr>
<tr>
<td>9</td>
<td>Girl</td>
<td>Spina Bifida</td>
<td>Wheelchair</td>
</tr>
<tr>
<td>11</td>
<td>Boy</td>
<td>Spina Bifida</td>
<td>Wheelchair, walking trolley</td>
</tr>
<tr>
<td>11</td>
<td>Girl</td>
<td>Polyneuropati</td>
<td>Wheelchair, splints</td>
</tr>
</tbody>
</table>

and asked for their permission to interview their child. The aim of the study was presented in the letter. The parents made contact with the researcher when they together with their child had made the decision to participate in the study. All the participants were guaranteed confidentiality.

Data collection

A semistructured interview guide was designed to assess the relevant issues of the study. The questions were open-ended and the child was requested to narrate. Areas included in the interview guide were: (a) type of games played, (b) play environment, (c) play mates. Example on questions used were: ‘Tell me about the type of games you like to play?; Tell me about how it looks like were you play?; ‘Tell me about your technical aids when you play’.

The children chose the site for the interviews themselves to ensure that it was a place where they would feel comfortable and safe. Six of the interviews were conducted in the homes of the children. One interview took place in the parent’s summer house and one took place in the child’s school. Before the interview, the interviewer spent some time with each child to establish trust. Before data collection began each child was told that he or she could stop the interview at any time. Each interview took an average of 1 h, and either one parent or a personal assistant was present during the interview. The interview was focused on the child’s own experiences, however, in some cases the parent or the personal assistant spontaneously added their own experiences as to how they perceived the child’s understanding of the issue. The interviews were tape-recorded by the interviewer and transcribed the same day into written format.

Data analysis

The study was influenced by the tradition of Grounded Theory (23, 24), the aim of which is to generate a preliminary model explaining the research problems investigated. A model or preliminary theory is, according to Glaser and Strauss, an approach to bridge the gap between the data and the emerging concepts and categories. The theoretical
Figure 1 A structural model of the child’s various relations in play situations.

framework for Grounded Theory is derived from the insights of symbolic interactionism. Interactionists assume that human beings create the world of experience they live in. They do this by acting on people and things in terms of the meaning they have for them (25). These meanings come from interactions. This study is focusing on the child’s interactions between people and things. The method of Grounded Theory was therefore judged to be the best method to answer the research question.

The analysis was conducted with the method and performed in sequences: (a) All transcribed data were first read to get an overall understanding; (b) The transcripts were then coded by open coding. Thereafter the transcripts were searched for significant themes related to the child’s experiences and meanings of play and the use of technical aids. The themes found were organized into categories; (c) The analytical process ended up with the core category, the child’s relations, which was related to the other categories. When forming the core category, the question was asked as to which category seemed to be behind all the other categories, being the main pattern or core theme that links all the other categories? The three categories found were related to the core category. During the process of analysing, there were two researchers in addition to the author and the researchers in the main project, who read the interviews and did their own coding of the data. In the final analysis all individual codings were merged into one common understanding.

The literature review identified several strategies to enhance accuracy, credibility and reliability of the data (26). The strategy was to have the research group involved in the analysis, checking the author’s (my) interpretations of the findings.

Findings
The major finding is that children with disabilities have three various types of relations in their play-situations (core category). These are grouped in three different categories: relation to technical aids, to adult assistants and to the play environment. Two types of relations included adults. Time for play requires that a parent or an assistant have to be present. To get into a playground requires the help of adults too. The third relation – the one to technical aids – is an individual one, as the technical aids were perceived differently by all the children. The technical aids were also seen as an extension of the child.

For an overview of the structure that exists for the various categories around the core category and in interplay with the child (see Fig. 1).

Category 1. Relation to technical aids
All the children in the study used technical aids in their play. The most common technical aids were the ones that assisted the children to move, such as: the children’s splints, crutches, wheelchairs for indoor and for outdoor use, walking trolley, tandem cycle and tricycle. One child had a specially designed aid to facilitate outdoor games in the form of a specially designed chair to assist him playing in the sandbox and in other games.

The younger children perceived their technical aids as a natural part of themselves and the children seldom reflected over the use of them. On the whole, younger children did not perceive their technical aids as something external, but rather as something related to their bodies and their functioning in daily life. On the question: ‘Tell me about your various technical aids?’ One young girl responded: ‘What, technical aid? What do you mean?’ When the question was specifically about her wheelchair she said, ‘Oh, is that what you mean. Yes I have a nice wheelchair.’

One young boy had a central role in a game he played with his peers, by using his ‘Permobil’ (electric wheelchair).

I pull a cart with my electric wheelchair on school breaks. I can carry my friends in the cart, which he describes as: ‘Yes, they like it they say it is fun.’ He also told about a specific event when he went to the forest with some other children: ‘We drove out to the forest to get firewood. The other children and I put the firewood in the cart and went back to the school to barbecue the sausages. I could easily drive my wheelchair and the cart despite the rocks, stones and stubs in the forest, we had a nice time’.
Therefore, the youngest children perceived technical aids as an integrated part of their own body. One exception was a young girl who saw her splints as two living objects in an animistic way separated from herself but with which she had a close relationship: 'They (the splints) are a bit clumsy, when they climb on the roof. They want to do that. They like to climb on the roof'. And she continued, 'When we are at the supermarket the splints sometimes want to return home without me'.

The older children (aged 10–11) began to realize that they had technical aids as means of assistance, something that other children did not have and also something that appeared to be a hindrance in their social life. The two oldest children (age 11) had begun to realize that there were differences between them and their nondisabled friends. When they were talking about games or other events they associated with play situations, they suddenly realized that they could not manage these without their technical aids. Their friends could, for example, travel by bus to different sport activities, which they could not do because there was no access for them to use the bus. But on the question: 'What do your friends say about you having a wheelchair?' One of the boys answered, 'My friends are not jealous of me', indicating that the wheelchair is not considered as something bad or stigmatizing.

One of the children gave another example of when she realized that there was a difference between her and her friends. In the winter she was swimming in the summer she needed her crutches to get into the water. In the water she had a problem when dropping the crutches, which she compensated for by attaching a float.

Category 2. Relation to play environment

The play environment could be divided into indoor and outdoor environment. Furthermore it could be divided into two seasons, summer and winter. The children's relation to the indoor environment was harmonious, and no one described any obstacles in the environment. The indoor play often consisted of listening to music, solving puzzles, and drawing or playing TV-games.

Playing outdoors was considered having fun, but a lot of the children described problems in the environment. It was, for example, difficult or impossible to them who used wheelchairs to get to the playground. Being there, one of the limitations was the surface of the ground, which often was sandy. Many playgrounds had sand on the entire area, which made it difficult or impossible to walk around with a walking trolley or to drive in a wheelchair. Several playgrounds were fenced which made them difficult to enter with a technical aid. Three children described their problems with accessibility in a similar way. One of them said, 'I cannot even get into the playground because of the wheelchair'.

The various play tools in the playgrounds, swings, chute and climbing facilities were difficult to access. Five out of eight reported that they needed assistance from adults in order to get on or off the different play tools. Their way of describing the problem was that it was difficult to get on the climbing facilities.

The design of the play tools also limited the children's ability to make use of them. A girl described it like this, 'it's like small rooms, not so big, but maybe if someone helps me I can drive (with the wheelchair) trough, but not play inside'. Several of the children were afraid when they were on top of the climbing facilities. There was no fence and some of the climbing facilities were very high, like towers. A boy narrates, 'its scaring on the top of the climbing tool'.

Sometimes other children's play on the playground was an obstacle for the children with disabilities. The games played by able-bodied children had a high speed and the children switched between the different play tools all the time. This made problems for the children with a disability, not daring to use the play tools as they liked. A boy said, 'the other children climb on the chute when I try to go down, they climb all the time'.

With regard to the seasons, it was found that the time of the year creates various presumptions about children's play. The writer prevented many children from playing outdoors. The snow was a barrier for the children with disabilities. It was slippery and difficult to be outside. Two girls described the winter like this,

'I'm indoors all the time and if I go outdoors I will feel cold. It's difficult to move outdoors, the way must be clear from snow. In the winter I mostly play indoors. The boy's experience of winter was also filled with barriers, but they showed a greater acceptance than the girls. A boy says,

'I can play ice hockey with my dad, but I don't have skates. I have my winter shoes. Ice-hockey is fun to play, but I have problems walking in the snow.

The summer season was easier to manage, although there were some barriers in the environment. On sunny days when friends go to the beach the child with a disability has problems going with them. He/she has problems walking in the sand, and walking with technical aids in the sand was almost impossible. In this situation the child was very much dependent for help from an adult, and he/she could not go to the beach alone with his/her friends. One boy said,

'I like to go to the beach with my friend, but it's impossible. I can't walk or drive my wheelchair in the sand.'

All the children describe play as fun, either playing by themselves or with friends. Play was important and all the children played everyday. On the question: 'Tell me about what you like to play'. Almost all the children responded that they play typical games for girls or boys. The girls answers were 'We play with dolls' or 'Yesterday we played

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with bookmarks'. The boys responded: 'We play soccer' or 'I usually play with my small cars'.

**Category 3. Relation to assistant/parents**

The children's relation to the assistant varied between children. The younger children saw the assistant as a part of their life. Sometimes even as a friend or as a playmate. A 6-year old boy said:

> Once we (he and the assistant) built a railway. It was with many curves. The train went into a skid. I have a railway of my own at home.

One girl tells this story:

> My assistant is a guy. Once he threw the ball high up in the sky, so high so we could not see the ball. It was great. Later the same day he pulled me on the sledge and turned me around so I got dizzy.

The oldest children's relation to the assistant was very inquiring. They did not understand why the assistant had to be there. On the question, 'Do you have a assistant', one of them said:

> Yes, I have an assistant, but I don't know why. He does not help me at all. He is just standing and staring at me wherever I go or whatever I do.

The relationship the children had with their parents was traditional. The father was described as the person they did things with that was fun. 'We drive moped together', or 'I can be with my dad in the garage and help him fix the car'. The mother's role was described as an organizer, she see that the child gets to school, drives him or her to activities such as, handicap riding or various sports activities. One child said, 'My mother follows me to the stiskling class every week in the winter'.

Many times an adult was a necessary condition for the child with a disability to play. Sometimes an adult had only to be around, but in some games the adults had to play an active part, even if there were other children in the play. The assistant or the parent was a necessary condition for the child to go to the place where the playing took place and even a condition for the child to use the various play tools in the game. The active part of the adult was to help the child to come up in the swings or the climbing facilities or to help with other play tools in the playground. The children also needed to be transported to friends' place because they could not go there by themselves.

The younger children did not reflect so much about continual adult presence. The older children on the other hand expressed a wish to be independent. A boy described it like this:

> I wish I could go into town with my best friend, and visit the museum of science and technology. I like to go without my parents, just my friend and I. It's bothersome to have the parent with you all the time.

**Discussion**

The purpose of the study was to gain a deeper understanding of how children with disabilities perceive their technical aids in play situations. The results of the interviews are presented in a structural model (see Fig. 1), showing how the children with disabilities have three types of relation to technical aids, adult assistant and the play environment.

Technical aids and adjustment in the environment creates the necessary conditions for children with disabilities for a 'normal' life with self-esteem and participation. Paulsson & Winnberg-Lindqvist (27) describe how important technical aids are for children with disabilities for their well-being and their possibilities for development. The way children use their technical aids is different from adults in many ways. The children grow up and need new equipment often, and they need technical aids working in many different environments. The children in this study describe their technical aids almost as an integrated part of themselves, something that helps them to get around, to play with others and to give them a feeling of independence. This has also been emphasized in other studies (1, 2).

There is little research on disabled children's attitudes towards technical aids. The results of this study show that the technical aids are not considered as barriers in play and the children do not feel different from their friends because of technical aids.

In Sweden, most children with disabilities attend their local community school and are expected to participate in all outdoor activities although the playgrounds have not been adapted (28). The findings in the category dealing with the play environment, show that barriers imposed by the play environment may severely limit the children's opportunities for free play. These barriers may be present in the home as well as in the community (playgrounds, recreational facilities and schools). Changes within the child's home environment may have been made to meet the child's individual needs, however, these modifications are rarely extended to the broader community environment. For the most part, buildings and playgrounds have been constructed to meet the needs of children without disabilities (29). According to Prohansky's & Fabian's (30) study, environments communicate symbolic messages to show if a person is welcome or not to this environment. A playground or a schoolyard, which is not adapted to persons with handicap, sends a message that this environment is meant for children without disabilities, and that other children are not welcomed here. It is in this way the physical environment can welcome or exclude certain groups of individuals and the excluding can be discriminating. The results of this study indicate that this can be the case also with regard to the subjects investigated. Furthermore, the absence of opportunities for play can
potentially handicap a child with a disability, as was shown by Missuna & Pollock (31).

Howard (32) found that children with disabilities spent more time in self-care and passive activities in their own homes compared with non-disabled children, and more than half of the activities of the children with disabilities were indoor games. These results were also found in this study where most of the children preferred indoor games and other passive activities. This was more apparent in the winter when the children needed more assistance from adults and when the accessibility to the outdoors places is next to nonexistent because of snow and sleet.

The third category describes the children's relation to the adults. Compared with children without disabilities who usually play with other children, the children with disabilities almost always have a grown-up with them when they play. These adults are almost a necessity for the child in order to be able to get to places where the activities take place, and as well, many of the games demand the participation of the adult for the sake of the disabled child, although there are other children playing. The results also showed that the adults often act as the children’s playmates at least for the young ones, however, none of the children had reflected much about it. The children describe the presence of an adult as a natural part of the game. Current international research shows that participation of an adult might cause restrictions on the child's free play. Missuna & Pollock (31) found that children with disabilities could loose their spontaneous relationships to other children because of the presence of grown-ups. This can affect the children’s creativity and fantasy in a negative way and can also increase their need for help from adults and make them less socially competent. The children in this study claimed to have many friends and said that they could participate in most of the games. Not one of the children perceived themselves as different from other children, even if the older children realized that there are limitations in their lives. The longing for independence and an existence without adults became apparent for the older children. 11 years and older. The playmates opportunity to play and participate in activities further away from home constitutes a big difference at this point for the children with disabilities that did not have the same possibilities. The adults and the assistants of older children are no longer considered as help but more as a hindrance. The disabled children more often choose to stay at home and to be alone than to go somewhere and have an adult with them. A question one can ask is, whether the adults with their presence or participation in the older children's play constitute a restriction to the children's opportunities for free play.

In summarizing, we consider that the findings from this small scale study is in accordance with previous research in some areas. For example, children with disabilities play more passive games and spend more time in self-care activities in their own homes in contrast to previous research. The children in this study did not perceive any limitations caused by their technical aids. According to the interviews, the children consider themselves having many friends and they say that they can participate in almost all games. They also perceive themselves as any normal child, i.e. without handicap, even if there, sometimes, are circumstances in their lives that tell them differently. The strength of this study is also the children's insider perspective of their own situation. Through the data collection and interviews, the children's accounts were central and a very good picture of the children's situation was obtained. In our opinion only the children themselves can, in a substantial way, judge what is important to them. This study thereby offers important insights into the world of disabled children.

The limitation of the study has to do mainly with the sampling issue. The investigated group was small and it was drawn from a clinical population. This means that it consisted only of children who were enrolled at the Children's Rehabilitation Clinic, a fact which means that the sample is not necessarily representative. As this study was carried out on mostly younger children aged 6–11, it would be interesting to see if older children aged 10–16, feel differently towards technical aids, adult assistance and friendship, and their relation to recreation activities.

Acknowledgements
We would like to thank all the children who participated in this study. Further thanks are expressed to Dr Sue McGinty, James Cook University, Australia, and to Maare Tamm, PhD in psychology, Luleå University of Technology, Sweden, for their valued opinions.

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Artikel III
How children with restricted mobility perceive their technical aids
by LISA SKÄR\(^1\) and MAARE TAMM

Luleå University of Technology, Department of Health Sciences, Boden, Sweden

Abstract

The purpose of this study was to describe how children with restricted mobility themselves perceive their technical aids, and how they believe that the technical aids help or hinder them, in their interaction with others, mainly peers. The group investigated consisted of ten children with restricted mobility, aged from 6 to 12 years, from northern Sweden. The children were interviewed about their technical aids and were observed using their technical aids in different situations. The interview transcripts and observations were analysed according to content analysis. The results showed that the children’s different technical aids had a status value to the children and that the status was estimated in relation to peers, rather than in relation to the usefulness of the different technical aids. The social value of the technical aids, then, was stressed by the children to a greater extent than the functional value of these technical aids. The powered wheelchair and the manual wheelchair, according to the children, have the highest status value, while the individual adapted chair had the lowest status value. Along the value dimension orthoses were the aid that the children perceived as most neutral. They were seen as part of the body that enabled walking and were also a prerequisite for using other technical aids. The results were discussed in terms of the children’s autonomy and with respect to the usefulness these results can have for professionals.

KEYWORDS: accessibility, children with restricted mobility, identity, peers, technical aids

INTRODUCTION

The use of technology to compensate restricted mobility is not a new phenomenon. As early as 2,500 BC, a wheelchair-like device was used in Egypt. It was a sort of sled pulled across the ground. In the 17th century, wheeled carts were developed, precursors of today’s wheelchairs. Despite this, it was practically unthinkable for those with restricted mobility to move around unaided, especially outdoors, until well into the 20th century. Those unable to walk had to rely on the environment for help in transfers. The use of technology in the field of disability began in earnest in the latter half of the 19th century and continued constantly to develop during the 20th century (1).

With present-day legislation and the disability policy (in Swedish, handikappolitiska målsättningsdokument) as a basis (2,3), the view on technical aids has radically changed in the last few decades. The view on technical aids as products to compensate a physical dysfunction has been replaced by a view with a strong emphasis on the importance of the technical aid for the quality of life and possibilities for equal opportunities in life. That is to say, technical aids must be designed to meet people’s need for security, privacy, participation in the community, among other things. But nevertheless, the ultimate function of technical aids is as a technological solution to existential problems.

When selecting and assessing technical aids for children with restricted mobility, there are many factors that professionals must take into account. The child must have optimal use of the chosen aid; the advantages of a certain aid must outweigh the disadvantages. The technical aid should facilitate the child’s social contacts with peers, and the aid that the child has must function in different settings — indoors, outdoors, in school, at home, in the playground, etc. (4).

To children with restricted mobility, technical aids (wheelchairs, walking trolleys, individual-adapted chairs etc.) are a part of their identity. In Mead’s (5) interactional theory the identity of a person is a social product. It means that the identity is developed in interactions with others. It is embedded in those interactional places (home, school, and play situations) and in those interactional relations (child-adult, child-child) that give recurring meaning to ordinary experiences. A child’s identity, according to Mead (5), is formed by the roles the child has in interaction with

1. Any correspondence should be sent to the first author
peers and by the activities he/she carries out together with peers in these roles. Based on Mead’s theories, it is in particular children’s interaction with peers in play, leisure-time and in schoolwork that creates the child’s self and develops the child’s identity. For children with restricted mobility technical aids provide possibilities to participate in games and activities in the same settings as their peers. It is therefore important that the technical aid used should fit into the particular environment where the activities are taking place (6,7). In her study, Andén (8) found that the wheelchair was one of the most significant technical aids used both indoors and outdoors. Children with restricted mobility can have difficulties in exploring their surroundings without access to a wheelchair or similar. Among the advantages of a wheelchair was the fact that the wheelchair allows children more independence and among the disadvantages was the fact that many children can have difficulties in operating a manual wheelchair themselves; many need assistance.

The restriction of physical activity imposed by a disability limits the children’s opportunities to explore their environment and limits their interactions with the peer group, and curtails their potential for independent behaviour. Ultimately these hindering factors are a threat to the identity itself. Researchers have shown that children with restricted mobility cannot participate in different activities to the same extent as children without restricted mobility (9,10). Research shows furthermore that children with restricted mobility find it difficult to gain or keep friends, that they are seldom spontaneously included in play situations with other children, and that they seldom participate in sports-oriented activities unless these activities are specifically intended for them (11,12,13). It is not solely the restricted mobility in itself, but also the technical aids that the children use that do not function adequately in all the environments where play and other activities take place (14,15).

The broad research question arises: in what way do the technical aids used by children with restricted mobility influence the children’s opportunities for active interaction with peers, and ultimately, affect the children’s identity development?

Today there is practically no research addressing children’s own perceptions of their technical aids (wheelchairs, powered wheelchairs, walking trolleys). Existing research deals with high technology, i.e. respirators, dialysis, intravenous nutrition etc. (16,17). In the sparse Swedish research we have noted that Mattsson (18) has investigated children with restricted mobility and their difficulties in school from a parent and teacher perspective. Paulsson and Christoffersen (19) have studied children with restricted mobility and their technical aids and found that children with restricted mobility who used technical aids became more active in their play environments and required less attention and assistance from others. Within disability research several researchers (20,21) stress that it is only those with restricted mobility themselves who can in a substantial way judge what is important for them and which obstacles there are. In developmental psychology, there is a growing awareness that it is the insider perspective, i.e. the perspective which studies children’s own perceptions, which should be at the focus of research. With this introduction as a background the purpose of this study was to describe how children with restricted mobility themselves perceive their technical aids, and how they believe that the aids help or hinder them, in their interaction with others, mainly peers.

**METHODS**

**Subjects**

In all, 10 children with restricted mobility participated in the study. They ranged in age from 6 to 12 years and were recruited from the Children’s Rehabilitation Clinic in the north of Sweden. The children selected for the study came from two mediumsized municipalities in a nearby geographical area. The children had restricted mobility related to medical diagnoses such as Spina bifida, Cerebral palsy and Polio syndrome. All the children were users of technical aids such as wheelchairs, walking trolleys, crutches or orthoses. They also had to be able to respond to open-ended questions. These inclusion criteria placed a limitation on the number of children taking part in the study, which made the sample selected a total one within this geographical area (the two municipalities).

The participating children were selected with the assistance of the chief physician in charge of the Children’s Rehabilitation Clinic. The chief physician sent a letter to the parents requesting permission to interview their child. The aim of the study was presented in the letter. The parents contacted the researcher when together with their child they had made the decision to participate in the study. All the participants were guaranteed confidentiality. The project was approved by the ethics group at the University College of Health Sciences in Boden, now the Department of Health Sciences, Luleå University of Technology.

**Interviews**

All the children were interviewed in their own homes by the first author. An open-ended interview approach
was used to cover a range of topics. These topics included, 1) How children perceived their technical aids; 2) How they used technical aids in different situations, for example in interaction with peers. Examples of questions used were: “Tell me about your technical aids”; “Tell me how you perceive them (the technical aids)”; “Tell me what it is like to play when using aids”; “Tell me how your friends act when you are using your aids”. Using open-ended interviews meant that children could raise issues they deemed important. Parents were present during the interview, but did not participate. The parent’s presence was considered an ethical necessity because the researcher was unknown to the child and because the parent’s presence represented a secure situation for the child, where he or she could feel free to express his/her thoughts. Besides this first formal interview with each child, the children were interviewed once again in school with supplementary questions clarifying points not clarified in the first interview.

**Observations**

In order to achieve an additional understanding of how the children perceived their technical aids in different situations, the interviews were complemented by observation of each child during one school day by the first author. The day was selected in consultation with the teacher and was a day featuring a series of different situations entailing transfers, e.g. between different buildings and in play situations during breaks. Informal questions about the children’s technical aids were put to the children during the observation period. These questions were added to the observations and served to enrich the observations. Also during the observation, field notes were taken. The questions and the field notes were transcribed the same day.

**Data analysis**

Content analysis is a research method that provides a systematic and objective means to make valid inferences from verbal and written data in order to describe the phenomena being studied (22). The method of content analysis can be described as a process of identifying, describing, and categorising the themes or patterns contained in the data (22,23).

The transcribed interviews and the observation texts were first independently read as a whole by both authors to obtain a sense of overall data. One of the most basic and important decisions in content analysis is the selection of the unit of analysis, which is guided by the research question to be answered. In the present case the unit of analysis was every communicative act where the children talked about how they perceived their technical aids and how it was to use them in interaction with others. For each technical aid, the following questions were asked based on the purpose of the study: “How does the child perceive his/her technical aid?”, “How do other children act when the child uses the aid?”, “What are the advantages and disadvantages respectively of the different technical aids?”. The objective of content analysis is not necessarily to document the shared meaning between the researcher and the researched. Since children are unable to interpret their own feelings and behaviours the authors had sometimes to make interpretations of the children’s statements in order to find meaning in them. The data was thus categorized according to the value the children gave their aids, i.e. how appreciated the children were by other children and how autonomous they felt with their aids. Alternating between the text and the output of content analysis (which was done jointly by the two authors) provided for validated and refined categories. After the categories were established in final form the data was once again coded by both authors independently and the inter-rater agreement between the authors’ coding was almost total, perhaps because the categories were quite broad.

**RESULTS**

The analysis is summarised in the form of a table in which the different technical aids are categorised along a dimensional representing the status value (high-low status) in relation to peers (see Figure 1).

<table>
<thead>
<tr>
<th>Status value</th>
<th>The meaning</th>
<th>Type of aid</th>
</tr>
</thead>
<tbody>
<tr>
<td>High status</td>
<td>An aid appreciated by peers</td>
<td>Power wheelchair</td>
</tr>
<tr>
<td>Neutral</td>
<td>A part of my body</td>
<td>Manual wheelchair</td>
</tr>
<tr>
<td>Low status</td>
<td>A necessary evil</td>
<td>Orthoses</td>
</tr>
</tbody>
</table>

Fig. 1. The status value and the meaning of the different aids.

As indicated by the display, the powered wheelchair has the highest status and the individual adapted chair the lowest, with the orthoses neutral on a status scale. Regardless of the status value, all technical aids had definite advantages and disadvantages. Regarding the orthoses, these were aids that differed from the others, as the children did not perceive them so an aid, but rather as a reinforcement of the body. Sometimes the orthoses were also regarded as a prerequisite for using the other technical aids.
Below follows a more detailed description of the meaning and the value of the different technical aids.

A technical aid appreciated by peers
The high status value of the powered wheelchair could be seen through the fact that the children with the powered wheelchair said that they acquired a central role in the peer group and that many other children were curious and wished to ride or try to drive it. One of the children said; "Everyone in my class says they want one, they say it’s cool, they want one even though they know it’s impossible." The status value also meant that the children said that they were more often able to initiate and/or take part in different games. Fore one girl this even became a problem and she did not wish other children to touch her powered wheelchair. She was afraid that playing with it would mean that her possibilities for independent transfer would be limited. "I don’t want the boys to toot and play with my car- it’s not a toy. Just think if it breaks". Also our observations showed that the children who used a wheelchair and especially a powered wheelchair, had more frequent interactions with peers than the children who were without a wheelchair. The wheelchair itself was seen as a kind of interesting “toy”, increasing interactive situations. The playground setting at school focused attention on situations, which had some novelty, and it seemed that playing with the wheelchair and with the wheelchair user provided the children such an opportunity.

Even the manual wheelchair attracted the attention and curiosity of the peers although somewhat less so. The wheelchair was used as an exciting toy and during games the peers pushed many of the children with restricted mobility in the wheelchair. The wheelchair was mainly used indoors, in school or at home. In school the wheelchair was used mostly for transfers between different buildings. “The wheelchair is good to have when I am going to the school library, because I don’t get nearly so tired when someone pushes me”. Most of the children drove themselves, but one of the boys was helped by his assistant, because the boy’s hands were too weak for him to drive by himself. The children who drove by themselves perceived the wheelchair as easy to manoeuvre and easy to access almost any location. The manual wheelchair was perceived by the children as aid that more than any other aid made them autonomous.

One disadvantage that many described was that the powered wheelchair was large and difficult to use in town. It was often too wide to be taken into small shops and too heavy to lift up stairs. Many of the children therefore had a smaller manual wheelchair, which they used on trips into town.

Another disadvantage the older children encountered had to do with their peers parents. One boy, for example, drove several kilometres along the main road to visit his friend and found the wheelchair to be of great help, but when he arrived he could not take the wheelchair inside because it was dirty. He had to crawl in to his friend; "They (the friend’s parents) don’t want me to take the wheelchair in, it gets so muddy." One girl had encountered a similar problem when she was going into town with a friend: the friend’s father did not want to take the wheelchair in the car; “He didn’t think there would be room, but every car has a boot”.

The manual wheelchair was perceived by the children also as a physical support and was used when the children felt physically weak. After a day in school with many transfers with orthoses, one girl felt that; “It’s good to sit in the wheelchair when I feel weak”. One girl expressed that it was good to be able to drive home from school herself; "Then I can be with my friend, we can walk together".

A part of my body
Along the value dimension orthoses were the aids that the children perceived as most neutral. The orthoses were necessary for walking or standing and at the same time were more or less invisible. All the children in the study used orthoses daily as a reinforcement of the legs during transfers. Sometimes orthoses alone were sufficient, but often another technical aid (wheelchair, walking trolley, etc.) was used as a complement. The children had begun to use orthoses at an early age, approx. 1½ - 2 years, and their perception of the orthoses was that they were practically a natural part of the body. "I don’t feel them, I don’t think about them at all", or; "It feels as normal, as if I didn’t have the orthoses", or; "The orthoses is like a leg".

The children described the advantages but also the disadvantages of their orthoses. Among the advantages the children described that the orthoses were a precondition for them being able to walk; "The orthoses are good to have for me to be able to walk or stand" and "They feel good because now I don’t have to walk on my toes any more".

The orthoses thus made the children look like other walking children and diminished the feeling of being different.

Among the disadvantages were aesthetic, physiological and mechanical aspects. Even though all the children used their orthoses daily, the older children saw their orthoses as aesthetically ugly and as something they did not wish to show to their peers. This is what some of the children said of their orthoses; “They are
good to have, but it's no fun when I can't wear shorts or a skirt because the orthoses become visible then and that's what I don't want." or; "The orthoses, are so ugly and I don't like people seeing them." or; "They must absolutely not be seen."

The children felt that their body, which is normally experienced as such, suddenly became part of conscious experience in a negative way under others critical gaze and it was something they wanted to avoid.

One of the disadvantages of orthoses that the children described was that the leg felt stiff and this was associated with a series of problems. For example, sitting down on a chair was difficult, and many of the children told of having to climb up on to chairs, and of the orthoses being the obstacle. Sitting on the floor was also difficult, as the leg was so stiff due to the orthoses and it was difficult to find a comfortable sitting position. One boy says; "When I'm going to sit down on the floor it's sometimes difficult to get down, but it's even harder to get up again. My legs get so stiff." Another disadvantage was that the orthoses chafed many of the children when the orthoses were old, worn and outgrown. Even new orthoses caused much chafing in warm summer weather. Walking on uneven surfaces such as sand or snow was another problem. Several of the children instead crawled in the snow or sand when playing, because the stiffness of the orthoses made it difficult for them to keep their balance when walking.

Several of the children also needed help from an adult in applying and removing the orthoses, as they were often difficult to apply or because it was difficult to position the foot correctly. Even so, the children said that it was like getting dressed in the morning; "It's like putting your socks on" or "I'd never forget to put them on, it's like getting dressed."

A practical transfer
The status value of the walking trolley was relatively low in relation to the powered wheelchair and the manual wheelchair. The walking trolley did not increase the children's interactions with peers even though it made them more autonomous than they were without this practical aid. The walking trolley was the technical aid that was given a practical purpose in the children's everyday lives. Five children, in school and at home, used it when the children were fetching school lunch, carrying books or practising walking. The boys who used the walking trolley used it at home for walking exercise and said that it was fun being able to walk, and unlike the girls they perceived the walking trolley as a useful walking aid. One of the boys said; "I can walk 600 metres, that's the record without a rest. It's so easy to walk, as long as you have a walking trolley". The girls concentrated more on the practical usefulness of the walking trolley; "The walking trolley is better than crutches, because then I can more easily take for example a book with me" or "When I have my walking trolley I can get my own lunch in school." The physiotherapist has tried to arrange for some of the children to replace time spent in the wheelchair with walking exercise using the walking trolley. These children perceived this as arduous and preferred to remain in the wheelchair. They perceived that they transferred quicker and more easily when using a wheelchair. One girl had been given a walking trolley in order to use her crutches less, thus relieving her shoulders. She perceived it as more arduous to walk with the walking trolley, since it snagged the floor mats and took up more room than when she walked with crutches.

A necessary evil
In school and at home five of the children used a special chair, with an individually adapted seat and back support. This chair had no status according to the children. Sitting in the adapted chair the children felt that they had lost their autonomy and were also distanced from their peers. The children described that they found it difficult to climb into the chair unaided. Several needed help from assistants or parents to climb into it. The difficulty in getting into place was largely due to the orthoses: the children's legs became stiff through the orthoses or the chair was high. Several of the children chose to remain in the wheelchair, rather than sitting on an ordinary chair during assemblies, as they then had the possibility to transfer themselves in the classroom. One boy said; "Yes the wheelchair is nicest to sit in because then I have back support, and sometimes it's fun when we sit in the assembly on ordinary chairs".

One girl had chosen not to sit on the adapted chair and used her wheelchair in the classroom instead. The consequence was that the other children in the class were sitting at desks and the girl in the wheelchair was then almost 40 cm lower than her classmates. She perceived that the teacher looked over her head when speaking to the class, and that she herself was not seen. She also felt that communication with the classmates at the next desks was hampered because of the big difference in levels. The reason why she still chose to remain in the wheelchair was that she wanted to be able to transfer herself in the classroom. The adapted chair was generally awarded a low status because it limited the children's possibilities to interact with their classmates, even though some of the children said that the chair gave support to the back when they were sitting in it or doing schoolwork.
The purpose of this study was to describe how children with restricted mobility themselves perceive their technical aids, and how they believe that the aids help or hinder them, in their interaction with others, mainly peers. The results showed that the technical aids had a status value to the children, and that the status was estimated socially, i.e. in relation to the peers and in relation to independence. The social value of the technical aids was stressed by the children to a greater extent than the functional value i.e. how the aids gave support for the back or facilitated sitting posture. This is interesting to note, as in prescribing technical aids for children, it is often the functional value that is focused on by the professional, and which governs what technical aids a child receives (4,24). Also in contacts with occupational therapists, we have noticed that children’s own wishes, for example, for a “cool” design, have been given a peripheral value when trying out technical aids and that it is the parents’ desires regarding technical aids that prevail. This findings of the study, i.e. the value of technical aids seen from the children’s perspective, can be important for professionals (occupational therapists and physiotherapists) to address (25).

The high value of a wheelchair
The fact that the powered wheelchair and the manual wheelchair had high status value also corresponds with Andén’s (8) study, which showed that the wheelchair was a significant technical aid. The functional aspects, i.e. the possibility of increased mobility were complemented by the high social status value and led to the children being both autonomous and participants in peer contacts on an equal basis. The children who had a powered wheelchair became more “interesting” in the eyes of the other children and therefore were allowed into different games. The question then is: is it possible that technical aids have both a functional and social value? That is, functional for the user and exciting for other children. Can it be that children are hampered in their social interaction, and in the long term, in their identity development as Mead (5) sees it, if their technical aids lack social value? This is an issue, which should be examined, in more detail in future longitudinal studies.

The disadvantages of the powered wheelchair and wheelchair were related to inaccessible environments. They were large and difficult to take into shopping malls and other buildings that were not adapted for these technical aids. Another disadvantage was related to adults rather than the children themselves. It was the friends’ parents who considered that these means of transfer were clumsy and difficult to handle. If these adults had known what status values the powered wheelchair and wheelchair had in the eyes of the children, they might have handled these issues in a different way than they actually did.

The difficulties that children with restricted mobility experienced in interactive peer situations have been noted in prior research (9,10,11,12,13,14,15). The obstacle has been partly the design of the technical aids, which made them difficult to use in some environments, but also made them a hindrance to the children’s being accepted into the peer group. If it is through technical aids that children with restricted mobility can become members of the peer group, then the development of new technical aids, with both social and functional value, should be given the highest priority. This should reinforce the children’s quality of life and opportunities for more equal living conditions and participation in society, which Winterberg (26) also advocates. It would ultimately contribute to the child’s identity, which according to Mead’s (5) theory takes place in that particular way – in interaction with other children.

The value of orthoses and the walking trolley
The technical aids that all the children in the investigated group considered to have neutral status value were the orthoses. The orthoses were aids that none of the children really identified as technical aid, but rather as something that reinforced their bodies. The orthoses were seen as belonging to the body in a similar way as e.g. clothes, and were perceived by the children not as objects arriving from an external source, but rather were perceived through “tacit knowing” in Polanyi’s (27) sense – something of an extension of the body that gave the children awareness of the sensation of walking. Despite the integration of body and orthoses, the orthoses were the aids whose disadvantages affected the children somewhat. The orthoses limited their mobility and access and also had aesthetic disadvantages, affecting their appearance in a detrimental way. The orthoses accentuated the fact that their legs could not be used to the same extent as their friends’ legs and were perceived, especially by older girls, as something ugly which they did not wish to show to their friends. This may be due to the fact that the older children in this study were approaching their teens, i.e. a time when identity development is central (see also Eriksson, 28) and therefore largely filled with preoccupation with appearance and a wish to resemble peers as much as possible (29). The aesthetic aspects of orthoses and other technical aids are worth attention in future studies.
The children in this study saw the walking trolley from different perspectives depending on gender. The girls talked more of the practical use of the walking trolley, for example when fetching school lunch or being able to carry a book, while the boys stressed the advantages of being able to practise walking stretches, and described more active handling of their walking trolley. The description of the walking trolley in literature (31) is that it is primarily used as a complement to the means of transfer that the person with restricted mobility already has, or as a compensatory support in practical activities such as walking exercise. Here too, autonomy, i.e. independent decision making in different situations, is in focus. A series of disadvantages is also described, such as difficulties in moving around in confined spaces or being able to walk backwards. The disadvantages that the children in the present study described were that the walking trolley hindered access by jamming in doorways and being difficult to manoeuvre in certain situations. The relatively low status value of the walking trolley was largely due to the fact that progress was slower than with the wheelchair, but was also due to the fact that the walking trolley demanded more energy when transferring. The children with restricted mobility perceived it to be arduous to transfer with the walking trolley.

The adapted chair of small value
The technical aid in the school setting consisted of an individual adapted chair. The chair had low status value in the eyes of the children, largely due to the fact that it was difficult to enter and to use in transfers. It differentiated the children with restricted mobility from the other children and tended to remind the child of his/her disability. This resembles the study by Morvan et al. (31), which showed that technical aids can have an ambiguous value, i.e. they can give autonomy but they can also become a reminder of the disability. As in this study, where the advantage of the chair, good seating comfort was in contrast with the disadvantage of it distancing the child with restricted mobility from his/her peers.

Creating a classroom environment where all the children have the same opportunities should be a self-evident goal, but is almost impossible to achieve when children with restricted mobility have difficulties in participating in assemblies sitting in a ring on the floor, difficulties in participating in group activities or difficulties in being able to fetch their own books in the classroom.

The starting-point for professionals who provide technical aids in our opinion should not be purely whether the child could use the technical aid functionally. Of at least equal importance is the question of how the child wants to take advantage of the technical possibilities of the aid and how the child values the aid from a social and psychological perspective. What then is a good technical aid according to the children with restricted mobility? If a good technical aid is one that does not merely fulfil a functional need, but also fulfils social, emotional and intellectual needs, i.e. identity-creating factors, then there is a large field where research from the children’s perspective, with the children’s own voices heard, is relatively sparse.

The strength and limitation of this study
The strength of this study is its insider perspective, i.e. that it describes the children’s own perceptions of the aids they use. In our opinion it is only the children themselves who can in a substantial way judge what is important for them. This study thereby offers important insights into the world of children. The limitations of the study are mainly related to the sampling issue. The investigated group was small and it was drawn from a clinical population. This means that it consisted only of children who were enrolled in the Children’s Rehabilitation Clinic, a fact that means that the sample is not necessarily representative. Another limitation has to do with the difficulties of interviewing children. When asking questions and getting answers from children who have limited vocabularies and who do not think in the same way as adults, there is always a risk of interpreting the interview text based on adult understanding. Future studies, with longitudinal designs and larger samples, should be designed to address the limitations of this study.

Implications for practice
The findings of this study have implications for physical and occupational therapists working with children with physical disabilities. The findings support a client-centred approach, in which the client’s (the child’s) individual values and perceptions of technical aids and usefulness of the technical aids are considered and the prescriptions of the aids are established mutually by child and therapist. The most important factor identified by the children was the social value of the aids, permitting them to have fun, to being with peers and to belong to a group. Perhaps more important than identifying functionally adequate factors of the technical aids is the need for therapists to develop their own listening and observation skills, to identify what is meaningful to each individual child. By providing children with opportunities to participate in playful activities through using their technical aids, physical and occupational therapists can assist them to develop...
both physical and social skills and also change the way in which technical aids are provided for children with restricted mobility.

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Lisa Skär
Maare Tamm
Luleå University of Technology
Department of Health Sciences
S-961 36 Boden, Sweden
Fax. +46 921 678 50
E mail: lisa.skar@hv.luth.se
How I Play: Roles and Relations in the Play Situations of Children with Restricted Mobility

MAARE TAMM and LISA SKÄR

From the Luleå University of Technology, Department of Health Sciences, Boden, Sweden


The purpose of this grounded theory study was to gain knowledge and understanding of how children with restricted mobility play in different play situations. The group investigated consisted of 10 children with restricted mobility, aged from 6 to 12 years, living in northern Sweden. In this study, the child with restricted mobility is defined as a child unable to move around without the aid of a wheelchair, walking trolley, crutches or other walking device. The children were interviewed about play and were observed in different play situations. The transcribed interviews and observations were analysed according to the constant comparative method of grounded theory described by Glaser and Strauss (1967). The analysis resulted in a model (How I play, core category) describing the child’s relations in different play situations, the factors that gave rise to different types of play and the consequences of the play. The different types of play were: (A) play with friends—a (a) interactive play and (b) onlooker play; (B) play alone; and (C) play with adults. The results were discussed on the basis of Mead’s theory of identity development and Bronfenbrenner’s theory of developmental ecology, that is how children’s play influences their development when adults are so often present. Key words: children with restricted mobility, microsystem, peers, play, relations.

INTRODUCTION

Play is considered by many theorists and clinicians in occupational therapy as a primary area of occupation [1–3]. Occupational therapists acknowledge the transaction between person and environment (both physical and social) that takes place in play. Play is considered to be a process by which children adapt to the environment or adapt the environment to themselves. The benefits of play described by occupational therapists include, among other things, the opportunities provided to engage in occupational roles as players, to explore and gain a sense of mastery over one’s environment and to experience joy and pleasure in interacting with peers [3–5].

Most disciplines working with children have described the importance of play. Specifically, play has been viewed as an all-encompassing activity through which a child develops skills in self-awareness, communications and socialization. Vygotsky [6] emphasized the social function of play and saw it as a principal factor in children’s total development. Piaget [7] considered that role play at pre-school age and games with rules at school age fulfill an important social function.

George Herbert Mead [8] considered that play and games are very important to the identity development of children. Unrestricted play permits children to imagine themselves in various social roles. Games have rules and therefore afford children the opportunity to assume their own role in relation to all of the other players in the game. In so doing, the player learns social rules and norms and internalizes them and, during this process, the child’s self-identity is formed. Therefore a child, according to Mead, cannot develop an image of him/herself without having other significant persons as a framework to relate to.

Inspired by the thinking of Mead, Urie Bronfenbrenner [9] offered a theoretical perspective for development, known as the ecology of human development. Fundamental to Bronfenbrenner’s model is a systems theory perspective. The system theory perspective is taken from biology, in which plants and animals together form the environment in which they live—a system in which each component is mutually dependent on the other components. By analogy, the child and its environment (both physical and social) are seen as a system of mutual dependence. The child’s primary environment is its family, which, according to Bronfenbrenner, forms a microsystem. A microsystem is characterized by a number of activities where the actors have their fixed roles and fixed relations with others. Other microsystems that the child belongs to are nursery school, school, the neighbourhood, different peer groups, etc. The older the child is, the more microsystems the child simultaneously belongs to. Microsystems in turn are incorporated in larger systems (meso- and exosystems) and these are all included in the overall macrosystem that characterizes society. The role of the macrosystem is to provide the “cultural blueprints” that define the social, political and ideological patterns of society [9].
As regards play, Bronfenbrenner considers it to be extremely significant in the child’s social development. In an ecological perspective on play, the child has different roles and relations in different play situations, and learning to master these roles and relations develops the child’s initiative and independence, and in the long term has substantial relevance to the child’s development in general. According to Bronfenbrenner, play and games in different ecological settings are topics where relevant research needs to be carried out. Contemplating children’s play from Bronfenbrenner’s perspective, we see that it extends over several microsystems. Children play at home, in playgrounds, in schoolyards, at friends’ homes, on the street, in woods, etc. The roles they adopt in their games and in relations with their playmates also vary, partly according to the children’s age, but also according to the games they play and the settings in which the games are played.

Researchers in occupational therapy who have studied the play of physically disabled children affirm that for children with restricted mobility, most play situations necessitate the presence or active participation of an adult, even if other children are taking part in the play [10–12]. To be constantly in the presence of an adult can deprive the play situation of its spontaneity and cause the disabled children to lose the spontaneous play contacts with other children that are so important to their development. Several investigators have found that well-intentioned parents and other adults tend to be overprotective of disabled children and prevent them from participating in normal play with playmates [11, 13, 14]. They point out that such a deprivation of normal play, caused by albeit well-intentioned adults, places the children in a relationship characterized by greater dependency on others, thereby causing secondary disabilities, such as poorly developed social skills and reduced self-esteem.

The research reviewed reveals that the play situation of children with restricted mobility is probably different from that of other children, but how the differences are manifested has, so far, been sparsely studied. How is play affected by constantly having an adult present? How does the accessibility of different play environments affect play activities? What, and with whom, do children with restricted mobility play? The questions are many and the answers few. There is a lack of research in this area, including Swedish research, presenting the children’s own opinions. Inspired by Mead’s symbolic interactionism [8] and Bronfenbrenner’s environmental perspective [9], the purpose of this grounded theory study was to gain knowledge and understanding of how children with restricted mobility behave in different play situations. The goals of the investigation were exploratory by nature with the aim of discovering a conceptual framework for describing and explaining the play of children with restricted mobility.

METHODS

The method was selected on the basis of the following starting points. We wanted to approach the play situations of children with restricted mobility with as open a mind as possible and to study the children’s social activities in these play situations. Therefore, even though we had certain prior theoretical knowledge, our aim was to work inductively. From these starting points it was natural to choose as a method grounded theory, as described by Glaser and Strauss [15], and Strauss and Corbin [16]. Grounded theory is particularly well-suited to studies attempting to understand a person’s experience of his/her interaction with others in the social sphere.

Subjects

In all, 10 children (five girls, five boys) with restricted mobility were selected to participate in the study. They ranged in age from 6 to 12 years and the reason for choosing this age range was that it is difficult to interview children aged less than 6 years, and after the age of 12 when the children reach their teens, they cease typical childhood games. The children had a good verbal communication skill (in order to enable their participation in the interview), that is they lacked any cognitive disability. They had restricted mobility related to medical diagnoses such as spina bifida, cerebral palsy or polio syndrome. All the children were users of technical aids such as a wheelchair, a walking trolley or crutches. The children selected for the study came from two adjacent, medium-sized municipalities. The inclusion criteria described above set a limit on the number of children taking part in the study, which made the sample selected a total sample within this geographical area (the two municipalities). The participating children were selected with the assistance of the chief physician at the Children’s Rehabilitation Clinic. The chief physician sent a letter to the parents asking for their permission to interview their child. The aim of the study was presented in the letter. The parents contacted the researcher when, together with their child, they had made the decision to participate in the study. All the participants were guaranteed confidentiality and the children were informed of their right voluntarily to withdraw from the study at any time. The project was approved by the ethics group at the University College of Health Sciences in Boden, now
the Department of Health Sciences, Luleå University of Technology.

**Data collection techniques**

Data collection techniques included informal and formal interviews, non-participated observations and field notes. The combination of such diverse data collection techniques helped to increase the accuracy and comprehensiveness of the data and the understanding of the phenomena under investigation, and thereby the reliability of the findings [17].

The interviews (carried out by the second author) were conducted as flexible, open-ended conversations in an attempt to increase the likelihood that respondents' own accounts and opinions would take priority. The first interview question was a broad one asking the children to talk about their play and playmates. After that, the interview consisted of a series of prompts focusing on topics such as: different types of game, play environment, playmates. Examples of questions used were: What types of game do you play? How does it look where you play? Whom do you play with? The second author also carried out the observations, which involved observing each child during a whole day in school, with special focus on play situations. During the observation period, children were asked informal questions about their play experiences. The focus of these questions was on the child's interactions with others. These questions were added to the observations and served to confirm or otherwise what had been observed.

**Data analysis**

Data analysis was carried out by both authors jointly. Transcribed interviews, observational field notes and notes made during play situations were used as the basis for analysis. As far as possible, the children's own language was used to capture the authenticity of the children's experiences.

During open coding the texts were broken down into discrete parts, labelled and compared for similarities and differences. The codes could be "initiating a game", "being left out", "having a personal assistant in the game", etc. The codes found were then grouped into categories. In this process, separate types of play situations emerged and were labelled "Play with friends", "Play alone" and "Play with adults", that is the categories around which the concepts could be grouped.

In axial coding, the focus of the analysis was on the conditions which gave rise to the separate play situations, the interactional processes in these situations and their consequences. The orienting conceptual framework of Bronfenbrenner and the interactionistic focus guided the questions. We asked, "Who initiated the game?" "What role had the disabled child in the game?" "Where (in which microsystem) did the game take place?" "What kind of feelings were aroused by the game?" The linking of categories at this point was quite complex and time-consuming, alternating between inductive and deductive thinking, proposing statements about relations and trying to confirm them against data. During this analytical phase there was also a purposeful sampling of information whereby the informants (the children) were asked additional questions in order to validate the relationships between the causal conditions, categories and consequences.

During selective coding the story line was conceptualized and the central phenomenon was given a name "How I play" (core category) which was, in our opinion, abstract enough to encompass all that had been described in the story. The outcome of this analysis was a preliminary conceptual model of the children's social activities in different play situations.

**RESULTS**

We can see from this theoretical model (Fig. 1) that children with restricted mobility play with friends (category A: play with friends), play alone (category B: play alone) and play with adults (category C: play with adults). Play alone was the most common form of play, closely followed by play with adults. There were certain factors that determined whether children played a particular type of game—with friends, alone or with adults—and each category had also certain typical characteristics and certain distinct consequences. Below follows a description of each separate type of play (category).

**Category A: play with friends**

This category could subsequently be divided into two subcategories: (a) interactive play and (b) onlooker play.

**Interactive play.** The principal factor behind this type of play was the lack of a participant in the game. When other children were to play a game, and a participant was lacking, the child with restricted mobility was asked whether he or she wished to participate, "When they play ice-hockey and don't have a goalie, they fetch me and I can be in it". Thus the game was set up mainly on the initiative of others. Occasionally, the children with restricted mobility themselves suggested games, but such initiatives seldom led to play, "I ask but it's not usually the right thing".
Play in this category could be role play, different indoor games (playing a game or playing cards) or group play and took place in the child's immediate environment—in the home, school or recreation centre. In role play, which was a frequent game, and played with younger children, the children had set roles, and the relationship that the child with restricted mobility had toward other children was determined by the role that the role play demanded. Although the roles in the game were dependent on the play theme, the children with restricted mobility were nevertheless given roles with a "lower status" than those of their playmates. For example a girl with restricted mobility when playing mothers and fathers would be assigned the role of a baby sister—a fairly passive role in the game, "I'm usually the little sister. But I only like it sometimes". A boy with restricted mobility, when playing a war game, was assigned the role of the enemy and was quickly killed by the winning side (the other participants), "They (the boys) came to my house because we were going to play war and then they hid in the bushes. I had a sword so I couldn't shoot so they went and shot me straight away. They had pistols. Then I was out of the game".

Sometimes in addition, games such as "tag" and "hide-and-seek" were played. The children with restricted mobility were allowed to participate here as it was a group game, in which the whole group was to take part. However, here too the children with restricted mobility were given an inconspicuous role, which can be illustrated by an interview transcript, "When we play hide-and-seek nobody comes to look for me".

Onlooker play. In this subcategory there were games where the children played with playmates and where they described themselves as players even if the observations showed that they were onlookers of the games of others. The games described were different ball games such as "ball hopscotch", football or ice-hockey. The nature of the games made it difficult for the children with restricted mobility to take part, and this meant that the children instead became onlookers to other children's games. A clear discrepancy existed here between that which the children experienced, what they recounted on prompting and what observation showed. The children's accounts indicated that they were active players. As one wheelchair-bound boy said, "We play football". It was not until we asked in more detail how this was done that the boy became uncertain and said, "Well, I don't play exactly. I probably don't ever play football, but I'm there". It turned out that he was an onlooker on the sideline, but that he still felt that he

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Fig. 1. How I play. The model of the children's different play experiences.
was taking part in the game. Another child said that she often played with other playmates out in the playground, but when describing in more detail she said, “It can be difficult to be in the game so I watch, but I’m still in the game somehow”. Observation showed that the children were in fact onlookers, even though they themselves considered that they were active participants in the game. The relations toward the other children were unilateral, that is, the others actively played against each other, which the children with restricted mobility did not do. Nevertheless, the feelings the children with restricted mobility described were ones of involvement and participation in the game, even though they were on the sidelines.

The play situations described above in the main category “Play with friends” can all be characterized as “play on the terms of others”. Either the initiative to start the game was taken by others, or the children with restricted mobility were allowed to participate for lack of other playmates. Even as “onlookers” they participated on the terms of others. It was not the children with restricted mobility who initiated these games, neither did they have an important role in them. The games were controlled by others, their theme and content were chosen by others and most of the activity and creativity came from others. The consequence of this type of play, that is play with friends was that the children with restricted mobility still felt relatively pleased, that is, they were satisfied having been allowed to participate, even though the games did not take place on equal terms.

Category B: play alone
The principal factor giving rise to play alone was previous experience. The children with restricted mobility declared that “Nobody wanted to play with me anyway”, that is previous experience was such that it was fruitless to expect to be with others in play situations. In order to avoid disappointment, they withdrew and said that they might as well play alone, “It’s easier that way”. In a way, the children made an independent choice and chose solitude instead of disappointment and found more enjoyment in these solitary play situations. As one of them says, “I mostly play alone. I have no choice. I’m almost never allowed to be in the games, because it doesn’t suit the others”.

“Play alone” was represented by all the children in the group investigated, and was the category containing the most games. Play alone took place in the immediate environment, that is in the home, in school or in the vicinity of these settings. The games the children described were typical boys’ or girls’ games (play with cars or dolls), creative play (painting, drawing), construction play (assembling puzzles), but also relaxing activities (reading or listening to music). Play alone could also take place in the presence of other children, e.g. in school or a recreation centre. The children then sat together with others, but were playing alone, as others played with each other, while no-one contacted the children with restricted mobility to invite them to take part in the game, “Sometimes I ask if anyone wants to play a game or something, but quite often nobody wants to. So I quite often play alone”. Observations also clearly showed that the children with restricted mobility were often left out of the game and became invisible to others, that is nobody took notice of whether they joined the peer group or sat talking. If the game then transferred to a new location, there was no peer who took the initiative to ask the child with restricted mobility to accompany them.

This type of game is characterized in particular by the children's invisibility. When the children with restricted mobility withdrew into their homes they became invisible to others, but also among peers they became invisible when playing alone in the middle of a peer group. The emotional consequences for themselves that the children described in connection with this type of play were in a positive perspective, a tranquil solitude, “It feels good to be by myself”; but in a negative perspective they expressed feelings of abandonment and alienation, “I am often a sort of reserve friend for others who have nobody to play with. I go around waiting for somebody to have nobody to play with so that I can play with them instead”.

Category C: play with adults
The factors giving rise to this type of play were the absence of playmates and the character of the play environment. Play with adults concerned games that took place together with family members or with the personal assistant. The initiative to play the game came from the adult when the child had no friend to play with and the adult thus came to replace the friends. The character of certain games or play environments could mean that the game could only be played with the help of an adult, e.g. play at a playground where the child needed a good deal of help in negotiating the existing environmental obstacles (inaccessible ground cover such as sand, difficulties in using the play equipment, etc.).

Play with adults took place both in the immediate environment and in the distant environment. In the immediate environment play was of a more sedate nature, meaning that the children played games or cards together either with parents or the personal assistant in the home. Play in the distant environment
gave the children a possibility to play in new locations beyond the home, e.g. at a playground or in the countryside. At the playground the personal assistant was a prerequisite for play. One girl describes playing at the playground as fun, but she had difficulties using the equipment. She needed help from the personal assistant to get on to the swings or to sit on the climbing frame, "I get help from Anna (fictitious name) to climb up, she's always with me if I'm playing in the park". In the countryside the children participated in shared recreational activities together with their parents, activities that were greatly appreciated by the children. For example a boy told of when he went to the woods with his father to find a piece of wood suitable for whittling, and another child told of when he had gone on a fishing trip with his father. He had had difficulties getting in and out of the boat, but described the fishing trip as a great success and characterized by a special relationship with the father.

Characteristic for this type of game is that the adults took the place of the friends and became the friend with whom the child played. Thus the adult replaced the friends and by several of the children was regarded as a playmate, "She (the personal assistant) is my pal. Yes, she's actually with me always". Observations showed that the adult (the personal assistant) sometimes could be an obstacle to other children being able to play with the child with restricted mobility, that the personal assistant took over the game, which resulted in the child with restricted mobility playing with the adult even though there were other children nearby. But also other practical tasks that the children needed help with due to disability took time, e.g. napkin changing, help in dressing; and the friends did not wish to wait, so the child was obliged to turn to an adult for a playmate, "I always have to changes nappies every other hour and sometimes my pals get tired of waiting and go home".

The consequence of this type of play was that the children felt it was still better to play with an adult than to be alone. In a long-term perspective, being together with adults instead of peers can lead to the children with restricted mobility being increasingly dependent on adults and less independent. Our observations showed also that the children often preferred adults to children, as games with an adult were easier to stage, since the adult (the personal assistant) was always at their side and offered his/her company. A positive long-term consequence of this adult presence could be that children find it easier to be with adults, which our observations also showed. The children with restricted mobility were drawn towards adults, to the personal assistant, to the teacher and also to the observers rather than to other children.

DISCUSSION

The purpose of this study was to acquire a deeper understanding of the play of children with restricted mobility. The study resulted in a preliminary model—How I play—which provides a fairly differentiated picture of the various types of play situations, of the roles and relations in these games and the environments where the play takes place. As shown in the model, there are three different play forms (categories) in which the children with restricted mobility are involved. In only one of these forms (category A, Play with friends) do the children interact with other children on equal terms. In the other forms, the games take place alone or in the company of adults.

These results are similar to those presented by Nabors and Badawi [18] who have examined the play interactions of pre-school age children with special needs in the playground. The researchers could show, as we could in the present study, that the children engaged in less co-operative play and were observed playing alone or with an adult more often than their peers. These results indicate that playing alone and playing with adults are frequent play forms for children with restricted mobility even at an early age and that these children no longer have much expectation of experiencing a change, that is of being allowed to play with other children.

The games played in interaction with other children (in the subcategory: Interactive play) were (among others) in the form of role play. Role play is a common form of play at pre-school age (7 to 8 years). The children in the present study however were considerably above pre-school age (mean age = 8 years and 5 month). Why children with restricted mobility participate in role play with other children at this age is not explained in the study. Can it be that owing to their restricted mobility they enjoy playing with younger children, as their demands of the game are less than their peers’ demands? Some studies indicate this [19]. It was also interesting to note that in role play, the children with restricted mobility were assigned roles of lower status than the roles of other children, which indicates that the games were played on the terms of the children without restricted mobility. The problem is also, as Bronfenbrenner sees it [9], that if required to play low-status roles, one risks beginning to act in accordance with the cultural stereotypes existing for these roles in society.

In the subcategory "Onlooker play" the games played were games with rules such as football, ice-hockey and other ball games. In these games the children with restricted mobility took an onlooker's
role, as their restricted mobility did not allow them to take part in the game. At the same time, they themselves felt that they were participating in the game. How should this be interpreted? Seen from an interactionistic perspective, human beings create the world of experience they live in by reacting to things in terms of the meaning the things have to them [9]. For the part of the children with restricted mobility, we can therefore assume that when they say that they are playing together with other children, they really feel that they are participating in the game, even though they are merely onlookers during the games of others. In other words, the child physically is an observer of a game, but psychologically she/he is a player. The significance of these games to them then is a sense of participation, even at a distance. Whether such a feeling of participation will exist in future, that is when they are older, is hard to determine. Only further studies can provide an answer.

As our results show, play in the category “Play alone” is often characterized by the fact that there is nobody to play with. All children occasionally play alone, but with the difference that play alone is not a first-hand choice for children with restricted mobility, but rather something they do since no other choice is available. One might say that “Play alone” is a strategy for the child with restricted mobility to resolve an unwelcome situation, that of being excluded from a peer group [see also 20].

To be alone and invisible to others in the middle of a playing peer group, as the participating children were, creates feelings of frustration. The frustration experienced by the children can cultivate apathy and withdrawal as other researchers have also shown [21], and, as a long-term consequence, they can negatively affect interaction with other children [11].

In the category “Play with adults”, adults came to replace the friends that the child with restricted mobility lacked. The fact that children with restricted mobility are often together with adults is a well-known phenomenon in prior research [10, 12, 22], even though nobody has described in more detail, as we have, why this is the case. To play with adults instead of children can create a state of dependency that prevents children with restricted mobility from becoming independent and makes them limited in their social interactions and isolated from other playmates [23].

Play with adults also had to do with the character of the physical play environment. The games took place in playgrounds and the children with restricted mobility were assisted by adults. Here, it was not only the restricted mobility that constituted a problem, but also insufficient accessibility in the environment. The playgrounds were not built to allow wheelchair-bound children to get to the playground, nor to the equipment. The personal assistants were obliged to carry the children and were therefore a prerequisite for the children with restricted mobility even to reach the playground. As a consequence of this, there were no opportunities for spontaneous play with peers in these settings. Environmental obstacles as a cause of a handicap have been noted by several researchers [24, 25]. According to Bronfenbrenner’s perspective on developmental ecology [9], the environment exists for the individual not as an objective phenomenon but as something subjectively experienced. Since children develop in interaction with their environment, the environment communicates messages to them about who they are and who they can be in the future [see also 26]. When the children with restricted mobility in this study discover that the physical environment in their play situations is limited and prevents their spontaneous play with others, this can communicate to them the fact that these settings (i.e. the playgrounds) are something solely for children without restricted mobility, and that they are not welcome there. Such an understanding, brought about by both physical and social barriers, can have a detrimental effect on their social development and identity formation.

When we consider the results obtained from Mead’s [8] and Bronfenbrenner’s [9] theoretical frame of reference we find the following and put forward some questions for study in continued research. According to Mead, it is through play the children’s identity develops, via the children’s interaction with their peers. It is thus essential for children to interact with other children of different ages in order to adapt to others and to learn to co-operate. Since physically challenged children in the present study spent a good deal of time with adults this may curtail the freedom they need in order to engage in play with other children. Additionally, they have less opportunity to make decisions about what to do, or with whom to be. As play, seen from the perspective of Mead’s theory, is an identity-forming activity, the question arises: what identity will the children with restricted mobility develop when the significant others (to use Mead’s terminology) who have a considerable influence on identity formation are adults and not children? Can it be, as so many researchers have shown [11, 12, 14, 19], that the children with restricted mobility gradually become more socially isolated from other children and increasingly dependent on adults, which can have detrimental consequences on the development of their self-esteem and identity?

Or can it be that these children’s close contact with the adult world does not damage their self-perception at all, nor does it create problems, but instead leads
to their maturing quicker than other children who lack this constant contact with the adult world? The adult researchers with restricted mobility who write of their own lives give this impression— that they are "survivors"— that have succeeded just because their circumstances have constantly forced them to struggle harder than other children [27, 28]. As yet we have no answer as to whether such a development occurs or even whether is it something desirable. Further studies, preferably longitudinal, can clarify these important issues.

The settings in which play took place in this study are the home, school, the playground and the recreational centre. These settings are probably identical for children without restricted mobility. However, what is noteworthy is that the children with restricted mobility do not have additional settings to play in, that they do not, for example, play at friends' homes or play out of doors with other children, in settings that are usual for children of this age. Similar results are found in prior research which finds that children with restricted mobility have limited opportunities to play in different settings [12, 20, 23, 29].

The strength of this study is the children's insider perspective on their play situation, with descriptions of the character and consequences of different forms of play. Through the collection of data in which the children's accounts were central, and which were complemented by observations and field, we obtained a very good picture of the children's play situation, where, in our opinion, only the children themselves can, in a substantial way, judge what is important to them. This study thereby offers important insights into the play world of disabled children. The limitations of the study have mainly to do with the sampling issue. The investigated group was small and it was drawn from a clinical population. This means that it consisted only of children who were enrolled at the Children's Rehabilitation Clinic, a fact that means that the sample is not necessarily representative. Another limitation has to do with the difficulties involved in interviewing children. Asking questions and getting answers from children who do not think in the same way as adults means that there is always a risk of interpreting the interview text based on adult understanding.

Although the scope of the study was sufficient to ensure that the major issues (i.e. the model "How I play") were elicited, the results may not represent the play situations of all children with restricted mobility.

**Implications for occupational therapy**

The study of children's play behaviour is important for occupational therapists since play is considered as a cornerstone of occupational behaviour. A child's play can not be isolated from the environment within which the child is playing. One of the goals of occupational therapy is to improve the reciprocal relationships between the child and its environment (both physical and social). To promote this interaction, the occupational therapists play a valuable role when they consult with parents, teachers and other professionals (for instance personal assistants) to enhance the play and social experiences of children with mobility restrictions. As regards the physical environment, occupational therapists can analyse the playground structure and recommend changes in playground design and playground equipment, thereby supporting or enabling the child's performance. These recommendations could be made through problem-solving discussions among family members and professionals as to what aspects of the environment can and should be modified [30]. Furthermore, occupational therapists need to assume an active role in planning other outdoor environments, such as community playgrounds and other recreational environments [31].

Regarding the social environment, occupational therapists can help to promote positive relationships between the child and significant others. When significant others lack understanding of the child's underlying ability impairments they are not able to help the child to develop positive interactions with its social environment. Thus the therapist has a crucial role in educating caregivers, peers and educators about the link between impairments and children's behaviour.

Many parents feel sorrow when they see that other children do not wish to play with their child. Occupational therapists here have an important role to play in co-operating with school staff to give support to parents and to find ways to help the children with restricted mobility to become active participants in games. One way, (which has been put forward by occupational therapists in child rehabilitation in our own county) is to develop different types of games for children with restricted mobility. These games should be of such a nature that they are interesting to other children and thereby give rise to common play. Initially, such games would need to be controlled by adults (e.g. occupational therapists and the personal assistant), but as the children learn each other's way of playing, spontaneous play could be developed. However, play is not the responsibility merely of the occupational therapists, and the entire rehabilitation team should co-operate to ensure a good result. The results of such work, subsequently, should be fed back to the school (to personal assistants and teachers). In order to be able to help these children and
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Address for correspondence:
Maare Tamm Luleå
University of Technology
Department of Health Sciences
SE-961 36 Boden
Sweden
Fax: +46 921 758 50
E-mail: maare.tamm@hv.luth.se
Artikel V
My Assistant and I: disabled children’s and adolescents’ roles and relationships to their assistants

LISA SKÄR & MAARE TAMM
Luleå University of Technology, Department of Health Sciences, S-961 36 Boden, Sweden

ABSTRACT The purpose of this grounded theory study was to describe how children and adolescents with restricted mobility perceive their assistant with a focus on their roles and relationships with one another. The group investigated consisted of 13 children and adolescents with restricted mobility from northern Sweden, aged from 8 to 19 years. The analysis resulted in five categories: 1, the replaceable assistant; 2, the assistant as mother/father; 3, the professional assistant; 4, the assistant as a friend; and finally 5, my ideal assistant. In each category the child/adolescent was seen in relation to the assistant, i.e. the main story ‘My assistant and I’ from different perspectives. The findings showed that relation towards/from the assistant were both mutual and non-mutual, and that there were relations that by the children/adolescents were perceived as ambivalent and unequal. The findings are discussed on the basis of the significance of these roles and relations in the children and adolescents’ development.

Introduction

Children with restricted mobility are often in need of assistance in their everyday lives; assistance in the form of practical support during trips to and from school, visits to the toilet, etc., but also as social support in the form of an escort service to enable the child to participate in social events. The possibility to obtain assistance is governed by different laws in Sweden. This law concerning support and service for persons with certain functional impairments (LSS), which came into force on 1 January 1994, is thus a very important one. The aim of Swedish disability policy is full participation and equality. The policy objectives are in line with the UN’s Standard Rules on the Equalization of Opportunities for Persons with Disabilities (Swedish Institute, 2001). As regards children, the Swedish government signed the UN’s Convention on the Rights of the Child (CRC) on January 1990, and ratified it in June 1990. In March 1999, parliament adopted a National strategy for the
implementation of the CRC, The International Save the Children’s Alliance (Save the Children, 1992). One factor of importance for the development of disability policy is the deeply-rooted tradition of popular movements in Sweden. The Swedish organisations of disabled people are run and dominated by people with functional impairments. Through their work there has been an assistant reform in Sweden, which has extended the rights of people with functional impairments by giving any person, including children, below the age of 65 the right to personal assistance. In Sweden the legal definition of a child is every person below the age of 18 (Swedish Institute, 2001).

It is a law which came to also apply to children and adolescents with impairments, and which gave them the right to assistance/assistance remuneration. For personal support in school, this group of children and adolescents has the right also to school assistants employed by the school authorities (Schools Act, 1991). The idea behind assistance reform was introduced by the Independent Living Movement in Sweden in the 1980s and was based on ideas to underline the user’s independence and possibilities to develop (Gough & Modig, 1995; Gough, 1997) This law—‘LSS’—therefore came about as a complement to the Social Services Act (SoL) and the Health and Medical Care Act (HSL), to help and improve the life situation of people with disability, and who are in need of support and service in their daily life. In this law (LSS) there are no details how the terms of employment for personal assistants should be regulated. Therefore, a personal assistant could be employed by the municipality, an organisation, a company or by the user him/her self. This law also does not have recommendations regarding education, which can lead to uncertainty both for the employer and the employee (Hugemark, 1998). The personal assistant is usually hired on the basis of the users personal taste and liking, and not on the basis of the assistant’s medical knowledge. For children and adolescents the personal assistant is usually hired on the basis of the parent’s personal taste and feelings (Hugemark, 1998).

The lives of children and adolescents involve many activities—play, different recreational activities, being with peers and school attendance. For children with restricted mobility this means that they need the help of an assistant in all these activities. Previous studies in this project have shown that adults, above all assistants, are important persons in these children’s lives (Skär & Tamm, submitted; Tamm & Skär, 2000; Skär, submitted). As regards play situations for children with restricted mobility, the assistant is important for the child to access the environment where play is carried out. Sometimes the assistant can also come to replace e.g. peers. Play with adults was one of the most frequent play forms among children with restricted mobility (Tamm & Skär, 2000). It is not only the play situations of children with restricted mobility that contain many adults and few friends. In a study in which we compared the social network of children and adolescents with and without restricted mobility, we could ascertain that the entire social network of children and adolescents with restricted mobility contained many adults and few peer friends. Also during the teens, adolescents with restricted mobility have few peer contacts (Skär, submitted; Bö, 1989; Spirito et al., 1991).

What is the significance of the fact that children and adolescents with restricted
mobility have so few contacts with the peer group of friends and that in many situations they are obliged to turn to adults (parents and assistants). Seen from the perspective of Bronfenbrenner’s (1979) developmental theory, the roles and relationships that children have, and the activities which they carry out and/or participate in are important in their development. Bronfenbrenner considers it important to children and adolescents to develop multiplex roles in their contacts with others. If their role repertoire is limited, a deficiency in their development appears. It is especially important that children and adolescents have relationships to their peers, since their development, at least from school start and onwards, takes place largely in the circle of peers in particular (see also Hartup, 2000).

Largely to consort solely with adults, as is the case for many children and adolescents with restricted mobility, can also bring obstacles to the development of identity (Pollock et al., 1997; Howard, 1996; Skär & Tamm, submitted). From an interactional perspective (Mead, 1934), which is also the starting-point for Bronfenbrenner’s theory, identity development takes place in different interplay situations with peers. According to Mead (1934), children develop their perception of themselves and their identity in play situations with other children. In these situations, children adopt different roles and perceive themselves in the role-plays that go on between playmates. For children with restricted mobility, often surrounded by well-meaning parents or other adults (e.g. assistants), this can mean that in different play situations, the child perceives him/herself in relation to adults and develops a dependence on adults, rather than the independence that is required among peers (Tamm & Skär, 2000). To mirror oneself in others is even more important in the teens, when friends and peers acquire a great importance for identity development (see also Erikson, 1969; Hartup, 1979). For adolescents with restricted mobility the constant presence of adults can be perceived as over-protectiveness and can hinder the adolescents’ possibilities to make decisions of their own. These adolescents often lack control over their lives and perceive it difficult to liberate themselves from their parents, as we found in one study (Skär, submitted). Similar results are to be found in Barron (1995), who considers that young people with disability who are dependent on the help of others are often denied the opportunity to influence their life situation and that they also have difficulties to develop their identity.

This constant presence of adults (parents or assistants) in the daily lives of children and adolescents with restricted mobility leads the researchers to the assumption that the assistant is a key person whose mission is to give the child practical support, and to enable the child to play with his/her peers and to participate in the different activities of the peer group. The assistant shall also be a support to enable children and adolescents to participate in the different ranges of activities offered by the community. As far as we know today, no studies have addressed children’s perspective on their life situation in relation to the assistant. Therefore, the purpose of this study was to describe how children and adolescents with restricted mobility perceive their assistant, with the focus on the roles and relationships they have towards one another, and how the presence of the assistant influences children’s and adolescents’ peer contacts.
Methods

Participants

A total of 13 children and adolescents with restricted mobility participated in the study. They were aged between 8 and 19 years, with a mean age of 13 years. The participants had the diagnosis spina bifida, muscular dystrophy and rheumatic illness, and due to these illnesses/disabilities they used some form of mobility aid. The participants had good communicative abilities. All the children and adolescents were in need of the help of an assistant for all or part of the day. The participating children and adolescents came from two middle-sized municipalities in northern Sweden. The participants’ assistants were nine females (three personal assistants and six school assistants) and four male school assistants. Five of the school assistants functioned also as escorts (three women and two men), which meant that they performed their assistant duties in the school, and as escorts gave the children/adolescents the opportunity to participate in different social events, such as visits to the cinema, café evenings, ice-hockey matches, etc. Five of the boys had a female assistant, while the other participants had an assistant of their own sex. The assistants’ ages varied between 21 and 54 years, with a median age of 32 years.

The authors knew all the participants, since they had participated in several preceding studies (Skär & Tamm, submitted; Skär & Tamm, 2000; Tamm & Skär, 2000; Skär, submitted). Therefore, the parents were contacted directly, since they had previously given the authors permission to contact them at a later date. The parents were informed of the purpose of the study in order that they together with their child or adolescent child could decide whether to participate. At the same time, they were informed that participation was voluntary, and that their child or adolescent child at any time might leave the project if wished. They were assured also that the data would be treated confidentially, i.e. in such a way that the child’s/adolescents’ identity would not be revealed. When they had made their decision to participate, they contacted the author to agree on a time and place for the interview. The study was approved by Luleå University of Technology ethical group for health sciences.

Data Collection

Data were collected through conversational interviews, which was carried out by the first author. A semi-structured interview guide was constructed focusing on a number of thematic questions, such as:

- how they perceived their assistant;
- what help they received from the assistant;
- how they perceived the relation to the assistant;
- how peer relations were affected by the presence of an assistant, etc.

The conversational nature of the interview meant that there was opportunity for the participants to bring up other question areas that they considered important regarding the assistant. Since the author had established a fairly close relation with the
participants during an earlier study, they could in confidence give more in-depth information, also on more detailed and sensitive issues, which thereby increased the validity of the answers (Lincoln & Guba, 1985). The interviews took approximately 45 minutes with each individual participant and were recorded for subsequent verbatim transcription.

Data Analysis

The interview transcriptions were read through by both authors separately and were systematically analysed from the perspective of grounded theory (Glaser & Strauss, 1967). Grounded theory was chosen, since it uses an interactional approach; that is, the method contributes to improved understanding of relationships and interactions between individuals. The major part of the analysis work was carried out by the first author, although discussions between the two authors took place continually.

The analysis began with an open coding, where all interview transcriptions were read through as a single corpus. Then the work continued with a search for passages in the text that addressed the question: How do the participants perceive their situation when they have an assistant? These texts were transformed into codes and annotated in the margin of the transcriptions. They were then assembled by theme. These themes were further sorted into different larger groupings and a pattern began to emerge, forming a number of categories. These preliminary categories were: peer relations and the assistant, the assistant’s different roles, etc.

The next step was axial coding, where each category was refined, developed and put in relation to other categories. The analytical process was concluded by a selective coding, where both authors searched for a main story. The main story was given the title ‘My assistant and I’, and it became the unifying link between the different categories. The analysis was carried out parallel with studies of research literature on this subject in order to stimulate theoretical sensitivity, i.e. to contribute ideas in accordance with the approach in grounded theory.

Findings

The findings consisted of five categories:

1. The replaceable assistant.
2. The assistant as a mother/father.
3. The professional assistant.
4. The assistant as a friend.
5. My ideal assistant.

In each of these categories the child/adolescent is seen in relation to his/her assistant (i.e. to the main story) from different perspectives. The categories gave a picture of the different roles and relationships of the children and adolescents, and of their relationships to their assistant. The child/adolescent described also what it means constantly to be in the company of an adult (the assistant) in different situations. The different categories described what it means to acquire and change assistants,
what different roles the assistant has and how the children and adolescents perceive their assistant in relation to themselves, and in relation to their peers. Here follows a description of each category in turn.

**Category 1: The Replaceable Assistant**

All the children and adolescents had long experience of having a personal assistant or a school assistant. Some children, by the age of 2 years, had already been given their first assistant in connection with their beginning at day nursery, whereas others had been given their first assistant at the age of 7 years, when starting school. All the children and adolescents had also changed to new assistants on several occasions, and it was the experience of all of them that the assistants are replaceable. The children/adolescents told of the difficulties of introducing a new person into their lives in connection with receiving a new assistant. There were many tasks that the assistant needed to be informed about, e.g. what help the child/adolescent needed, how the help was to be given, what the children/adolescents could manage to do, etc. When introducing a new assistant, the children/adolescents or their parents might forget to mention certain things, which according to the children/adolescents resulted in irritation for the personal or school assistant, who then did not know how a task was to be carried out or what rules applied. ‘Perhaps you forget to mention something and the assistant can get grumpy because you haven’t said everything’. Constantly to change assistants meant that the children and adolescents time after time had to ‘tell all’ about themselves to a new and unfamiliar person, which was perceived as an invasion of privacy. The relationship that the children had toward their assistant was not perceived as mutual. ‘They (the assistant) know everything about me, but I hardly know a thing about them. They barge right into my life’. It was the duty of both the personal assistant and the school assistants to help the children and adolescents with practical things like opening doors, taking out schoolbooks from bags, dressing and undressing, or helping the children/adolescents with more intimate matters such as visits to the toilet or to the shower after P.E. To obtain help with practical things meant difficulties for the children and adolescents when instructing the assistant in how they wanted to receive help, and certain practical situations were perceived as more difficult than others. Intimate situations in particular were perceived by all the children and adolescents as a difficult situation in which to obtain help. For example, one girl says: ‘It is more difficult to say how I want help in the toilet than how I want to put on my jacket’. It was also perceived as more difficult to obtain help in intimate situations if the assistant was of another sex than the child or adolescents, which was the case for five of the boys, who had female assistants. One of the boys says: ‘It’s no fun getting help from a girl, it would have been better if it had been a guy. But it’s lucky that my female assistants have been slightly older—you have no choice when you need help, you have to take what you are given’. Other children and adolescents who had an assistant of the same sex as themselves could not consider having help with intimate matters from an assistant of the opposite sex. ‘I want help only from girls in the toilet, if it was a boy, I would rather
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"do without help" said one of the girls, and other girls and boys expressed the same view.

Despite the fact that most of the assistants involved had worked with the children/adolescents for more than 6 months and according to the children/adolescents should have known how the children wanted the help, they were obliged to instruct the assistants in every new situation where they needed help. Daily to instruct the assistant in how to carry out different practical tasks was perceived by the children/adolescents as frustrating, since the assistants (both personal and school assistants), nonetheless, often carried out the task on their own terms.

Few of the children/adolescents perceived that the assistant really listened to their views. Some of the children said; 'He doesn't listen to me, but always does things his way, and I don't think that's good' said one child about a the assistant. Another child with a personal assistant said: 'It is hard work to say how the assistant is to do different things, but it's not easy to get her to do things in a new way either'.

In addition, children and adolescents' experiences of their assistants in different practical and social situations gave the picture that the assistants had different roles in different situations, and that the children and adolescents were allocated different roles by the assistant. Below follows a description of the assistants' different roles in four different categories.

Category 2: The Assistant as 'Mother/Father'

The assistant in the role of 'mother/father' gives a description of the children and adolescents' experiences of an assistant perceived to have the role of 'mother/father', both in relation to the children and adolescents, and in relation to their peers. Half of the interviewed children perceived that the assistant had the role of 'mother/father', a role that was not appreciated by the children/adolescents. The children and adolescents felt that the assistant decided over them in different situations and seldom asked their opinion. For example, one 10-year-old child said this, 'The assistant is like a mother who is always deciding. Even if my own mother has promised I can play with friends after school, the assistant can say no', or as one 18-year-old girl says; 'She (the assistant) thinks she's my mother and is supposed to bring me up'. The assistant in the role of 'mother/father' was a woman/man aged over 35 who was a personal or school assistant.

When the assistant had the role of 'mother/father', the children and adolescents perceived that they were treated like 'children'. However, the younger children perceived it as natural for an adult to decide over them in different situations even if they were not always pleased at this decision-making, while the adolescents (those aged over 13 years) felt wronged when they were treated like children. One of the adolescents gives an example, 'She sees me only as a child and that is not pleasant'. The adolescents thought also that the assistant in the role of 'mother/father' was an obstacle to their self-determination and they perceived that they had limited opportunities for autonomy. 'The assistant often becomes a mother even though that is not desired, slightly older assistants often tend to decide and say to those in their care things that a mother usually says, for example how to do different things. It is easy to feel like a child
now and then and I don’t think that’s really right. When the assistant wants to decide what you’re to do, it’s no fun’.

The assistant in the role as ‘mother/father’ according to the children/adolescents became a hindrance in the peer relations, since the assistant often took for example over a play situation, and decided how and what the children were to play or decided on the adolescents’ behalf what they were to do. The younger children (pre-teens) perceived that their peers did not want to play with them if the assistant was present. ‘My friends don’t want to play with me if the assistant is there so I sit mostly and watch when they play’. On the other hand, the adolescents were worried that their assistant could be perceived by their peers as a biological mother and that they themselves therefore by their peers would be perceived as different. ‘Several of them have asked if I have my mother with me and I think that’s a drag. It’s embarrassing and you don’t want to be embarrassed in front of your friends’.

When the assistant was not actively participating in the game or activity, she still did not leave the children/adolescents alone with their friends. The children/adolescents said that the assistant stood nearby and watched when they were together with their friends, which was perceived by both the children/adolescents and their friends as a disturbance to their game and/or interplay. Then the friends often withdrew and did not wish to play with the children or be with the adolescents. ‘He often looks on when I start playing and then my friends go away, so I mostly sit and look’.

Category 3: The Professional Assistant

In the following category, the professional assistant, there were only three adolescents aged between 12 and 14 years who perceived their school assistant as a professional assistant. These three adolescents said that they appreciated this type of assistant, who was a woman aged under 30 years. She was perceived as a support in practical situations and showed the adolescents respect and showed sensitivity to their wishes and views. ‘She is with me in the classroom but during the breaks I want to be in peace so she goes to the staff room’.

The adolescents perceived that the professional assistant saw and treated them as the persons they are rather than as the disability they have. ‘She sees me as Anna (fictitious name), as a person. Because that’s what I am’. This was appreciated by the adolescents, who thereby felt more similar to their friends. The assistant gave the adolescents scope to be adolescents with requirements for independence and autonomy.

To the adolescents, it was important that the assistant should not participate when they were together with their friends, but that the adolescents with restricted mobility and their friends might be left alone. The school assistant in the role of a professional helped the adolescents practically to get to the peer group, but did not actively participate in the activities, withdrawing on the adolescents’ initiative. ‘I ask her to go and drink coffee, so that I can be in peace with my friends’. For the adolescents it was important to be able to be in peace with their peers, since the assistant could be seen as something that labelled them as different. Therefore, the adolescents appreciated the fact that the assistant was sensitive to this and discreetly withdrew.
Category 4: The Assistant as a Friend

In this category, the assistant is described as a friend. This was not a frequently occurring role, and was seen only by one child of 11 years and some of the adolescents aged between 16 and 19 years, all boys. The assistant in the friend role in the cases in question was a male school assistant aged under 25, who according to the child/adolescents shared the same interests, activities and tastes as themselves. The assistant as a friend was much appreciated since he often actively participated in games and activities. ‘It is more fun if you are more similar and can have the same interests. He is my friend’. When the child/adolescents perceived the school assistant, as a friend, the relationships were mutual in that the assistant also saw them themselves as friends. They felt that in school the assistant saw them as friends when they played together or participated in activities. However, they felt that during spare time activities when the school assistant acted as escort, for example, when visiting cafés or shopping, the assistant no longer saw them as friends, but instead as children or adolescents with restricted mobility. The adolescents’ interpretation of this was that in his capacity as escort, the assistant did not wish to be seen together with them in public. ‘He doesn’t want to be seen together with me. Perhaps he is afraid to meet somebody he knows when I’m present’. This caused disappointment, especially among the adolescents who felt let down in their friend relationships with the assistant and this brought limitations in their participation in different social events in the community.

In peer relationships, the school assistant was perceived as both help and a hindrance. The school assistant was perceived as a help when he gave the child or the adolescents access to the settings where games or activities took place, or when the assistant was the initiator of enjoyable games and activities in which peers could participate. In contrast, the school assistant was perceived as a hindrance if the peers played more actively with the assistant instead of with the child with restricted mobility or if the assistant took the place of the adolescents with restricted mobility in card games or other activities. It was the experience of the child and the adolescents that an assistant who was a friend was in demand among other children as a participant in games and activities, and thereby the other children felt that they had lost their assistant to others. The child and adolescents said that they sometimes even refrained from being with peers if there was a risk that their school assistant might take their place in the peer group. ‘Sometimes they ask the assistant whether he wants to take part before they ask me, and that’s no fun’.

Category 5: My Ideal Assistant

In this category, an ideal assistant is described, something all the children and adolescents include in their accounts. The ideal assistant was not a specific type of assistant (personal/school/escort assistant), but was described more as a person with certain desirable properties or behaviour. It was important that the ideal assistant should be younger than 25 years, since the children and adolescents perceived that it was easier to play or carry out different activities with a younger assistant. In
addition, a younger assistant would not decide over the children or adolescents, in the opinion of the interviewees, but would give them greater opportunities to develop independence and autonomy. The ideal assistant would also be of the same sex as the children/adolescents, in order to be able to help in practical intimate situations, where none of the children or adolescents could consider accepting help from a person of the opposite sex. The children and adolescents considered that it was important that they themselves should be able to choose their ideal assistant based on their own criteria for a good assistant. One of these criteria was that the assistant should give confidence and security. 'I want to choose my assistant myself, because you have to trust the person who’s going to help you', or as one of the adolescents put it, 'I prefer to be helped by someone strong if I am to be moved or lifted, it feels safer then'. Also, the ideal assistant was to be available on the children’s and adolescents’ own terms: ‘She should be there only when I need her, otherwise I would (like to) be on my own’, and it was important also for the assistant to be kind and cheery. In spite of the fact that few of the children and adolescents had experience of their own assistant in the role of a friend, it was the friend role that was given for an ideal assistant. ‘I wish that my assistant was my friend’, said one child, and several of the children and adolescents expressed the same opinion.

When the children and adolescents wished that the assistant were like a friend, they also wished the assistant to see them as a friend, since it would lead to a mutual relation on more equal terms. ‘I wish for him to see me as a friend. It would be nice if we were friends, then I wouldn’t have to be alone’. The adolescents thought that a mutual friend relation toward the assistant would bring about greater opportunities for them to participate in the different activities offered by the community. ‘If we were friends we would go to discos and that would be fun’.

As regards peers, according to the children/adolescents it was an advantage if the ideal assistant also had the role of friend, partly in order that the assistant could be the ‘admission ticket’ to the game or, for adolescents, to the peer group. The children wished the assistant to help them to be selected for the games or to help with practical matters so that the game would function. ‘It would be better if the assistant asked if we (child and assistant) might take part when my friends do something special, because he is better at asking’. In contrast, the adolescents expressed a wish for the assistant to be their friend and to replace other friends, since their earlier experiences of peer relations indicated difficulties in both acquiring and keeping friends.

Discussion

The purpose of this study was to describe how children and adolescents with restricted mobility perceive their assistant. The findings showed that the relationships the children/adolescents had to their assistant were quite complex and ambivalent. In the first category, ‘The replaceable assistant’ the children and adolescents described how difficult and time-consuming it was to achieve a good and close relationship to a person (assistant) who entered their lives in the most intimate way imaginable. It was especially difficult, in the experience of the children/adolescents,
when they had to communicate their most intimate needs, which people usually attend to alone and still more difficult when the assistant was of the opposite sex. These views agree with Gough (1997), who has studied the experience of assistance of adults with disability. Gough considers that the need for assistance can mean vulnerability through loss of privacy and integrity by the person receiving assistance. This was the experience also of the children and adolescents we interviewed, when they stated that time after time they were required to expose their life circumstances and reveal their most intimate life to a series of new assistants.

Neither was the relationship towards the assistant by the children/adolescents perceived as mutual. The children and adolescents perceived that they were obliged to tell everything about themselves and their surroundings without receiving corresponding confidences in return. The asymmetrical relation was perceived as disturbing and an invasion of privacy. All child-adult relationships are certainly asymmetrical to a degree, in that the adult has more deciding rights and according to Bronfenbrenner (1979) children and adolescents develop through having experience of different types of relationship, and also through learning to deal with relationships in which one party has more power than the other. Nevertheless, the assistant relationship differs from these. In a way, it is a unique relationship, and is extremely difficult to form an opinion on the way in which it influences children/adolescents for better or worse, since there is a lack of research in this field. However, based on Gough's (1997) research, one should try to bridge the asymmetry that is integrated in the assistant relationship by arriving at a more professional approach from both sides. The professional assistant was, indeed, the assistant most appreciated by both children and adolescents, and represented one property possessed by the ideal assistant.

The continuity in the relationship with the assistant is very important in providing a sense of security. The continuity in the relationship can be seen as an asset, provided that the assistant and the user get along together. If the relationship is not working, the continuity can be frustrating. The children in the present study, who had several assistants under a limited time period, perceived the lack of continuity as something negative. In Sweden today there is a fairly large turnover when it comes to personal assistants, since many of the assistant's consider the work as something temporary and not as a profession. This might be the reason why these children and adolescents have experiences of a large turnover of personal assistants (Gough & Modig, 1995).

In the category 'The assistant as mother/father' it was shown that the assistant often decided over the children and adolescents, and seldom asked their views, which was perceived as a hindrance to the development of their independence and autonomy. Several studies (Johnson, 1995; Sathananthan & David, 1997; Blomqvist et al., 1998; Skär, submitted) have been able to show that well-meaning adults who often, more or less unwittingly, over-protect children with disability, make the children more dependent on adults. As a consequence of this, the children perceived that they lack control over their own lives and they feel tied when trying to liberate themselves from their parents and become independent. When the assistant in our study was perceived to have the role of mother/father, the children/adolescents in a
way acquired ‘double parents’, i.e. in addition to the biological parents the assistant too became a parent. To have ‘double parents’, particularly if both restrict the children’s/adolescents’ freedom, probably does not promote their development. Especially in the teens, adults who do not encourage independence are a hindrance in the developmental process (Bronfenbrenner, 1979; Erikson, 1969; Hartup, 2000). Adolescents who feel expectations to the contrary—that parents and assistants demand independence in theory, but in practical life are overprotective and regard them as a child—can find it difficult to become an adult and to develop the independence that according to Bronfenbrenner (1979), and other researchers (cf. Craig, 2000) is of central importance to healthy maturity and growth.

In the category ‘The professional assistant’, the adolescents perceived that the assistant saw them as the persons they are and ignored their disabilities. The adolescents perceived also that the relation to the assistant was mutual and without asymmetry, i.e. the adolescents perceived that they had influence over their own life situation and that there was a good balance in the power relationship between them and the assistant. The fact that relationships are mutual is considered important to the individual’s development and also prepares them to form relationships later in life (Bronfenbrenner, 1979). For through mutuality in a relationship, with interchange of knowledge and experiences, and a mutual respect, a child can develop as an individual. The interviewed adolescents also felt on a more equal footing with their friends when the assistant was professional, and research into identity development (Erikson, 1969; Hartup, 1996, 2000) points out that during the teens in particular it is important to reflect oneself in others, and that adolescents strive to consolidate with their peers attitudes and world views when searching for their own identity. The ‘professional assistant’ was thus an assistant who met the expectations of the law (LSS), i.e. the assistant was a human aid that carried out what the disabled children and adolescent hands and feet, ears, eyes and/or cognitive ability could not.

When the children and adolescents described their assistant in the category ‘The assistant as a friend’, they perceived an ambivalent relationship towards the assistant, that is, the relationship was sometimes perceived as mutual, sometimes not. The mutual relationships were perceived as desirable, occurring above all in the school situation where the assistant was a friend and saw the child/adolescent as a friend. When the assistant became an escort and went with the child/adolescent to different events in the community outside school hours, the relationship was no longer perceived as mutual and the children/adolescents felt let down in their friend relationship towards the assistant. The children and adolescents perceived that the assistant did not want to be seen together with them in public places. The assistant’s changed relationship with the child/adolescents may be due to the assistant’s own ambivalence in relation to the person being assisted. Guldvik (2000), who has researched into assistants’ work situation, describes just such an ambivalence existing in a friend relationship, and considers that many assistants find it difficult to differentiate between their role as assistant and their role as friend. The assistants in Guldvik’s study describes in particular the difficulties to maintain the necessary distance between oneself and the person receiving assistance, since the relationships
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between them are so close. Gough (1997) too emphasises that assistants in their work have expectations that the relation to the person receiving assistance should be professional, but that close relationships contain many emotional elements and therefore can bring apprehension over possible conflicts, feelings of envy or disappointment. Disappointment specifically was the feeling among the children and adolescents in this study when they felt that the assistant’s relation to them changed and was no longer mutual. In order to utilise such ambivalent experiences and stimulate development, Bronfenbrenner (1979), feels that the children can need help to deal with ambivalent situations by instead trying to develop further the relationship. The children in this study wanted to have the assistant as a friend, but this relationship is difficult to achieve, since friendship is something that happens spontaneously, and is characterised by mutual feelings of appreciation and is a result of free choice (Alberoni, 1987). This does not exist in the relationship to the assistant since this is a working one, where one person gets paid for his/her contribution.

In the children/adolescents’ experiences of their assistant, there were also accounts of how they wished an assistant to be. The ideal assistant represented the children and adolescents’ wishes for independence and opportunities to develop. In general, liberation from adults (parents and the assistant) was perceived as a precondition for self-realisation in adult life. Researchers consider that young people with disability cannot make choices in their personal life in the same way as others, since they need care and assistance (Söder, 1989; Barron, 1995; Gough, 1997; Skär, submitted). For the children and adolescents in this study it may be assumed that the lack of autonomy influenced the description of the ideal assistant. In the descriptions of the ideal assistant, there was a wish for the assistant to be a friend, and also to regard and treat the children/adolescents as friends. In one of our previous studies (Tamm & Skär, 2000), we could see that children with disability lacked friends, and often played or were together with adults. Perhaps there were similar reasons why the adolescents in this study wished for an assistant to be their friend and fill this gap.

To sum up, it can be established that for children and adolescents with disability it was both difficult and time-consuming to establish a relationship with their assistant. Relation’s to/from the assistant were both mutual and non-mutual, and there were also relationships that were perceived as ambivalent. The relationships which the children/adolescents did not perceive as mutual brought disappointment, as did the relationships that were ambivalent, while the mutual relationships were perceived as developing and desirable. There was also an unequal power-balance between the children and their assistance. For the assistance it seemed to be normal to have a power to control the children’s lives and this was done when taking a role as a mother or father substitute or a caretaker in general. The children and adolescents were not given opportunities to control the decision-making processes, which shaped their ever-day life. In contrast to official policy (expressed in the United Nations Convention, and the Act concerning Support and Service for Persons with Certain Functional Impairments, 1994), which states that children and young people should have the right to influence decisions concerning their own life.
and well fare, these rights were not accepted, maybe not even comprehended, by the assistants. In order to balance the power, one needs insight into who has the power, know how to use it and eliminated the threat of illegitimate use of power. This means that children and assistants have to agree upon how the power (i.e. the responsibility) between them should be distributed and carried out. The assistant reform, which is very much a human-right reform, is not without its problems as we have seen from this study. These problems have probably to do with the uncertainties that exist in the LSS law today, i.e. the lack of education the uncertainty of what the work entails and that the user also is an employer. For assistants who are to support children and adolescents with disability in different practical and social situations, it is therefore important to receive this knowledge, described in present study.

The Strength and Limitation of this Study

The strength of this study is the insider perspective, i.e. that the children and adolescents themselves have told of how they perceive roles and relationships towards their assistant. The children and adolescents knew the interviewer well after having participated in previous studies, and therefore in confidence could provide a more substantial reply to sensitive questions, which they did not mention otherwise. According to Kvale (1997), a conversational interview is an adequate method to use when the interviewee is given the opportunity to describe experiences from his/her own perspective. The limitation of the study has mainly to do with the sampling issue. The investigated group was small, although among the children and adolescents there was a broad spread of ages in the age range 8–19 years, and therefore one cannot know whether saturation was reached (Glaser & Strauss, 1967). It is possible that the finding would have been different if there had been interviews with more children and adolescents with disability, for example, more categories might have been obtained.

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REFERENCES

Artikel VI
Adolescents with disabilities – their roles and relations to peers and adults

Lisa Skär, RN, PhD student
Luleå University of Technology
Department of Health Sciences
S-961 36 Boden, Sweden

ABSTRACT
The purpose of this grounded theory study was to gain knowledge of what it is like to grow up with a disability, with focus on roles and relations to peers and adults. The group investigated consisted of 12 adolescents from northern Sweden, aged from 15 to 19 years. The transcribed interviews were analysed according to the constant comparative method of grounded theory, described by Glaser and Strauss. The analysis resulted in a core category (Who am I) describing how the adolescents perceive themselves. The core category was related to three subcategories. In category 1., ”Relations to friends” – described the adolescents’ experiences of peer relations; category 2. ”Relations to adults” – described relations to adults in their life, and category 3. ”Thoughts about relations in the future” – comprises wishes for future relations. The results showed that the adolescents with restricted mobility saw themselves as regular members of the adolescent group and that it was the others who saw them as being different. Relationerna till jämnåriga kamrater var bristfälliga eller saknades helt, medan relationerna till vuxna ofta var ambivalenta eller asymmetriska, dvs vuxna gav hjälp och stöd samtidigt som de hade inflytande, bestämde och överbeskyddade ungdomarna. Det framgick dock att ungdomarna hade en positiv framtidstro trots att många hinder fanns att övervinna.

Key word: Adolescent, disability, roles, relations, peers.
INTRODUCTION
Already at an early age people are involved in various social relationships in which they must learn to adjust to other persons in their social surroundings. This process of adjustment helps the individual to develop multiple and complex roles in life. From Bronfenbrenner's theory “The ecology of human development” (1979), the development of roles has its origins in intricate interactions within the family, which can be seen as the individual’s immediate environment or a micro system (i.e. the individual’s living environments such as home, place of study or neighbourhood). Because the child grows up to become a member of several social systems (e.g., preschool, clubs and associations, and secondary school), new roles and relationships are developed. The individual’s development does not take place only within these new social surroundings, but also the roles, relationships, and activities that children and adolescents take part in contribute or affect important aspects of this development (Bronfenbrenner, 1979). During the teenage years, a person’s peer group is particularly important because peers, in addition to family members, help develop the person’s social roles and relationships in the various micro systems in which the individual is a member. Furthermore, the peer group and family function as prototypes for future social relationships. Bronfenbrenner means that it is important for young children and adolescents to develop a multitude of roles and relationships in their contacts with others, suggesting that a limited role repertory could result in seriously impeding their general development.

The adolescent years represent a time in which a great deal takes place in the life of a young person, including physical, social and emotional adjustments and changes. Moreover, it is this period in which adolescents begin to seriously search after their own identity. The sense of a personal identity summarizes the young person’s experiences in various situations and surroundings, such as a young family member, among friends of the same age and as a pupil in school. Beyond family and school, there exists a special connection with friends that is significant for the individual’s ability to discover his or her individuality (Eriksson, 1969). It is common for adolescents to use the peer group to compare themselves with others, test and develop their roles and interpret other’s impression of their own identity. According to Mead (1934), the individual’s personal development occurs through such social processes in which roles and relationships develop and are maintained through interaction with others. Therefore, according to Mead, adolescents cannot develop an image of themselves without having other significant persons as a framework in which to relate to.

During the sensitive adolescent years, peers largely come to take over the role and functions of the adult and peers even come to serve as a form of protection as an increased influence over the adolescent’s life begins to develop (autonomy). All teenagers strive to attain self-realization and liberation from parents though this is not an easy process. To develop autonomy implies different types of
independence: an emotional independence occurs when the adolescent brakes his or her dependency to parents; behavioural independence is needed in order that the adolescent can choose his or her own activities, friends, etc.; and value independence is necessary so that one's own norms and values can develop (Gardner, 1982). For an adolescent with a disability, the adolescence period encompasses a wide range of perspectives on independence because disabled adolescents' life situations differ from those of nondisabled adolescents (Söder, 1989; Blum et al, 1991). For instance, disabled young people face extreme difficulties regarding social integration (e.g., autonomy and independence, mobility, accessibility of public buildings, means of transport and communication facilities, and opportunities for leisure activities and holidays) not experienced by nondisabled young people. Disabled young persons are frequently referred to adults for support and help in a wide variety of situations; this occurs at the same time that they have few friends their own age (Skär & Tamm, submitted; Barron, 2001). Research has established that adolescents with a disability find it difficult to acquire or maintain friendships. Moreover, these adolescents are often excluded from peer groups in a variety of settings, including school and different types of leisure activity (Blomqvist et al., 1998). They are seldom spontaneously included in activities with others because of their disability and seldom participate in sports-related events and activities, unless these are specifically intended for them (Tamm & Skär, 2000). This tendency often leads to their lacking friends to confide in and identify with in their daily life activities. In addition, because of severe mobility constraints during the transition from childhood to adolescence, adolescents with disabilities experience extreme social isolation (Blomqvist et al., 1998).

Spirito et al. (1991) observed that the desire to be with friends diminishes when persons perceive themselves as being different from their peers. The self-image of adolescents with a disability is profoundly influenced by how others perceive them, i.e. by the attitudes toward disability that prevail in society. People with a disability are often recognised by society as dissimilar from others and in desperate need of help (Winter and DeSimone, 1985). These issues can be difficult to deal with because the persons with a disability see themselves through the reactions and judgements of others. The implication is that people with a disability have not developed the same self-esteem and sense of security as "normal" people (Rundqvist, 1980; Söder, 1989; Blum et al., 1991).

Research dealing with the issue of individual development of independence in adolescents with disabilities (Johnson, 1995; Sathananthan & David, 1997; Blomqvist et al., 1998) has shown that adolescents with disabilities feel overprotected, extremely dependent on others for support, sheltered, and unable or unwilling to make their own decisions. The restriction of physical activity imposed by a disability limits the adolescents' opportunities to explore their world, inhibits their interactions with peer groups, and curtails their potential for
independent behaviour (Campos & Barenthal, 1987). In short, young persons with disabilities sense a general lack of control over their lives as they struggle to attain freedom from control or influence of others.

From recent research on disability in young people, it appears that the adolescent years for these people is considerably more complex as compared with healthy adolescents. The relationships with schoolmates and other peer groups are strained or do not exist at all and many adolescents with disabilities experience social isolation from those groups they wish to be a part of (Barron, 1997; Blomqvist et al., 1998). However, to our knowledge, few studies have been conducted on young people’s experiences of what it is like to be an adolescent with a disability and what it means to have restricted mobility during adolescent years. Therefore, the purpose of this study was to enhance our knowledge of what it is like to grow up with a disability, with particular focus on social roles and relationships to peers and adults.

METHOD
Participants
Twelve adolescents (6 girls and 6 boys; mean age 18.8 years, range 15-19 years) with restricted mobility participated in the study. Adolescents with restricted mobility were defined as persons unable to transport themselves from one location to another without a wheelchair, walking trolley or other walking device. In setting these criteria, the selected adolescents represented the following medical diagnoses: spina bifida, cerebral palsy, muscular dystrophy, and rheumatic disease. In addition, the adolescent who participated in the study was required to have the capacity to respond to questions in an interview. These inclusion criteria -- restricted mobility and good verbal communication skills-- placed a severe limitation on the number of adolescents with restricted mobility within the geographical area where the study was conducted, which included two adjacent medium-sized municipalities in the north of Sweden.

The participants were thus selected based on the above-mentioned criteria, with assistance from the chief physician in charge of a Children’s Rehabilitation Centre. After the selection process, the chief physician presented the purpose of the study and asked the adolescents whether they were willing to participate in the study when they visited the Children’s Rehabilitation Centre during a rehabilitation week. When the adolescents had given their consent to participate, the researcher contacted each adolescent. All the participants were guaranteed confidentiality and informed that they could withdraw from the study at any time. The project was approved by the ethics group at the Department of Health Sciences, Luleå University of Technology.
Data collection method

The data collection method consisted of repeated interviews (three to four times) with each adolescent. The first interview was conducted as a flexible, open-ended conversation in an attempt to increase the likelihood that the message that is intended or expressed by the respondent is given priority. Using this open-ended interview also implied that adolescents could raise any issues they thought relevant. The first question was broad in scope, asking the adolescents to give an account of how they had experienced their disability during their childhood and adolescent years. The interview subsequently consisted of a series of prompts focusing on such topics as social roles and relationships in childhood, youth, and schooldays. Below, are three examples of the questions asked of the participants.

How have you perceived your childhood regarding friendships? How have you perceived your relationships in schooldays? How do you perceive being an adolescent with a disability?

Follow-up interviews were used to complement and expand upon the first interview. In the follow-up interviews, the researcher achieved closer contact with the adolescents, which gained the confidence of the respondents to respond to questions that were more sensitive. Examples of questions during the follow-up interviews included the following: Do you feel different in comparison with your friends? How has your disability affected your relationships with a boyfriend/girlfriend?

The repeated interviews served to enhance the understanding of the phenomena under investigation and the comprehensiveness of the data, both of which helped to improve the reliability of the findings (Lincoln & Guba, 1985). The interviews were tape-recorded and took place in the respondent’s home. The initial interview took approximately 1 hour, whereas each of the subsequent interviews took about 30 minutes. Consequently, each respondent was interviewed between 2 and 2.5 hours.

Data analysis

The interview data were systematically analysed using the constant comparative method of Glaser & Strauss (1967). The method of constant comparison is a combination of systematic coding, data analysis and theoretical sampling procedures that helps the researcher to make interpretive sense of much of the diverse patterning in the data by developing theoretical ideas at a higher level of abstraction than the initial data descriptions. The analysis and collection of data was carried out in parallel, i.e. when the analysis so required, there was additional gathering of information from the respondents. As far as possible, the respondents’ own words were used in an effort to capture the authenticity of their experiences. The analysis began with an open coding system, which was made possible by taking the interview text and asking, “How do the adolescents
view their situation?” The texts were broken down into discrete components and then labelled and compared for similarities and differences. The data were sorted into categories and a pattern began to emerge that formed three categories: relationships to friends, relationships to adults, and wishes for the future – relationships to the future.

The next step involved axial coding, where each category was refined and developed and then the refined category is put in relationship to other categories. The focus of the analysis concerned three issues in the form of questions: How did the adolescents perceive themselves? What was the basis for their opinion? and How did they perceive other persons’ views of them? The analytical work terminated with a selective coding process. This process resulted in the identification of a core category (called “Who am I?”), which was then related to the other categories. The core category was abstract enough to encompass all that had been described in the story.

RESULTS
The findings consisted of the core category – "Who am I?" – which gave a general picture of how the adolescents with restricted mobility perceive themselves in relationships with peers and adults in different contexts. The core category was then related to three subcategories: relationships to friends – describes the adolescents experiences of relationships to peers; relationships to adults – depicts relationships to adults; and thoughts about relationships in the future – delineates the respondents’ wishes for the future. The categories are described from different perspectives as to what it means to have a disability during adolescence, with special focus on social roles and relationships.

The core category: Who am I?
Most of the adolescents reported that their disability had only little significance for how they see themselves and how they identify with others in the adolescent group. The following citation amply reflects what the majority of the adolescents reported: “I am just like all teenagers.” The personal presentations consisted of different attributes that the adolescents possessed, including happy, kind, determined, and careful. In addition, it was important to the adolescents to present themselves through things they are good at doing. When the disabled adolescents reported about their experiences as to how they apprehended the way others looked upon them a determinant factor was often their disability, i.e. their feeling was that they often were judged based on their disability rather than whom they were as a person. Because of that, several adolescents were unwilling to talk about their disability when interacting with others, especially peers. Their unwillingness to discuss their disability largely stems from a fear of negative social consequences.
The adolescent’s experiences showed also that accessibility to different surroundings (both physical and social) affected how they perceived themselves and how others regarded them (pictured them as different). In physical surroundings where accessibility was good (e.g., in the home) the adolescents saw themselves as any other teenager. On the other hand, physical surroundings (e.g., different outdoor locations such as schoolyards or public places) with poor accessibility entail that young people with a disability often felt unlike others and pictured themselves as different from peers and adults. Inaccessible locations and facilities resulted in that even the social milieu (e.g., peer groups) became inaccessible, i.e. when young people could not, for example, reach a destination or come into different premises where other young people spend time, the young disabled persons could not take part in the social comradeship either.

The way in which adolescents perceive themselves is affected by the accessibility of physical and social milieus though it is also affected by how they are received or looked upon and which social roles they are assigned or occupy. The three subcategories relationships to friends, relationships to adults, and thoughts about relationships in the future, described in detail below, give a picture of how adolescents relate to peers and adults in the numerous places in which they spend time.

Relationships to friends
This subcategory provides a description of the adolescents’ perceptions of peer relationships. Relationships to peers, which were both strained and flawed, took place primarily in school surroundings. The adolescents perceived that their disability had always restricted them in making social contact with their peers and that the disability was the reason why peers saw them (gave them the role) as different. For example, it was difficult to be in the same settings as their peers because the settings were not congenial to persons with technical aids (e.g., wheelchair, crutches, and orthoses). The disability also entailed that some of the adolescents suffered physical pain or did not have the same stamina as their peers. Thus, they could not engage in some of the activities outside the school or had to abruptly leave in the middle of some activity. "I've never had the strength to carry on as long as my friends and I've always had to go home first." "Certainly, it was hard work always trying to keep up with my friends when it hurts."

The relationships to agemates included even social barriers in the form of attitudes, which resulted in that the adolescents already from early school years adopted new roles in order to be accepted by their peers. The attitudes of agemates were often negative, which were manifested in the taunts they expressed toward the adolescents with disabilities. For instance, the peers used such expressions as "lame duck" or "wooden-leg." Some of the disabled adolescents recounted that they had sometimes taken up a new role in order to be accepted by their peers. For example, some of the adolescents took on a role as a jokester.
One adolescent gave the following account: "I took on a new style, which made me fun and jovial. When I showed that I could joke about my handicap and that I could say all the taunts myself, it was no longer fun to tease me." Another role used by adolescents with a disability was to become more or less obscure, "I avoided the others in the class and never went out during breaks." These social roles seldom corresponded to how they really wanted to be, but was a strategy they used to gain acceptance by their peers.

Several of the adolescents reported that in order to acquire relationships with agemates, they had chosen to play with both younger and older children. They had chosen younger children as friends because younger children did not make the same demands regarding participation in games and activities as children their own age or older children. Some adolescents had chosen older persons as friends when they perceived that they had outgrown persons of the same age. One disabled adolescent stated, "The older ones were easier to be with because we were at the same level." Another adolescent said, "I outgrew my classmates and I remember thinking they were so childish." During their early years, several of the adolescents chose to be with the opposite sex in that they perceived that it was easier to be accepted then. Above all, boys chose to play with girls: "I suppose I've mostly been with girls because it's been easier. Girls are kinder."

According to the adolescents' descriptions of their relationships with their friends, it appears that they feel largely excluded from the peer group and that they have few experiences of peer contact outside regular school hours. The disabled adolescents felt that the reason for this is that at an early age they were already excluded from the peer group because they were unable to participate on equal terms in different physical environments and hence could not establish deep bonds of friendship. They also experienced that their relationships with friends were not always mutual, i.e. they were the ones that had to take the initiative if they wanted to participate in some activity. "There is never anyone who asks if I want to take part." Even if friendships with other individuals of the same age were few, today's technical development (e.g., the Internet) offered disabled persons unique possibilities to create new relationships through participation in different discussion groups online. Adolescents with disabilities reported that they could remain anonymous in these relationships via the Internet, which commonly occurred at home, and that they did not have to reveal their disability to their Internet "friends." Thus, this strategy of anonymity about their disability helped them to feel like any other adolescent.

Relationships to adults.
The subcategory relationships to adults describes the disabled adolescents view of their relationships to adults (e.g., parents, assistants, and teachers).
Relationships to parents largely took place in the home of the adolescents. The disabled adolescents described their relationship to their parents as ambivalent. The relationships were often described as close and mutual at the same time as neither close nor mutual, which was because the adolescents perceived that their parents controlled them. The disability imposed that the adolescents needed help in planning their daily living activities, such as scheduling travel to and from school and setting up appointments with a physiotherapist. The majority of the adolescents were pleased with this assistance but felt that it led to an asymmetrical relationship. The relationship to the mother, in comparison with the relationship to the father, was often described as emotionally closer because the mother was seen as the one who gave both practical and emotional support. "My mother is closer to me regarding my handicap. She understands what I need when it comes to support and help."

The relationship with parents was also asymmetric when the parents’ role was based on control and where only the parents were involved in decision-making processes. According to the adolescents, the parents were obstacles to their attainment of independence. The adolescents did not feel that they were on equal terms with friends because the parents restricted their possibilities of becoming self-reliant. "I can never go anywhere without telling my parents where I’m going or when I plan to return home. My parents would prefer that I stay home. I would certainly like to have a little more freedom and do want I want without having to ask. I am in fact 18 years old." The adolescents were concerned that they might come into conflict with their parents, if they did not openly express their appreciation and satisfaction with the help they received from them. At the same time, the adolescents with disabilities had a strong desire to be like other adolescents and make their own decisions regarding what they wanted to do in life.

The adolescents’ reported that their relationship to the assistant was also characterized by ambivalence, i.e. sometimes they felt the relationship was reciprocal and sometimes they felt it was nonreciprocal. When the adolescents experienced a relationship that displayed mutual respect, it was seen as highly positive. Such a relationship existed primarily during school hours when the assistant gave practical support or when the assistant played the role as friend and actively engaged in a wide range of activities with the adolescents. Because of the assistants’ work schedule, however, they could not escort the adolescents to social activities in the community (e.g., discothèque), which often occurred in physical milieus that were inaccessible. The adolescents felt that when they did not receive the support they needed from the assistants, the relationships were no longer indicative of reciprocity. "I have been to a discothèque one time because it is so difficult to find someone willing to go with me." Because the assistants’ work schedule implies limitations for adolescents regarding participation in social activities in the community with their peers, the adolescents felt the assistants abandoned or somehow betrayed them. Several of the adolescents reported that they were
highly disturbed by their total dependency on the assistants. As with parents, the relationship with the assistants was also characterized by a lack of symmetry, particularly when the assistants dominated the decision-making process. In this sense, the adolescents felt that the assistants simply took over the role of the adolescent’s mother or father. When the assistants treated the adolescents as children (gave the adolescents the role as child), the adolescents felt offended because they were older and wished to make their own decisions. "When the assistant determines what I should do, I don’t find that amusing." Furthermore, the adolescents felt that when the assistants played the role of mother/father, the possibility of self-determination was hindered as was their likelihood of becoming autonomous.

The adolescents reported that their relationship to their teachers was nearly nonexistent in that the adolescents were primarily assigned to the assistants. Few of the disabled adolescents had experience with ever speaking to a teacher as the teachers normally discussed things with the adolescents via the assistants. Thus, the teacher instructed the nondisabled pupils in the classroom about different school assignments, but in the case of adolescents with restricted mobility the instructions came directly from the assistants. When the disabled adolescents attempted to directly communicate with the teachers, they were either ignored or referred to the assistants, which the adolescents interpreted as an expression of contempt. Instead of being with the teacher and the other pupils in the classroom, the disabled adolescents were also given special tasks (often in another room) together with the assistants. This isolation resulted in reduced contact with both the other pupils and the teachers. In addition, the disabled adolescents often felt that they were singled out by the teacher as being different when they were not allowed to take part in many of the school activities. "I was always the one who was seen as different because I was the one who couldn’t take part."

Thoughts about relationships in the future
In the subcategory thoughts about relationships in the future the adolescents described their goals and ambitions for the future. The girl adolescents in the study expressed a desire to have an education for care-related vocations, such as a doctor or a nurse. They explained their choice by a desire to help others, particularly children with a disability. "I would very much like to become a doctor to help other children who are ill." Some of the girls also mentioned the desire to become a teacher or journalist. The boy adolescents reported interests in the field of computing (e.g., as a designer of websites or as an IT consultant).

To meet someone romantically was another important ingredient in the disabled person’s wishes regarding future relationships. All 12 respondents had wishes of having a boyfriend/girlfriend and had aspirations to fall in love with someone. However, they were mindful that their disability was an obstacle if they should enter into a romantic relationship. For several of the boys, there was uncertainty
as to how they should go about meeting someone. "I would like to share my future with a girl, but I don't really know how that is going to come about." The girls saw their problems primarily in terms of finding a boyfriend that would be willing to help in matters of personal care and other forms of practical help. "How can you ever meet someone you can care for if you need so much help with everything?"

Independent living in a dwelling of one's own was another desire that the adolescents harboured. Despite that many of the adolescents required a personal assistant, they still preferred to manage on their own. Above all, they wanted to meet a girlfriend/boyfriend who could help them with these personal needs. Help from an assistant took second priority though the adolescents realised their need of help. "I want to move to my own flat, preferably together with a girlfriend who can take care of me. But it will probably still be with the help of an assistant if I'm going to live on my own." Half of the adolescents had already moved away from home to a school boarding house when they started upper secondary school in another community. This move was a first step toward independent living and an adult role. Yet, several adolescents felt that they were closely watched by the staff at the school boarding house, which left little room for a private life. "I can never go anywhere without saying where and really you're never alone. I'd like to live completely on my own." The adolescents also wanted to have relationships to peers because their earlier experiences of peer relationships indicated difficulties in both acquiring and keeping friends.

DISCUSSION
The purpose of the study was to penetrate what it is like to grow up with a disability. The study also sought to investigate disabled adolescents' roles and relationships to peers and adults. From the analyses, a core category emerged (Who am I?), which showed that the disability had little significance for how persons conceptualise themselves, whereas it is a determining factor as to how one is conceptualised by others. The adolescents gave a description of themselves as a regular member of the adolescent group though they were fully cognisant of their disability. At the same time, however, the adolescents felt that others saw them as radically distinctive because of their disability. Barron (1997) reported findings consistent with ours. In her study, young disabled people perceived themselves as being like "regular" young people, whereas others saw them as unique. Such a conflict, in which adolescents do not feel they are different but are treated as though they are different, can have a detrimental affect for adolescents who are in the process of defining and developing their identity. According to Mead (1934), identity develops from social interactions, i.e. how others see the individual. In accordance with this view, the peer group is important because in the interaction with friends the adolescents discover who they are, who they wish to become, and which social world they are members of. To then be viewed as different from others can result in being labelled as deviant, someone that is different in character or quality from the normal or
expected. This, in turn, fosters a negative identity development in these individuals (cf. Goffman, 1968).

Because they did not wish to be associated with their disability, none of the adolescents mentioned their disability when replying to the question about who they considered themselves to be. Comparable findings have been reported in other studies. For instance, D'Auria et al. (1997) found that adolescents were unwilling to discuss their chronic illnesses or disability for fear that this might bring about negative social consequences when attempting to form friendships. According to D'Auria et al., children and adolescents with chronic illnesses or disabilities are trying to understand their illness and deal with their situation at a time in their lives when they are most vulnerable (i.e. susceptible to emotional injury) and concerned about not being different from their peers (see also Hartup, 1996). Similar tendencies were found in the present study, where adolescents with disability wished to be as others rather than being branded as unlike others.

In the subcategory relationships to friends the findings indicated that the adolescents had few experiences of positive relationships with their peers. Because the disability limited the person's possibilities to explore new settings, it functioned to restrict interpersonal relationships, a conclusion that other researchers also have drawn (Bywater, 1981; Spirito et al., 1991). Access to different physical and social environments (Proshansky & Fabian, 1987) and the presence of friends as exemplars and social models (Erikson, 1969; Hartup, 1979) are important in to avoid antisocial behaviours and to develop socially in a healthy way. One question that arises is what are the consequences of not having friends? According to Bronfenbrenner's (1979) theoretical framework, human development is facilitated through interaction with peers and participation in an ever-broadening repertoire of social roles in different physical and social environments. Reciprocal relationships play an important part in the individual's preparations to create healthy, adult relationships. It is thus essential for adolescents to have access to varying environments and interact with different people in order to communicate and co-operate with others.

In the subcategory relationships to adults the relationships were described as both ambivalent and lack of mutual respect. The ambivalent relationship is found again in relationships to both the parents and assistants and was depicted sometimes as reciprocal and sometimes as nonreciprocating. The relationships that were characterised by reciprocity, which were experienced as positive, were observed in situations in which the mother served as emotional sustenance and when the assistant viewed the adolescents as a friend. When the assistants could not take part in different community activities because of their schedule at work, the adolescents felt deserted in their friendship to the assistants and the relationship was no longer seen as reciprocal. Reciprocal relationships are considered
important for the individual’s development and they help prepare one to create relationships in the future (Bronfenbrenner, 1979). Adolescents can develop as individuals through reciprocal relationships with exchange of knowledge and experiences and reciprocal respect.

The adolescents’ relationship to their parents and assistants was asymmetrical, i.e. a relationship in which one party has more power than the other. When the parents or the assistant did not provide the adolescents sufficient space for spontaneous activities or autonomy, the adolescents felt controlled by the adults and the relationships were described as lacking mutual respect. Barron (1997), who has studied young persons with disabilities, describes how disability and careful planning of daily activities can affect development of independence. An adolescent’s disability can mean that a normal childhood and relationships with friends are restricted because most of the individual’s time is devoted to training for increased mobility and physical independence. If adults (who help and plan the daily life of adolescents with disabilities) do not provide the necessary room for the development of independence, conflicts and experiences of disappointment can develop in the life of the adolescent. Concern for conflicts was precisely what the adolescents in this study described, if they did not feel grateful and satisfied with the help they received from adults. Concurrently with these anxious feelings, the adolescents wished to be like other young people and take command over their own life. Relationships between adolescents and adults are often lacking an interchange of ideas and, according to Bronfenbrenner (1979), adolescents need to experience various types of relationship for their development. Moreover, to grow emotionally and intellectually it is important to deal with relationships in which one person possesses more power than the other. On the other hand, when adults use their power to restrict adolescents’ freedom, it is not likely to promote the adolescents’ emotional and social development, and especially during the adolescent years, adults who fail to encourage independence act as a major obstacle in the developmental process (Bronfenbrenner, 1979; Hartup, 2000). Adolescents that do not feel free from external control and constraint, a phenomenon reported by adolescents in the present study, could exhibit difficulties in developing their independence, which is a process that is essential for adolescents to attain their full emotional development (cf. Craig, 2000).

The adolescents described that their relationships to the teachers in school were essentially absent in that the adolescents were for the most part allocated to the assistants. Such poor relationships to the teachers can have negative consequences regarding the adolescents’ development because norms and values, social skills, and emotional relationships with others are often established and developed subtly in school through interplay with the teachers (Andersson, 1986). Pupils’ performance is not of primary importance in school per se; rather, the essential objective is to which degree does school performance contribute to building the
individual’s future competence, such as the ability to develop stable relationships (Bronfenbrenner, 1979). If the school surroundings are not capable of fulfilling pupils’ needs to participate in activities, play different roles and have numerous relationships, then it is reasonable to infer that the pupils’ development is likely to move in another course than what one would prefer.

The subcategory thoughts about relationships in the future describes the adolescents’ wishes as regards vocations, their own dwelling, and an independent life. Consistent with Sjöholm (1994), the adolescents’ choice of vocation shows that females with a disability prefer to choose careers in care and nursing because of their desire to help others in the same situation. Male adolescents, on the other hand, prefer technical vocations. Both male and female adolescents also considered a future that emphasised their self-reliance. Adolescents whose expectations are not realised—a wish for independent living but in reality exist under the control of adults—may have difficulty developing independence that, according to Bronfenbrenner (1979) and other theorists (e.g., Craig, 2000), is important for their development and later maturity.

A future together with someone you are fond of is a common preference among most adolescents. The fact that the adolescents in this study (despite their expression of a desire to be with someone intimately) experienced extreme difficulties in establishing contact with the opposite sex can be due to a lack of correspondence between their own self-perception and how others perceive them. According to Hartup (1979), the experience of being different to one’s peers acquires greater significance in the teens in general and above all when a relationship with the opposite sex is initiated. Sjöholm (1994) found that difficulties with finding a partner were often linked to a functional disability and that the reason was partly the disability itself and partly underdeveloped social skills. The adolescents in the present study lacked peer relationship encounters and there was sizable uncertainty as to how a relationship with the opposite sex was to be initiated. Whether the adolescents had social skills that were particularly underdeveloped or mature were not examined in the present study. Future research, however, should address issues related to disabled adolescents’ social knowledge and skill competencies (e.g., their ability to act together with others) that are based upon empirical, data-based research.

Summary and conclusion
In summary, the overriding conclusion to be drawn from this study is that disabled adolescents have serious difficulties and obstacles to overcome in their endeavour to form relationships with peers and adults. The barriers were twofold: the inaccessibility to many physical and social environments and that adults tend to plan and control (restrain) their life. Disabled adolescents’ relationships to peers were strained and activities and milieus in which social contacts could eventually develop were significantly limited. The relationships
with peers were also characterised by social barriers in the form of attitudes that resulted in social isolation from the group of persons the disabled adolescents most wished to be a member of. The adolescents' understanding of themselves did not correspond well with how others saw them. Moreover, "Who am I" was a social role which implied that adolescents were always required to adapt to what others wanted, with little room given to let adolescents decide themselves which social roles they wanted to have across their life span. Further research needs to broaden our knowledge of what it means to disabled adolescents to grow up with the perception of being different and with few peer relationships, as well as what consequences a disability has to a young person's life from a long-term perspective.

The strength and limitation of this study
The strength of this study is its 'insider' perspective, i.e. that it describes the adolescents' self-perceptions of their life situation. Our view is that only the adolescents themselves can judge what is important to their social well being. From this perspective, the study offers important insights into the demanding (and sometimes unkind) world of adolescents with disabilities. The limitation of the study is primarily related to our sampling procedure. The target group was small and it was drawn from a clinical population, consisting only of adolescents who were enrolled in the Children's Rehabilitation Clinic. We elected to study this group because studying the entire population would be impractical and cost-prohibitive. Thus, the present sample is not an unbiased sample that is representative of the entire population of interest (i.e. disabled adolescents). Future studies, with longitudinal designs and larger samples, are needed to build a more comprehensive knowledge base about young persons with disabilities. Such a knowledge base would provide policy makers and researchers with up-to-date information and allow for more detailed and in-depth exploration of many of the complex issues.

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REFERENCES


Barn och ungdomar med rörelsehindernas uppfattningar om roller, relationer och aktiviteter

The general aim of this thesis was to describe how children and adolescents with restricted mobility perceived their roles, relations and activities in relation to peers and adults in different settings. The thesis includes six sub-studies, which are based on interviews, observations and field notes with children and adolescents with restricted mobility aged from 6 to 19 years.

Using Bronfenbrenners theory the Ecology of Human Development as the main theoretical framework, the ambition was to understand the children and adolescents social world from their perspective. The principal finding was the lack of peers in the children and adolescents social network. Furthermore, this tendency of isolation from peers was found to increase during the transition from childhood to adolescence. Their relationships to peers were strained and activities and surroundings in which social contacts could develop were limited. The relationships with peers were also characterised by social barriers in the form of attitudes that resulted in social isolation from the group of persons the disabled children and adolescents most wished to be with. When relations to peers were limited, the disabled childrens social life was restricted to adults. The results further showed that the children and adolescents roles and relations often were significantly different from their peers. The children and adolescents arrived at a concept of themselves that differed from the way others .....(cont.)